Doctoral Thesis

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

March 2023

Factors Associated with Caregivers' Responses to Individuals Affected by Eating Disorders

Doctorate in Clinical Psychology

Lancaster University

Emily Rothwell

2020 intake

Word Count

Section	Main text	Appendices (including references, tables and figures)	Total
Thesis abstract	298	-	298
Literature review	7854	12,718	20,572
Empirical paper	7805	7766	15,571
Critical appraisal	4000	2044	6044
Ethics section	3680	6859	10,539
Total	23,637	29,387	53,024

Thesis Abstract

Eating disorders can impact the whole family. Caregivers may engage in certain behaviours, termed *accommodation* and *enabling* behaviours, as an attempt to reduce conflict. Whilst understandable, the cognitive interpersonal maintenance model suggests that engaging in these behaviours may inadvertently maintain the eating disorder. This can become a vicious cycle. The emotional climate of families can be measured by the construct of expressed emotion (EE). High familial EE is associated with poorer treatment outcomes, as well as increased caregiver distress. It is therefore important to understand factors which are associated with accommodation and enabling behaviours, and EE, in families affected by eating disorders.

Section One of this thesis is comprised of a systematic literature review, which explores the factors associated with/correlates of accommodation and enabling behaviours in caregivers of individuals affected by an eating disorder. Factors associated with both the caregiver and the person affected were identified, which can be used to identify caregivers who may be more vulnerable to engaging in accommodation. This provides valuable information regarding the targeting of support to relevant caregivers.

Section Two reports an empirical study investigating the relationship between guilt, shame, blame, EE and self-compassion, in caregivers of those affected by eating disorders. It also examines whether self-compassion moderates the relationship between guilt/shame/blame and EE. Emotional overinvolvement (EOI), one component of EE, was positively associated with guilt and shame, and negatively associated with self-compassion. Guilt predicted EOI once other variables had been accounted for. Critical comments, a second component of EE, had a significant positive association with guilt, shame and blame.

Blame was the only significant predictor of criticism when other factors had been accounted for. There were no significant moderating effects of self-compassion.

Section Three considers the implications of these findings, and the importance of language when discussing these themes.

Declaration

The research presented in this thesis has been undertaken for the Doctorate in Clinical Psychology at the Division for Health Research, Lancaster University. The work presented throughout the thesis is the author's own, except where due reference is made. The work has not been submitted elsewhere for the award of any other academic award.

Name: Emily Rothwell

Date: 14th February 2023

Acknowledgments

Firstly, I would like to say a big thank you to each person who participated in this study. I recognise that caring for someone affected by an eating disorder can often be exhausting and relentless, so I really appreciate you taking the time to engage in the survey; the research would not have been possible without you. Thank you also to the experts by experience who provided feedback on the design of the study and supported this to be advertised – it was humbling to see the way in which you use the difficulties you have been through to support others. I am also grateful to those who supported me with advertising the study, particularly Beat. As a trustee of Beat, I am proud of the work they continue to do to support those affected by eating disorders.

I would also like to thank my supervisors Bill Sellwood and Hannah Wilson. Bill, thank you for your confidence in me and your critical insights. Hannah, thank you for being my compassionate cheerleader, for sharing your wealth of wisdom and for encouraging me to let my voice be heard. Thank you also to my clinical tutor, Jen Davies, for helping me to connect with my compassionate self in those moments of overwhelm.

Thank you to my family and friends for your love, support and encouragement throughout this process. Many of you know all too well the impact that eating disorders can have, so thank you for never giving up on me. Thank you to the wonderful people I have met as part of the doctorate; it has been an honour to go through this alongside you and your support has been invaluable. Finally, thank you to Matt, for your unfaltering belief in me, saving my tech disasters and for never failing to make me laugh throughout.

Contents

SECTION FOUR – ETHICS PROPOSAL 4-1

Section One - Systematic Literature Review

Correlates of Accommodating and Enabling Behaviours in Caregivers of People Affected by Eating Disorders: A Systematic Review

Word count (excluding references, tables and appendices): 7854

Abstract: 191

Emily Rothwell

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Prepared in accordance with *European Eating Disorders Review*[1] submission guidelines for authors.

All correspondence should be sent to:

Emily Rothwell
Doctorate in Clinical Psychology Lancaster University
Furness College
United Kingdom
LA1 4GY

Email: e.rothwell@lancaster.ac.uk

Declarations of interest: None

---

[1] See Appendix A for submission guidelines

Abstract

Objective: Eating disorders can have a devastating impact on families. Caregivers may engage in *accommodation* and *enabling* behaviours to reduce distress; however, these may inadvertently maintain the eating disorder. This systematic review identifies factors associated with/correlates of these behaviours in caregivers of those affected by eating disorders.

Method: CINAHL, Embase, MEDLINE, PsycINFO, SocINDEX were independently searched to identify studies which met the a priori inclusion criteria. PRISMA guidelines were followed.

Results: Fifteen studies published between 2009 and 2022 were included. Several variables associated with both the person affected by the eating disorder, and their caregiver were identified as factors associated with/correlates of accommodation. These included positive associations between accommodation and caregiver distress, caregivers' own eating difficulties and expressed emotion. Positive associations between accommodation and distress of the individual affected by the eating disorder, comorbidities and eating disorder symptoms were also noted.

Conclusions: Key factors were identified which may help with the identification of caregivers vulnerable to accommodation and provide possible routes to intervention. Studies tend to be homogeneous with regards to their sample characteristics, thus future research with greater variety of caregiver types and eating disorder diagnoses would be beneficial.

Keywords: eating disorders; accommodation and enabling; caregivers

Highlights

- Several caregiver factors and factors associated with the individual affected by the eating disorder have been associated with accommodation and enabling behaviours.
- Although the direction of these associations cannot often be inferred, these factors may inform targets for intervention and suggest who may be most at risk of engaging in accommodation.
- Current research is limited regarding the range of caregivers’ experiences studied; thus, research must ensure that there is diversity in samples outside of mothers of individuals affected by restrictive eating disorders.

Correlates of Accommodating and Enabling Behaviours in Caregivers of People Affected by Eating Disorders: A Systematic Review

The Impact of Eating Disorders

Eating disorders do not discriminate; they can affect individuals of any age, gender or ethnicity (Treasure, Duarte, et al., 2020). They carry significant risks to physical health, including an increased risk of mortality (Arcelus et al., 2011), as well as psychological wellbeing, psychosocial functioning and quality of life (Bohn et al., 2008; de Vos et al., 2018). The global burden of anorexia nervosa, bulimia nervosa, binge eating disorder and other specified eating disorder (OSFED) was estimated as 6.6 million disability-adjusted life-years (DALYs) (Santomauro et al., 2021). DALYs represent the sum of the years of 'healthy' life lost. Despite this, research into eating disorders receives relatively little funding (MQ, 2019).

Eating disorders can also have a significant impact on both the physical and mental health of individuals' loved ones. Caregiver burden is common (Padierna et al., 2013) and is greater among caregivers of those affected by eating disorders, compared to those affected by depression or schizophrenia (Martín et al., 2015). This burden is associated with stress, anxiety and depression (Coomber & King, 2013; Kyriacou et al., 2008; Stefanini et al., 2019). Caregivers commonly report feeling burned out and helpless (Beat, 2017; Perkins et al., 2004), and have described the impact of the eating disorder as a "living nightmare" (Robinson et al., 2020, p. 756). Whilst the need to support and empower caregivers has been recognised (Academy for Eating Disorders, 2022; Beat, 2019; NICE, 2017), caregivers commonly report a lack of support (Robinson et al., 2020). For some, this was heightened during the COVID-19 lockdown periods, where family members were less able to attend appointments or access support for themselves (Clark Bryan et al., 2020; Shaw et al., 2021).

Although most of the research focuses on parents as caregivers, studies have also highlighted the substantial impact that eating disorders can have on siblings (Hutchison et al., 2022; Maon et al., 2020). For instance, rates of depression are significantly higher in sisters of females affected by an eating disorder, compared to those without an affected sibling (Latzer et al., 2015). Similarly, partners have reported feeling stressed and isolated, unsure how to best support their partner, and questioning of their own potential role in the development of the eating disorder (Beat, 2017; Fischer et al., 2015; Highet et al., 2005; Schmit & Bell, 2017).

Guidelines highlight the need to involve caregivers in the treatment of those affected by eating disorders (Academy for Eating Disorders, 2022; Couturier et al., 2020; Heruc et al., 2020; NICE, 2017; Royal College of Psychiatrists, 2022). Presently, family interventions are the recommended first-line approach for children and young people affected by anorexia nervosa and bulimia nervosa (Couturier et al., 2020; NICE, 2017). This is a sea-change from the historic view, with reports from the late 19th century stating that family and friends are "generally the worst attendants" (Gull, 1997, p. 501) to support someone diagnosed with anorexia nervosa. Although outcome evidence supports family interventions (Jewell et al., 2016; Lock, 2018), this is not synonymous with attributing blame to the family for the development of the eating disorder, which Eisler (2005) states is an "unwarranted leap" (p. 111). Treatment protocols for family interventions[1] highlight that neither the individual nor the parent are to blame, and instead encourage therapists to take an agnostic view to the aetiology (Rienecke & le Grange, 2022). Giles et al. (2021) suggest that rather than being based on "scientific rigour" (p. 14), this allows clinicians to explore family factors which may

---

[1] Family intervention has been used as an umbrella term for interventions including Family-Based Treatment (FBT), and eating-disorder-focused family therapy, also known as The Maudsley approach, anorexia-nervosa-focused family therapy (FT-AN) or bulimia-nervosa-focused family therapy (FT-BN). A description of the differences is beyond the scope of this review.

be maintaining or exacerbating the eating disorder, without the notion of blame. This is particularly important given that parental self-blame has been identified as an emotional block, which may impact parents' ability to engage with the tasks required to support recovery (Lafrance Robinson et al., 2014).

Caregiver Interventions

One approach to empowering families to best support their loved one is through the provision of caregiver interventions. A range of interventions have been developed, including Experienced Carers Helping Others (ECHO; Hibbs, Magill, et al., 2015), Overcoming Anorexia Online (Hoyle et al., 2013), and Supporting Carers of Children and Adolescents with Eating Disorders in Austria (SUCCEAT; Franta et al., 2018). A systematic review of these interventions concluded that they have the potential to benefit both caregivers and the person affected by the eating disorder (Hannah et al., 2022). For example, ECHO has been found to have positive outcomes for individuals receiving inpatient care for anorexia nervosa; individuals whose caregivers engaged with ECHO had reduced eating disorder psychopathology, increased quality of life and spent less time as an inpatient, compared to those receiving standard care. Additionally, caregivers reported less burden at six months although the effects were diminished at the two-year follow-up, which the authors suggested was due to a loss of statistical power (Magill et al., 2016).

Accommodation and Enabling Behaviours

ECHO was developed based upon the cognitive interpersonal maintenance model of anorexia nervosa (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013; Treasure, Willmott, et al., 2020). Whilst the model was developed in relation to anorexia nervosa, it has been proposed that it can be applied transdiagnostically (Goddard et al., 2011). The interpersonal domain of the model hypothesises that caregivers' own vulnerabilities and ways of coping, such as attachment difficulties and sensitivity to stress and anxiety, may become heightened by the eating disorder. This can lead caregivers to engage in behaviours which accommodate and/or enable the eating disorder, in an attempt to alleviate the stress and conflict. Inadvertently, these responses may maintain the eating disorder, thus are targeted by the ECHO intervention (Rhind et al., 2014). This followed Whitney and Eisler's (2005) proposal that families can become "reorganized" (p. 575) around the eating disorder, thus routines change to accommodate expressed needs such as food preferences and enable behaviours such as binge eating.

The Accommodation and Enabling Scale (AESED) was developed to assess accommodating and enabling behaviours (henceforth "accommodation") in caregivers of those affected by eating disorders (Sepulveda et al., 2009). At the time, accommodation was associated with parent-reported psychosocial impairment in children affected by obsessive compulsive disorder (OCD) (Storch et al., 2007), and treatment outcomes in families affected by OCD (Storch et al., 2008). Due to the theoretical overlap between eating disorders and OCD and their similarities around family functioning (Erol et al., 2007), it was hypothesised that, consistent with the cognitive interpersonal maintenance model, this would follow for eating disorders. The AESED consists of 33 items, which have demonstrated good internal consistency ($\alpha = 0.92$) (Sepulveda et al., 2009). Five factors have been identified:

- Avoidance and modifying routine: the extent caregivers modify their routine or avoid doing activities due to wanting to reduce their loved one's anxiety/difficult emotions in relation to the eating disorder
- Reassurance seeking: the extent caregivers provide reassurance around thoughts, feelings and behaviours related to the eating disorder

- Meal ritual: the extent caregivers accommodate behaviours around mealtime processes and rituals
- Control of family: the extent caregivers allow the person affected by the eating disorder to control cooking, food purchases, and what other family members eat/do
- Turning a blind eye: the extent caregivers ignore difficult behaviours the person affected by the eating disorder has engaged in, such as money being taken.

The role of accommodation was explored using the ECHO intervention (Goddard et al., 2011). Following ECHO, caregivers self-reported significantly lower anxiety and depression scores. Changes in accommodation (measured by the AESED) were found to significantly moderate the impact of ECHO on caregivers' depression and anxiety; ECHO was found to be most effective for caregivers with high levels of accommodation. However, the link between accommodation and eating behaviours is inconsistent. Whilst there was a negative correlation between changes in accommodation and global functioning of the individual pre- and post-ECHO, the association between changes in accommodation and changes to individuals' eating behaviours was not significant (Goddard et al., 2011). This suggests accommodation partly mediates the effects of ECHO on global functioning, but not eating behaviours. Moreover, accommodation scores have been found to be a significant predictor of eating disorder scores at the end of treatment, with greater accommodation predicting greater symptom persistence (Anderson et al., 2021). However, greater accommodation has also been reported to positively predict body mass index (BMI) at one-year follow-up (Monteleone et al., 2022), thus contradicting the cognitive interpersonal model.

Rationale for Review

The cognitive interpersonal maintenance model illustrates a theoretical basis for the impact of accommodation on caregiver wellbeing and treatment outcomes, and potential predictors of accommodation. Although there has been some preliminary evidence that caregiver interventions reduce caregiver distress and ameliorate accommodation, findings are inconsistent as to whether accommodation impacts eating disorder symptoms, and the direction of potential associations.

No systematic review has been conducted to explore the factors associated with accommodation in caregivers of those affected by eating disorders. Systematically synthesising the available literature would provide insight into whether accommodation is associated with caregiver wellbeing and/or eating disorder behaviours. It would also identify other potential correlates of accommodation. This information could be used to inform possible targets for intervention, as well as suggesting who may be most at risk of accommodation, thus for whom support may be most valuable.

Research Question

What are the factors associated with/correlates of accommodating and enabling behaviours in caregivers of people affected by eating disorders?

Method

Due to the heterogeneity of the data available and the number of outcome variables measured, a narrative description is provided, rather than a meta-analysis. This systematic review was conducted in accordance with the recommendations stated in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021). The review protocol was registered with the International Prospective Register of

Systematic Reviews (PROSPERO) and published on 10th October 2022 (registration number CRD42022355238).

Initial Search

To identify the suitability of the review topic, initial scoping searches were completed using Google Scholar and PubMed. No existing systematic literature reviews were found, published in English, which explored the relationship between factors associated with/correlates of accommodating and enabling behaviours in caregivers of individuals affected by eating disorders.

A Priori Inclusion and Exclusion Criteria

Inclusion:

- Published in peer reviewed journal, English language, up to 12th October 2022
- Study sample must include those who identify as caregivers of someone affected by an eating disorder. Caregivers are defined as "anyone, including children and adults who look after a family member, partner or friend who needs help because of their…mental health problem… The care they give is unpaid" (NHS England, n.d.)
- Studies must report quantitative factors associated with/correlates of accommodating and enabling behaviours
- If an intervention study, factors associated with/correlates of accommodating and enabling behaviours must be in relation to the baseline data.

Exclusion:

- Unpublished papers, conference papers, dissertations, theses, systematic reviews, meta-analyses, or non-empirical papers

- Studies where data from caregivers of those affected and not affected by eating disorders are grouped, and not reported separately
- Studies investigating factors associated with/correlates of caregiver accommodation and enabling following an intervention (without correlates being explored in relation to baseline data)
- Studies reporting caregiver accommodation and enabling behaviours, without reporting their correlates.

Search Strategy

The search strategy was developed in collaboration with an information specialist. Unique search strategies were developed for each database, using database-specific subject/keyword/MeSH title. Five bibliographic databases were searched from their commencement until 12th October 2022: CINAHL, Embase, MEDLINE, PsycINFO, SocINDEX. No specific methodological search filters were applied, to reduce the risk of excluding relevant studies.

Relevant searches and keywords were identified through reading pertinent systematic reviews (e.g., Anastasiadou et al., 2014; Zabala et al., 2009). Searches consisted of terms pertaining to four concepts: eating disorders, caregivers, accommodation and enabling behaviours, and factors associated with/correlates. Full search terms are included in Table 1. Next, searches were merged across the databases and Bramer et al.'s (2016) deduplication process was followed. The remaining papers were uploaded to the online software Rayaan (Ouzzani et al., 2016). The titles and/or abstracts of the remaining papers were read. Following the application of the inclusion and exclusion criteria, citation chaining was conducted; the reference lists of the included full-text studies were examined to identify additional papers which may meet inclusion criteria. The 'cited by' function of Google

Scholar was then used to identify any further papers which have subsequently cited relevant systematic reviews.

[INSERT TABLE 1]

Data Extraction

Relevant data were extracted into a standardised data extraction table. This contained characteristics data including author(s); year of publication; participant demographic information (of both the caregiver and individual affected by an eating disorder where provided); measure(s) used; statistical test(s) used; and study outcomes in relation to accommodation (Table 2).

Quality Assessment

The quality of the included studies was assessed using the tool proposed by Kmet et al. (2004). This has been designed to evaluate primary research papers, across a range of study designs. This tool was selected as the authors provide an extensive manual to aid scoring, with the aim of providing a reproducible assessment. A scoping search on Google Scholar highlighted that the tool had been utilised by many systematic reviews exploring mental health difficulties, including eating disorders.

The quality checklist comprises 14 items (Appendix B). These include assessing for the appropriateness of the method, sample size, analytic methods and whether the results are reported in sufficient detail. Items are scored based upon the extent that the checklist criteria are met (“yes” = 2, “partial” = 1, “no” = 0). If items are not applicable to a study design, they are marked “n/a” and excluded. The total score is calculated through summing the individual scores across relevant items and dividing by the total possible score. Higher scores are indicative of higher quality research. The authors noted that the cut-off scores for quality categorisation is dependent upon the distribution of quality scores, as well as resource availability and time. Total scores were not used to include/exclude studies, but were used to weight evidence deriving from each study.

Studies were assessed independently by the author. A sub-sample of five randomly selected studies were also independently rated by a colleague, to indicate the reliability of the appraisal. The scores were compared; five discrepancies out of a possible 55 (9.09%) were identified; two of these were around the provision of subject information, two around sample size, and one around the estimate of variance. These differences were resolved so that both raters agreed a score, through discussion and studying the manual together.

Results

Study Selection

An overview of the results of the systematic search are noted in the PRISMA flow diagram (Page et al., 2021), Figure 1. A total of 574 records were identified through database searching. Following the removal of duplicates, the titles and abstracts of 356 articles were screened. Of these, 53 papers were viewed as potentially relevant, thus the full text was read. Following this, 13 studies fulfilled the inclusion criteria. Additionally, citation searching identified four potentially relevant articles. The full text of these were read, and two studies fulfilled the inclusion criteria. Fifteen studies were included.

[INSERT FIGURE 1]

Study Characteristics

Table 2 summarises the main characteristics of the 15 included studies. Studies were published between 2009 and 2022. Six studies used cross-sectional design (Anastasiadou et al., 2016; Anderson et al., 2021; Stefanini et al., 2019; Stillar et al., 2016; Wagner et al., 2020; Weber et al., 2019); six studies used cross-sectional design of baseline data (Goddard et al., 2013; Hibbs, Rhind, et al., 2015; Marcos et al., 2016; Rhind et al., 2016; Sepulveda et al., 2009; Stillar et al., 2022) and three studies were intervention trials where baseline accommodation was studied (Monteleone et al., 2022; Salerno et al., 2016; Timko et al., 2022).

Of these, three studies (Monteleone et al., 2022; Rhind et al., 2016; Salerno et al., 2016) analysed data from the same original randomised controlled trial (Rhind et al., 2014). As each analysed a different sub-sample from this cohort, the individual studies have all been included. Six studies were conducted across the United Kingdom (Goddard et al., 2013; Hibbs, Rhind, et al., 2015; Monteleone et al., 2022; Rhind et al., 2016; Salerno et al., 2016; Sepulveda et al., 2009); four in the United States of America (Anderson et al., 2021; Timko et al., 2022; Wagner et al., 2020; Weber et al., 2019); two in Canada (Stillar et al., 2016, 2022); and one in Italy (Stefanini et al., 2019).

[INSERT TABLE 2]

Participants

The 15 studies reported data from 1879 caregivers. However, there are replicate caregivers within this number, due to the multiple subsequent analyses taken from Rhind et al. (2014) and being unable to identify which participants are included in more than one sample. Caregiver sample sizes ranged from 11 (Weber et al., 2019) to 325 (Hibbs, Rhind, et al., 2015), with a mean of 125.3 caregivers.

Where reported, mean caregiver age ranged from 44.9 years (specifically mothers; Anastasiadou et al., 2016) to 51.5 years (Goddard et al., 2013). The percentage of female caregivers ranged from 27.3% (Weber et al., 2019) to 95.3% (Monteleone et al., 2022). Five studies reported the ethnicity of their caregiver sample (Anderson et al., 2021; Hibbs, Rhind, et al., 2015; Rhind et al., 2016; Timko et al., 2022; Weber et al., 2019); the percentage of the sample who were White ranged from 88.8% (Rhind et al., 2016) to 95% (Hibbs, Rhind, et al., 2015). One study included partners only (Weber et al., 2019), five studies included parents only (Anastasiadou et al., 2016; Rhind et al., 2016; Salerno et al., 2016; Stillar et al., 2022; Timko et al., 2022); and nine studied caregivers including family members other than just parents.

In relation to the person affected by the eating disorder, the mean reported age ranged from 13.7 years (Wagner et al., 2020) and 48.5 years (Weber et al., 2019). The percentage of females ranged from 66.7% (Anderson et al., 2021) to 100% (Stillar et al., 2022). Three studies reported the ethnicity of the individuals affected by the eating disorder; 82.5% White sample (Wagner et al., 2020), 88.9% White sample (Rhind et al., 2016) and 100% Caucasian sample (Anderson et al., 2021). Six studies reported the mean length of eating disorder duration/duration of eating disorder behaviours; these ranged from 19.8 months (Salerno et al., 2016) to 6.7 years (Goddard et al., 2013).

Four studies did not describe the specific diagnoses (Hibbs, Rhind, et al., 2015); three of these reported clinical behaviours, such as restriction and purging (Sepulveda et al., 2009; Stillar et al., 2016, 2022). Of the remaining 11 studies, one included any DSM-5 (American Psychiatric Association, 2013) diagnosis (Stefanini et al., 2019); one included only those affected by binge eating disorder (Weber et al., 2019); and one included only those affected by anorexia nervosa (Timko et al., 2022). Of the remaining eight studies, eight included people affected by anorexia nervosa; seven included people affected by eating disorder not otherwise specified (EDNOS)/other specified feeding and eating disorder (OSFED)/unspecified eating disorders; three included people affected by bulimia nervosa

(Anastasiadou et al., 2016; Anderson et al., 2021; Marcos et al., 2016); and one included people affected by avoidant restrictive food intake disorder (ARFID) (Weber et al., 2019).

Quality Appraisal

Table 3 provides the quality assessment scores (Kmet et al., 2004), for each study. Quality scores range from 80% (Timko et al., 2022) to 95.5% (Goddard et al., 2013; Monteleone et al., 2022; Rhind et al., 2016; Salerno et al., 2016; Weber et al., 2019), with a mean score of 90.4%. Points were most commonly lost in relation to a) whether variance was reported for each outcome; ten studies scored *partial – 1*, and b) whether the sample size was appropriate; eight studies scored *partial - 1*, with studies commonly acknowledging the small sample size and/or lack of statistical power. Four studies scored *partial – 1* regarding the controlling of confounding variables (Hibbs, Rhind, et al., 2015; Salerno et al., 2016; Stefanini et al., 2019; Stillar et al., 2016); three studies scored *partial – 1* regarding sufficient description of the sample (Stillar et al., 2016; Timko et al., 2022; Wagner et al., 2020); and two studies scored *partial – 1* regarding the method of sample selection (Stillar et al., 2022; Timko et al., 2022). Finally, one study scored *partial – 1* regarding sufficient reporting of results (Anderson et al., 2021) and one study scored *partial – 1* regarding definition of measurements (Stillar et al., 2016). Overall, the general quality of the studies is high.

[INSERT TABLE 3]

Measures

As depicted in Table 4, there is a large variety of measures utilised throughout the included studies, in relation to caregiver variables. Accommodation is measured in every study by the AESED. The second most common caregiver variable measured is expressed emotion, with nine of the 15 studies measuring this, using the Family Questionnaire (FQ;

Wiedemann et al., 2002). Caregiver distress and eating disorder symptoms/behaviours are measured by several different measures, the most common being the Depression Anxiety and Stress Scales (DASS-21; Lovibond & Lovibond, 1993) and Short Evaluation of Eating Disorders (SEED; Bauer et al., 2005) respectively.

[INSERT TABLE 4]

Variables Associated with Accommodation

Caregiver Characteristics

Caregiver Type. Two studies indicated non-significant differences between mothers and fathers (Anastasiadou et al., 2016; Salerno et al., 2016). However, sample sizes were small, which may reduce the reliability and generalisability of the findings. A further study with a larger sample size reported that accommodation behaviours were significantly lower in fathers of adolescents affected by anorexia nervosa or EDNOS, compared to mothers (Rhind et al., 2016).

Contact Time. Goddard et al. (2013) reported a significant positive association between accommodation and contact time. This was supported by Rhind et al. (2016) in mothers, where total time spent caregiving predicted accommodation. Compared to caregivers with less than 21 hours contact, those who had 21 or more hours with their loved one scored higher on total accommodation, as well as the AESED subscales avoidance and modifying routine; reassurance seeking; and control of family (Sepulveda et al., 2009). Although Stefanini et al. (2019) found that accommodation did not differ according to time spent with the caregiver or whether the person was receiving inpatient or outpatient support, they reported that primary caregivers (those who provide the most care) had higher reassurance seeking and avoidance and modifying routine subscale scores, compared to secondary caregivers.

Caregiver Distress. As illustrated in Table 4, several different measures of caregiver distress and wellbeing have been used. The associations of these measures in relation to total accommodation and accommodation subscales has been described in Table 5. These highlight that although there are differences regarding specific accommodation subscales and measure of distress, overall, there is a clear and consistent association between accommodation and distress.

For example, accommodation has been significantly positively correlated with caregiver distress as measured by the DASS, in caregivers of both adolescents and adults (Goddard et al., 2013; Hibbs, Rhind, et al., 2015; Rhind et al., 2016). Rhind et al. (2016) reported that for mothers, the relationship between total time spent caregiving (predictor) and caregiver distress (outcome), was mediated by accommodation. They also noted a significant association between accommodation and caregiver distress for mothers and fathers. Whilst this differs from the finding that this association between accommodation and distress is only significant for mothers (Timko et al., 2022), Timko et al. (2022) noted that their study was underpowered for the analysis. Both studies explored this association with caregivers of adolescents, however, service users differed whether they were receiving inpatient (Timko et al., 2022) or outpatient (Rhind et al., 2016) support. This may affect the time spent with the individual and medical concern regarding the eating disorder. Additionally, Goddard et al. (2013) reported that this association between accommodation and distress depended upon caregivers' history of eating problems, which also was associated with caregiver distress.

[INSERT TABLE 5]

Caregiver Eating Difficulties. Caregivers' own history of eating difficulties has been associated with greater levels of accommodation, compared to those who have not reported these difficulties (Goddard et al., 2013; Sepulveda et al., 2009; Stefanini et al., 2019). This has been found particularly in relation to meal rituals and turning a blind eye (Sepulveda et al., 2009) and reassurance seeking subscales (Stefanini et al., 2019).

Caregiver Fear and Self-Efficacy. Stillar et al. (2016) found that in caregivers of individuals either receiving or waiting for treatment, fear in relation to caregivers' engagement in recovery tasks (such as refeeding) positively predicted accommodation. This association held in relation to the control of family subscale, reassurance seeking subscale and avoidance and modifying behaviours subscale. Stillar et al. (2022) studied this relationship separately in mothers and fathers. They reported that treatment engagement fear significantly predicts accommodation in mothers only. This association is slightly, but not substantially, strengthened when self-efficacy is added, which the authors interpreted as fear significantly predicts self-efficacy and accommodation. The same relationship was not present in fathers; neither self-efficacy nor treatment engagement fear predicted accommodation, however, this may reflect the sample size of fathers who completed the AESED ($n = 37$). Wagner et al. (2020) also found that in caregivers of those affected by ARFID, the control of family accommodation subscale was significantly positively associated with fear symptoms associated with ARFID.

Expressed Emotion. A significant positive association has been found between accommodation and expressed emotion, as measured by the FQ (Goddard et al., 2013; Hibbs, Rhind, et al., 2015; Monteleone et al., 2022; Rhind et al., 2016; Sepulveda et al., 2009). When distinguished from overall expressed emotion, both emotional overinvolvement and critical comments (two components of expressed emotion) were associated with most components of accommodation (Marcos et al., 2016; Sepulveda et al., 2009).

Appraisal of the Caregiving Process. Appraisal refers to how caregivers perceive the experience of caregiving. This can be measured by the Experience of Caregiving Inventory (ECI; Szmukler et al., 1996) in relation to both positive and negative aspects of caregiving (Szmukler et al., 1996). Two studies measured appraisal, however, only analysed the negative subscales (thus higher scores indicated more negative appraisals). They reported a positive and significant association between accommodation and negative caregiving appraisal (Marcos et al., 2016; Sepulveda et al., 2009), thus greater accommodation was present when more negative aspects of caregiving were perceived. Although the studies differed in the accommodation subscales these negative appraisals were associated with, their overall message was consistent. Sepulveda et al. (2009) reported an association between all the accommodation subscales, whilst Marcos et al. (2016) reported an association between each AESED and ECI subscales, apart from between meal ritual and both effects on family and loss, and between control of family and need to back up. Both studies included caregivers aside from just parents, and the demographics of the individuals affected by the eating disorder were similar.

Congruence Between Caregiving Styles. Salerno et al. (2016) explored whether the relative congruence between mothers' and fathers' accommodation impacted upon the symptoms of their children's eating disorder. They reported that neither congruence nor incongruence between parents' accommodation was related to initial symptoms. However, symptoms increased when both parents had high baseline accommodation, and decreased when both parents had low baseline accommodation. Additionally, symptoms decreased when one parent had lower baseline accommodation compared to the other parent. The authors concluded that accommodation is associated with eating disorder symptoms; outcomes are best when both parents are low in accommodation, moderate when one parent has high accommodation and one parent has low accommodation, and poor when both parents have high accommodation. Although the findings may be limited to those with a short illness duration, due to the sample, it provides longitudinal support for the cognitive interpersonal model.

Caregiver Self-Blame. Stillar et al. (2016) reported that caregiver self-blame significantly positively predicted accommodation, in caregivers who consented to partake in a caregiver intervention. This association held in relation to the control of family subscale, accommodation of meal rituals subscale and avoidance and modifying behaviours subscale.

Psychological Control. Goddard et al. (2013) reported a significant positive association between accommodation and psychological control displayed by caregivers towards the individual affected by the eating disorder, thus supporting the cognitive interpersonal maintenance model.

Caregiver Skills. Accommodation has been significantly negatively associated with caregiver skills in relation to managing the eating disorder, such as self-care, tolerating frustration and emotional intelligence (Hibbs, Rhind, et al., 2015; Rhind et al., 2016). This supports the cognitive interpersonal model, as suggests that increasing caregiver skills would reduce accommodation.

Social Support. Rhind et al. (2016) reported that accommodation was significantly negatively correlated with caregivers' social support, highlighting the value in ensuring that caregivers are appropriately supported. Similarly, Monteleone et al. (2022) also performed a secondary data analysis of data from Rhind et al. (2014). They confirmed this negative association between accommodation and social support (Monteleone et al., 2022).

Emotional Arousal. Weber et al. (2019) measured emotional arousal through recording couples' interactions and studying the vocal fundamental frequency. They found that emotional arousal in the conversation between partners, one of whom is diagnosed with binge eating disorder, was not associated with accommodation. However, when the caregiver partner had high levels of accommodation, the caregiver's emotional arousal was reactive based upon the emotional arousal of the individual affected by the eating disorder. Nevertheless, this was based upon a limited sample of 11 couples only.

Post-Traumatic Stress Symptoms. In mothers, accommodation correlated with perceived post-traumatic stress symptoms, as well as the intrusion, hyperarousal and avoidance subscales. These associations were not present in fathers of adolescents diagnosed with anorexia nervosa, who were receiving medical stabilisation in hospital (Timko et al., 2022). However, this was based upon a small sample size ($N = 47$), where less than 30% of individuals were fathers.

Cognitive Flexibility. Accommodation was significantly positively correlated with caregiver cognitive rigidity and attention to detail, in mothers and fathers of adolescents diagnosed with anorexia nervosa, who were receiving medical stabilisation in hospital (Timko et al., 2022).

Family Functioning. In family members of individuals admitted to a speciality residential programme, turning a blind eye subscale scores were significantly positively correlated with two dimensions of family functions; roles and behavioural control (Anderson et al., 2021). Roles refers to the patterns of behaviour that allow the maintenance and management of the family and how tasks are divided among family members, whilst behaviour control refers to the way that families express and maintain standards around family member behaviour.

Characteristics Relating to the Individual Affected by the Eating Disorder

Distress. Goddard et al. (2013) reported that accommodation is significantly positively associated with distress of the individual affected by the eating disorder. Additionally, a network analysis by Monteleone et al. (2022) illustrated a positive association between accommodation and depression in adolescents affected by anorexia nervosa.

Comorbidities. Based upon caregivers' reports, Sepulveda et al. (2009) reported that 45% of their sample of individuals affected by an eating disorder experienced comorbid impulsive behaviour. Caregivers of those perceived to experience comorbid impulsive behaviours had higher reassurance seeking and turning a blind eye scores, compared to those without comorbidities.

Diagnosis. Levels of accommodation have been compared across differing eating disorder diagnoses. Caregivers of those affected by anorexia nervosa have been found to have higher scores in respect to control of family and turning a blind eye (indicating greater accommodation), compared to those affected by bulimia nervosa (Sepulveda et al., 2009). Similarly, Stefanini et al. (2019) found that caregivers of those affected by anorexia nervosa had higher avoidance and modifying routine, reassurance seeking, and total accommodation scores, compared to those affected by bulimia nervosa. In relation to ARFID, a significant difference was reported between caregivers of those affected by anorexia nervosa and ARFID, with caregivers of those affected by anorexia nervosa scoring significantly higher on reassurance seeking compared to those affected by ARFID (Wagner et al., 2020).

Eating Disorder Symptoms and Behaviours. Timko et al. (2022) explored the behaviours and responses of caregivers of adolescents who were hospitalised for medical stabilisation due to a diagnosis of anorexia nervosa. Both mothers' and fathers' accommodation were significantly positively correlated with their child's eating disorder symptoms. This association was consistent with Anastasiadou et al. (2016) who found that total accommodation positively correlated with disorder eating attitudes and behaviours, for both mothers and fathers. Additionally, for fathers, accommodation and anxiety were found to account for 31% of variance in symptom severity.

In caregivers of both children and adolescents affected by anorexia nervosa and ARFID, Wagner et al. (2020) reported total accommodation was significantly positively correlated with picky eater symptoms associated with ARFID. Although the overall pattern was consistent, the associations between subscales differed between diagnosis. For caregivers of those affected by anorexia nervosa, accommodation avoidance was significantly positively related to picky eater symptoms, appetite symptoms, eating disorder dieting and eating disorder symptoms total scale. For caregivers of those affected by ARFID, accommodation avoidance was significantly positively related to oral control symptoms; and reassurance seeking was significantly positively correlated with eating disorder dieting.

This association was not found for those affected by binge eating disorder. Weber et al. (2019) reported that the association between accommodation and binge eating disorder severity at baseline was not significant. Additionally, pre-treatment accommodation did not predict post-treatment binge eating severity, even after controlling for severity and gender, however it did explain 17% of the variance in post-treatment severity.

Eating Disorder Outcomes. Baseline accommodation has been found to predict eating disorder symptoms at the end of residential treatment, for adolescents and adults affected by eating disorders (Anderson et al., 2021). The majority of the caregivers were mothers, although fathers and spouses were also included. Similarly, Salerno et al. (2016) reported that individual’s symptoms of anorexia nervosa were described as higher when both parents demonstrated high levels of accommodation, and lower when both parents demonstrated lower levels of accommodation. This contrasts findings which reported that accommodation prior to a couple-based intervention for binge eating disorder, did not predict post-intervention binge eating severity, even after controlling for pre-intervention binge eating severity and gender (Weber et al., 2019). Notably, the sample was limited to only 11 couples.

Additionally, a network analysis of clinical outcomes in adolescents diagnosed with anorexia nervosa or EDNOS reported that caregivers' baseline accommodation positively predicted BMI at one year follow-up (Monteleone et al., 2022). The authors noted that this was inconsistent with the cognitive interpersonal model. They hypothesised that it may be that accommodation only has a negative impact when prolonged, or that a certain level of emotional overinvolvement (a construct which includes accommodation behaviours) may have clinical benefits.

Social Aptitude. Rhind et al. (2016) explored whether social aptitude, as rated by the caregiver in relation to the broader development of the individual affected by the eating disorder, was associated with accommodation. They found social aptitude was significantly negatively correlated with mothers' accommodation and distress.

Discussion

Key Findings

This review aimed to synthesise findings from studies investigating the factors associated with/correlates of accommodating and enabling behaviours in caregivers of people affected by eating disorders. Following a systematic search, 15 studies were included. A narrative description of these has been provided. Figures 2 and 3 provide infographic summaries of the factors associated with/correlates of accommodation, relating to caregiver factors and factors associated with the individual affected by the eating disorder respectively.

Consistent with the cognitive interpersonal model, significant positive associations were found between accommodation and caregiver distress (e.g. Goddard et al., 2013; Rhind et al., 2016); caregivers' own eating difficulties (e.g. Sepulveda et al., 2009); expressed emotion, in particular the components of emotional overinvolvement and critical comments (e.g. Hibbs, Rhind, et al., 2015); and negative appraisals around caregiving (e.g. Marcos et al., 2016). Additionally, fear in relation to treatment engagement was found to positively predict mothers' accommodation (Stillar et al., 2022). Whilst the direction of these associations is not known, these findings could indicate that fear and anxiety-based responses drive accommodation. Qualitative findings support how emotive supporting a loved one can be, and how this may result in caregivers engaging in accommodating behaviours with the hope of reducing distress. For instance, Whitney et al. (2005) reported a father saying: "You cling to any sign of eating something, you put up with very lengthy trips to the supermarket, sometimes hours, in the hope they will actually allow you to buy something" (p. 447). This highlights the desperation caregivers may feel and how this can impact upon their behaviours. It therefore follows that when caregivers feel supported and are taught skills to help them to recognise and manage the difficult emotions that arise, accommodation is lower (e.g. Hibbs, Rhind, et al., 2015; Rhind et al., 2016). This supports interview data which describes caregivers as feeling unable to cope of their own, and a need for both practical advice and emotional support (de La Rie et al., 2005).

Although this review did not explore the interaction between individual factors which are associated with accommodation, it is likely that these factors do not act independently. Both self-blame and experience of one's own eating difficulties were associated with greater accommodation. Although this relationship has not been explored, it could be hypothesised that caregivers who have had their own eating difficulties place greater blame on themselves for their loved one's eating disorder. This is consistent with worries from caregivers regarding passing on "bad genes" (Coelho et al., 2021, p. 12), which may be heightened considering rates of eating disorders are higher in female children whose mothers have a history of an eating disorder (Bould et al., 2015). This may lead to caregivers inadvertently overlooking difficult behaviours, including behaviours around mealtime processes (turning a blind eye and meal ritual), as well as providing increased reassurance, due to their own difficult feelings and understanding of an eating disorder. Additionally, caregivers' history of an eating disorder may also interact with the association between both cognitive rigidity and attention to detail and accommodation. Individuals affected by an eating disorder have been found to have an inherent bias towards focusing on detail, and difficulties with set-shifting (Roberts et al., 2011; Wang et al., 2021).

Inconsistent results were also noted throughout the review, for example, the association between accommodation and caregiver type. This may reflect a common limitation of the studies, that frequently samples consist of a low proportion of fathers/stepfathers, thus are inadequately powered. The heterogeneity around factors such as duration of the eating disorder could also account for inconsistencies. For example, whilst Goddard et al. (2013) supported a positive association between accommodation and contact time, this was not supported by Stefanini et al. (2019). This could reflect differences across samples such as duration of the eating disorder, with the mean duration of eating disorder varying between these studies from 2.8 years (Stefanini et al., 2019) to 6.7 years (Goddard et al., 2013). Thus, one may postulate that the positive association between accommodation and time spent with the individual is dependent upon the duration of the eating disorder, which is correlated with caregiver distress (Goddard et al., 2013). It also reflects findings that elevated expressed emotion, in particular critical comments, is associated with longer duration of eating disorder (Duclos et al., 2012).

Caregiver accommodation was also found to be significantly positively associated with distress of the individual affected by the eating disorder (Goddard et al., 2013; Monteleone et al., 2022). Whilst the direction of this association is not known, it highlights that accommodation is heightened at times when the individual experiences increased distress, thus supporting the idea that accommodation is an attempt to ameliorate distress. Accommodation was commonly reported to be higher in those supporting someone affected by anorexia nervosa, compared to bulimia nervosa or ARFID (Sepulveda et al., 2009; Wagner et al., 2020). This may reflect that those affected by anorexia nervosa are often visibly underweight (Whitelaw et al., 2018), which may communicate feelings of distress in a way that individuals who are not underweight does not. Considering pro-social behaviours from the public, such as empathy and a desire to help, are similar across anorexia nervosa and bulimia nervosa (Angermeyer et al., 2013), these differences in emotions evoked may be specific to caregivers. This could be explained by caregivers' fears around physical health, considering the increased mortality rates of anorexia nervosa, compared to other eating disorders (Arcelus et al., 2011). Taken alongside the finding that with the exception of binge eating disorder (Weber et al., 2019), accommodation was positively associated with an increase in eating disorder symptoms and behaviours (e.g. Timko et al., 2022) and comorbid impulsive behaviours (Sepulveda et al., 2009), this suggests that the perceived severity of the eating disorder influences caregivers' accommodation.

With regards to the association between accommodation and eating disorder outcomes, findings are more inconsistent. Whilst some studies report that individual's outcomes are worse when parents have increased baseline accommodation (Anderson et al., 2021; Salerno et al., 2016), this was not supported in couples where one individual was affected by binge eating disorder (Weber et al., 2019). The dearth of evidence around both caregivers and people affected by binge eating limits the conclusions that can be drawn around this. However, it may indicate support for the view of binge eating disorder as "less impairing (and) less severe" (Reas, 2017, p. 1267), thus lower levels of accommodation. Contrastingly to the cognitive interpersonal model, accommodation was also found to positively predict BMI at one year-follow up (Monteleone et al., 2022). The authors suggested that this may be due to the duration of accommodation, or that certain accommodating behaviours, such as those reflected by emotional overinvolvement, may have clinical benefits (Rienecke, 2020).

Implications for Practice and Policy

In accordance with both national and international guidelines, this review highlights the importance of both involving and empowering caregivers. Whilst it is already recommended that caregiver wellbeing is assessed (Academy for Eating Disorders, 2022; NICE, 2017), it advocates for the importance of extending this assessment to explore feelings of distress and fears around caregiving. It also highlights the need for clinicians to remain curious around caregivers' own experiences of eating difficulties and to refer to the appropriate support if required. Additionally, it encourages the routine assessment of caregivers' levels of expressed emotion; interventions designed to reduce this should be discussed with caregivers accordingly (Philipp et al., 2020).

Although services should still strive to meet Beat's caregiver empowerment standard, "offer all carers opportunities to learn the necessary skills to provide optimum support for their loved ones" (Beat, 2019, p. 2), this review identifies individuals who may be more vulnerable to increased accommodation. These individuals could be prioritised to be invited to skills-based/psycho-education groups (Hannah et al., 2022). This may be particularly relevant to caregivers of children and young people, since family therapy is the first-line recommendation for those affected by anorexia nervosa or bulimia nervosa (Couturier et al., 2020; NICE, 2017). The need to enhance the efficacy of family interventions has been noted, considering evidence suggesting there is a noteworthy proportion for whom family interventions are not effective (Dare et al., 2001), and benefits are not maintained (Fisher et al., 2019).

Strengths, Limitations and Future Research

This is the first review to examine the factors associated with accommodation in caregivers of people affected by eating disorders. A strength is that the review has focussed on the broad array of factors that have been studied, both from the service user and caregiver perspective. Studies were included from four countries, thus a variety of healthcare systems, including both publicly and privately funded care, implying the results are generalisable across high-income Westernised countries. Through helping to screen who is vulnerable to increased accommodation, the results can identify those who are likely to require priority support, which is particularly necessary considering the growing demand on eating disorder services (Viljoen et al., 2022). Further strengths lie in the fact that five broad databases were used and that of the 15 included studies, 13 were identified via the initial search strategy. There may, however, be a few relevant papers that were not identified; constraints were implemented around the types of publications included, with the review limited to English speaking, peer-reviewed journals. This introduces limitations such as publication bias and subjective editorial decisions, which are likely to lead to the homogenisation of findings (Tennant & Ross-Hellauer, 2020). This is particularly concerning in the field of eating disorders, where research funding is considerably less than other mental health conditions, despite having a higher prevalence than many of these (Beat, 2021).

Although the overall quality of the literature base was strong (Table 3), approximately half the studies had limited sample sizes, which may have prevented smaller effect sizes from being detected, and results from being generalisable to a wider population. Additionally, three studies analysed data from the same randomised controlled trial. Whilst different sub-samples were analysed, the overlap of individuals is not known, which may risk certain experiences being unduly prioritised and mishandling in the data analysis. Variance data, such as effect sizes, were not reported in about one-third of studies, thus limiting how clinically useful the reported statistics are (Cumming et al., 2012). The heterogeneity of the included studies also raises difficulties for drawing conclusions, since several variables were only explored in one study and where the same variables were explored, different measures were commonly utilised. The cross-sectional design of most studies also limits the ability to draw conclusions regarding the direction of the reported associations. Prospective studies and longitudinal studies across the course of the eating disorder are needed to explore the direction of these associations, thus future research should address this gap.

In line with eating disorder research field more broadly, certain experiences have been prioritised across the included studies. People affected by eating disorder diagnoses other than anorexia nervosa are commonly overlooked (Beat, 2021), as are the experiences of males, older individuals and those who are not White. This lack of representation does not match the demographics of those affected by eating disorders, since the lifetime prevalence of binge eating disorder is greater than anorexia nervosa (Qian et al., 2022). Future research must address this disparity. Additionally, it is important to explore the experiences of caregivers other than parents. For example, siblings commonly play a key role in the family of those affected by eating disorders, and report trying to protect their sibling with the eating disorder through keeping their secrets, as well as attempting to support their parents (Maon et al., 2020). Siblings also describe witnessing their parents attempts to accommodate the eating disorder (Dimitropoulos et al., 2009). It is therefore important that their own experiences of accommodation are explored, and they are supported to manage these difficulties.

Conclusion

There are several significant associations between accommodation and factors associated with both caregivers and the individual affected by the eating disorder. Non-significant and inconsistent findings are also reported. This has important clinical implications, as it provides evidence around who may be more vulnerable to engage in accommodation, thus for whom support should be prioritised. Studies have mainly drawn upon parents of those affected by anorexia nervosa or restrictive eating disorders, thus future research expanding the samples to include different eating disorder diagnoses, caregiver groups, and greater diversity around ethnicity and culture would be valuable.

References

Academy for Eating Disorders. (2022). *World eating disorder healthcare rights*. Https://Www.Worldeatingdisordersday.Org/about/World-Ed-Rights/.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)*. https://doi.org/10.1176/appi.books.9780890425596

Anastasiadou, D., Medina-Pradas, C., Sepulveda, A. R., & Treasure, J. (2014). A systematic review of family caregiving in eating disorders. *Eating Behaviors*, *15*(3), 464–477. https://doi.org/10.1016/j.eatbeh.2014.06.001

Anastasiadou, D., Sepulveda, A. R., Parks, M., Cuellar-Flores, I., & Graell, M. (2016). The relationship between dysfunctional family patterns and symptom severity among adolescent patients with eating disorders: A gender-specific approach. *Women & Health*, *56*(6), 695–712. https://doi.org/10.1080/03630242.2015.1118728

Anderson, L. M., Smith, K. E., Nuñez, M. C., & Farrell, N. R. (2021). Family accommodation in eating disorders: A preliminary examination of correlates with familial burden and cognitive-behavioral treatment outcome. *Eating Disorders*, *29*(4), 327–343. https://doi.org/10.1080/10640266.2019.1652473

Angermeyer, M. C., Mnich, E., Daubmann, A., Herich, L., Wegscheider, K., Kofahl, C., & von dem Knesebeck, O. (2013). Biogenetic explanations and public acceptance of people with eating disorders. *Social Psychiatry and Psychiatric Epidemiology*, *48*, 1667–1673. https://doi.org/10.1007/s00127-012-0648-9

Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry*, *68*(7), 724–731. https://doi.org/10.1001/archgenpsychiatry.2011.74

Atkinson, J. E. (1978). Correlation analysis of the physiological factors controlling fundamental voice frequency. *The Journal of the Acoustical Society of America, 63,* 211–222. https://doi.org/doi:10.1121/1.381716

Bauer, S., Winn, S., Schmidt, U., & Kordy, H. (2005). Construction, scoring and validation of the Short Evaluation of Eating Disorders (SEED). *European Eating Disorders Review: The Professional Journal of the Eating Disorders Association*, *13*(3), 191–200. https://doi.org/10.1002/erv.637

Beat. (2017). *Delaying for years, denied for months: The health, emotional and financial impact on sufferers, families and the NHS of delaying treatment for eating disorders in England.* https://www.beateatingdisorders.org.uk/uploads/documents/2017/11/delaying-for-years-denied-for-months.pdf

Beat. (2019). *Best practice in the engagement and empowerment of families and carers affected by eating disorders*. https://www.beateatingdisorders.org.uk/uploads/documents/2019/7/family-empowerment-guidance-1.pdf

Beat. (2021). *Breaking the cycle*. https://www.beateatingdisorders.org.uk/about-beat/policy-work/all-party-parliamentary-group-appg-on-eating-disorders/

Bohn, K., Doll, H. A., Cooper, Z., O'Connor, M., Palmer, R. L., & Fairburn, C. G. (2008). The measurement of impairment due to eating disorder psychopathology. *Behaviour Research and Therapy*, *46*(10), 1105–1110. https://doi.org/10.1016/j.brat.2008.06.012

Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., Waltz, T., & Zettle, R. D. (2011). Preliminary psychometric properties of the Acceptance and Action Questionnaire–II: A revised measure of psychological inflexibility and experiential avoidance. *Behavior therapy, 42*(4), 676-688. https://doi.org/10.1016/j.beth.2011.03.007

Bould, H., Sovio, U., Koupil, I., Dalman, C., Micali, N., Lewis, G., & Magnusson, C. (2015). Do eating disorders in parents predict eating disorders in children? Evidence from a Swedish cohort. *Acta Psychiatrica Scandinavica*, *132*(1), 51–59. https://doi.org/10.1111/acps.12389

Bramer, W. M., Giustini, D., de Jonge, G. B., Holland, L., & Bekhuis, T. (2016). De-duplication of database search results for systematic reviews in EndNote. *Journal of the Medical Library Association: JMLA*, *104*(3), 240. https://doi.org/10.3163/1536-5050.104.3.014

Cella, D., Yount, S., Rothrock, N., Gershon, R., Cook, K., Reeve, B., Ader, D., Fries, J. F., Bruce, B., & Rose, M. (2007). The Patient-Reported Outcomes Measurement Information System (PROMIS): Progress of an NIH Roadmap cooperative group during its first two years. *Medical Care, 45*, S3. https://doi.org/10.1097/MLR.0b013e31805468b0

Clark Bryan, D., Macdonald, P., Ambwani, S., Cardi, V., Rowlands, K., Willmott, D., & Treasure, J. (2020). Exploring the ways in which COVID-19 and lockdown has affected the lives of adult patients with anorexia nervosa and their carers. *European Eating Disorders Review:*

The Journal of the Eating Disorders Association, *28*(6), 826–835. https://doi.org/10.1002/erv.2762

Coelho, J. S., Suen, J., Marshall, S., Burns, A., Lam, P.-Y., & Geller, J. (2021). Parental experiences with their child's eating disorder treatment journey. *Journal of Eating Disorders*, *9*, 1–14. https://doi.org/10.1186/s40337-021-00449-x

Coomber, K., & King, R. M. (2013). A longitudinal examination of burden and psychological distress in carers of people with an eating disorder. *Social Psychiatry and Psychiatric Epidemiology*, *48*(1), 163–171. https://doi.org/10.1007/s00127-012-0524-7

Couturier, J., Isserlin, L., Norris, M., Spettigue, W., Brouwers, M., Kimber, M., McVey, G., Webb, C., Findlay, S., & Bhatnagar, N. (2020). Canadian practice guidelines for the treatment of children and adolescents with eating disorders. *Journal of Eating Disorders*, *8*(1), 1–80. https://doi.org/10.1186/s40337-020-0277-8

Cumming, G., Fidler, F., Kalinowski, P., & Lai, J. (2012). The statistical recommendations of the American Psychological Association publication manual: Effect sizes, confidence intervals, and meta-analysis. *Australian Journal of Psychology*, *64*(3), 138–146. https://doi.org/10.1111/j.1742-9536.2011.00037.x

Dare, C., Eisler, I., Russell, G., Treasure, J., & Dodge, L. I. Z. (2001). Psychological therapies for adults with anorexia nervosa: Randomised controlled trial of out-patient treatments. *The British Journal of Psychiatry*, *178*(3), 216–221. https://doi.org/10.1192/bjp.178.3.216

de La Rie, S. M., van furth, E. F., de Koning, A., Noordenbos, G., & Donker, M. C. H. (2005). The quality of life of family caregivers of eating disorder patients. *Eating Disorders*, *13*(4), 345–351. https://doi.org/10.1080/10640260591005236

de Vos, J. A., Radstaak, M., Bohlmeijer, E. T., & Westerhof, G. J. (2018). Having an eating disorder and still being able to flourish? Examination of pathological symptoms and wellbeing as two continua of mental health in a clinical sample. *Frontiers in Psychology*, *9*, 2145. https://doi.org/10.3389/fpsyg.2018.02145

Dimitropoulos, G., Klopfer, K., Lazar, L., & Schacter, R. (2009). Caring for a sibling with anorexia nervosa: A qualitative study. *European Eating Disorders Review: The Professional Journal of the Eating Disorders Association*, *17*(5), 350–365. https://doi.org/10.1002/erv.937

Duclos, J., Vibert, S., Mattar, L., & Godart, N. (2012). Expressed emotion in families of patients with eating disorders: A review of the literature. *Current Psychiatry Reviews*, *8*(3), 183–202. https://doi.org/10.2174/157340012800792975

Eisler, I. (2005). The empirical and theoretical base of family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family Therapy*, *27*(2), 104–131. https://doi.org/10.1111/j.1467-6427.2005.00303.x

Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster family assessment device. *Journal of Marital and Family Therapy, 9,* 171–180. doi:10.1111/j.1752-0606.1983. tb01497.x

Erol, A., Yazici, F., & Toprak, G. (2007). Family functioning of patients with an eating disorder compared with that of patients with obsessive compulsive disorder. *Comprehensive Psychiatry*, *48*(1), 47–50. https://doi.org/10.1016/j.comppsych.2006.05.004

Fairburn, C. G., & Beglin, S. J. (1994). Assessment of eating disorders: interview or self-report questionnaire? *International Journal of Eating Disorders, 16,* 363–70.

Fischer, M. S., Baucom, D. H., Kirby, J. S., & Bulik, C. M. (2015). Partner distress in the context of adult anorexia nervosa: The role of patients' perceived negative consequences of AN and partner behaviors. *International Journal of Eating Disorders*, *48*(1), 67–71. https://doi.org/10.1002/eat.22338

Fisher, C. A., Skocic, S., Rutherford, K. A., & Hetrick, S. E. (2019). Family therapy approaches for anorexia nervosa. *Cochrane Database of Systematic Reviews*, *5*. https://doi.org/10.1002/14651858.CD004780.pub3

Franta, C., Philipp, J., Waldherr, K., Truttmann, S., Merl, E., Schöfbeck, G., Koubek, D., Laczkovics, C., Imgart, H., Zanko, A., Zieler, M., Treasure, J., Karwautz., & Wagner, G. (2018). Supporting Carers of Children and Adolescents with Eating Disorders in Austria (SUCCEAT): Study protocol for a randomised controlled trial. *European Eating Disorders Review, 26*(5), 447-461.

Garner, D. M., & Garfinkel, P. E. (1979). The Eating Attitudes Test: An index of the symptoms of anorexia nervosa. *Psychological medicine, 9*(2), 273-279. https://doi.org/10.1017/S0033291700030762

Giles, E. M., Cross, A. S., Matthews, R. V., & Lacey, H. J. (2021). Disturbed families or families disturbed: A reconsideration. *Eating and Weight Disorders: EWD*. https://doi.org/10.1007/s40519-021-01160-1

Goddard, E., Macdonald, P., Sepulveda, A., Naumann, U., Landau, S., Schmidt, U., & Treasure, J. (2011). Cognitive interpersonal maintenance model of eating disorders: Intervention for carers. *The British Journal of Psychiatry*, *199*(3), 225–231. https://doi.org/10.1192/bjp.bp.110.088401

Goddard, E., Salerno, L., Hibbs, R., Raenker, S., Naumann, U., Arcelus, J., Ayton, A., Boughton, N., Connan, F., Goss, K., Lacey, H., Laszlo, B., Morgan, J., Moore, K., Robertson, D., Schreiber-Kounine, C., Sharma, S., Whitehead, L., Schmidt, U., & Treasure, J. (2013). Empirical examination of the interpersonal maintenance model of anorexia nervosa. *International Journal of Eating Disorders*, *46*(8), 867–874. https://doi.org/10.1002/eat.22172

Goldberg, D. P., and Williams, P. (1988). *A users' guide to the General Health Questionnaire*. London: GL Assessment.

Gormally, J. I. M., Black, S., Daston, S., & Rardin, D. (1982). The assessment of binge eating severity among obese persons. *Addictive behaviors, 7*(1), 47-55. https://doi.org/10.1016/0306-4603(82)90024-7

Gull, W. W. (1997). Anorexia nervosa (apepsia hysterica, anorexia hysterica). *Obesity Research*, *5*(5), 498–502. https://doi.org/10.1002/j.1550-8528.1997.tb00677.x.

Hannah, L., Cross, M., Baily, H., Grimwade, K., Clarke, T., & Allan, S. M. (2022). A systematic review of the impact of carer interventions on outcomes for patients with eating disorders. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*, *27*(6), 1953–1962. https://doi.org/10.1007/s40519-021-01338-7

Heruc, G., Hurst, K., Casey, A., Fleming, K., Freeman, J., Fursland, A., Hart, S., Jeffrey, S., Knight, R., & Roberton, M. (2020). ANZAED eating disorder treatment principles and general clinical practice and training standards. *Journal of Eating Disorders*, *8*(1), 1–9. https://doi.org/10.1186/s40337-020-00341-0

Hibbs, R., Magill, N., Goddard, E., Rhind, C., Raenker, S., Macdonald, P., Todd, G., Arcelus, J., Morgan, J., & Beecham, J. (2015). Clinical effectiveness of a skills training intervention for caregivers in improving patient and caregiver health following in-patient treatment for severe anorexia nervosa: Pragmatic randomised controlled trial. *British Journal of Psychiatry Open*, *1*(1), 56–66. https://doi.org/10.1192/bjpo.bp.115.000273

Hibbs, R., Rhind, C., Salerno, L., lo Coco, G., Goddard, E., Schmidt, U., Micali, N., Gowers, S., Beecham, J., Macdonald, P., Todd, G., Campbell, I., & Treasure, J. (2015). Development and validation of a scale to measure caregiver skills in eating disorders. *International Journal of Eating Disorders*, *48*(3), 290–297. https://doi.org/10.1002/eat.22362

Highet, N., Thompson, M., & King, R. M. (2005). The experience of living with a person with an eating disorder: The impact on the carers. *Eating Disorders*, *13*(4), 327–344. https://doi.org/10.1080/10640260591005227

Hoyle, D., Slater, J., Williams, C., Schmidt, U., & Wade, T. D. (2013). Evaluation of a web-based skills intervention for carers of people with anorexia nervosa: A randomized controlled trial. *International Journal of Eating Disorders, 46*(6), 634-638.

Hutchison, S., House, J., McDermott, B., Simic, M., Baudinet, J., & Eisler, I. (2022). Silent witnesses: The experience of having a sibling with anorexia nervosa. *Journal of Eating Disorders*, *10*(1), 1–8. https://doi.org/10.1186/s40337-022-00655-1

Jewell, T., Blessitt, E., Stewart, C., Simic, M., & Eisler, I. (2016). Family therapy for child and adolescent eating disorders: A critical review. *Family Process*, *55*(3), 577–594. https://doi.org/10.1111/famp.12242

Kmet, L. M., Cook, L. S., & Lee, R. C. (2004). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields*.

Kocalevent, R. D., Berg, L., Beutel, M. E. Hinz, A., Zenger, M., Härter, M., Nater, U., & Brähler, E. (2018). Social support in the general population: standardization of the Oslo social support scale (OSSS-3). *BMC Psychology 6* (31). https://doi.org/10.1186/s40359-018-0249-9

Kyriacou, O., Treasure, J., & Schmidt, U. (2008). Understanding how parents cope with living with someone with anorexia nervosa: Modelling the factors that are associated with carer distress. *International Journal of Eating Disorders*, *41*(3), 233–242. https://doi.org/10.1002/eat.20488

Lafrance Robinson, A., Dolhanty, J., Stillar, A., Henderson, K., Mayman, S., Robinson, A. L., Dolhanty, J., Stillar, A., Henderson, K., & Mayman, S. (2014). Emotion-focused family therapy for eating disorders across the lifespan: A pilot study of a 2-day transdiagnostic intervention for parents. *Clinical Psychology & Psychotherapy*, *23*(1), 14–23. https://doi.org/10.1002/cpp.1933

Lafrance, A., Strahan, E. J., & Stillar, A. (2022). Treatment-engagement fears in family-oriented interventions: validation of the caregiver traps scale for eating disorders. *Eating Disorders, 30*(6), 670-685. https://doi.org/10.1080/10640266.2021.1993706

Latzer, Y., Katz, R., & Berger, K. (2015). Psychological distress among sisters of young females with eating disorders: The role of negative sibling relationships and sense of coherence. *Journal of Family Issues*, *36*(5), 626–646. https://doi.org/10.1177/0192513X13487672

Levinson, C. A., & Byrne, M. (2014). The fear of food measure: A novel measure for use in exposure therapy for eating disorders. *International Journal of Eating Disorders, 48*(3), 271–283. https://doi.org/10.1002/eat.22344

Liddle, E. B., Batty, M. J., & Goodman, R. (2009). The social aptitudes scale: An initial validation. *Social Psychiatry and Psychiatric Epidemiology, 44,* 508-513. https://doi.org/10.1007/s00127-008-0456-4

Lock, J. (2018). Family therapy for eating disorders in youth: Current confusions, advances, and new directions. *Current Opinion in Psychiatry*, *31*(6), 431–435. https://doi.org/10.1097/YCO.0000000000000451

Lovibond, S. H., & Lovibond, P. F. (1993). Manual for the depression anxiety stress scales (DASS). Psychology Foundation Monograph. *Sydney, Australia: University of New South Wales*.

Magill, N., Rhind, C., Hibbs, R., Goddard, E., Macdonald, P., Arcelus, J., Morgan, J., Beecham, J., Schmidt, U., & Landau, S. (2016). Two-year follow-up of a pragmatic randomised controlled trial examining the effect of adding a carer's skill training intervention in inpatients with anorexia nervosa. *European Eating Disorders Review*, *24*(2), 122–130. https://doi.org/10.1002/erv.2422

Maloney, M. J., McGuire, J. B., & Daniels, S. R. (1988). Reliability testing of a children's version of the Eating Attitude Test. J*ournal of the American Academy of Child & Adolescent Psychiatry, 27*(5), 541-543. https://doi.org/10.1097/00004583-198809000-00004

Maon, I., Horesh, D., & Gvion, Y. (2020). Siblings of individuals with eating disorders: A review of the literature. *Frontiers in Psychiatry*, *11*, 604. https://doi.org/10.3389/fpsyt.2020.00604

Marcos, Y. Q., Quiles Sebastián, M. J., Aubalat, L. P., Sepúlveda García, A. R., & Treasure, J. (2016). The Spanish validation of the Accommodation and Enabling Scale for Eating Disorders among carers: A pilot study. *European Eating Disorders Review*, *24*(1), 62–68. https://doi.org/10.1002/erv.2378

Martín, J., Padierna, A., van Wijngaarden, B., Aguirre, U., Anton, A., Muñoz, P., & Quintana, J. M. (2015). Caregivers consequences of care among patients with eating disorders, depression or schizophrenia. *BMC Psychiatry*, *15*(1), 124. https://doi.org/10.1186/s12888-015-0507-9

Monteleone, A. M., Cascino, G., Salerno, L., Schmidt, U., Micali, N., Cardi, V., & Treasure, J. (2022). A network analysis in adolescent anorexia nervosa exploring the connection between both patient and carer reactions and outcome. *European Eating Disorders Review*. https://doi.org/10.1002/erv.2933

MQ. (2019). *UK Mental Health Research Funding*. https://www.mqmentalhealth.org/wp-content/uploads/UKMentalHealthResearchFunding2014-2017digital.pdf

NHS England. (n.d.). *Who is considered a carer?* https://www.England.Nhs.Uk/Commissioning/Comm-Carers/Carers/

NICE. (2017). *Eating disorders: Recognition and treatment*. NICE Guidelines. https://www.nice.org.uk/guidance/ng69

Olson, D. H., Portner, J., & Bell, R. Q. (1982). FACES II: Family adaptability and cohesion evaluation scales. Minnesota: Family Social Science, University of Minnesota.

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—a web and mobile app for systematic reviews. *Systematic Reviews*, *5*(1), 1–10. https://doi.org/10.1186/s13643-016-0384-4

Padierna, A., Martín, J., Aguirre, U., González, N., Muñoz, P., & Quintana, J. M. (2013). Burden of caregiving amongst family caregivers of patients with eating disorders. *Social Psychiatry and Psychiatric Epidemiology: The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*, *48*(1), 151–161. https://doi.org/10.1007/s00127-012-0525-6

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., & Brennan, S. E. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *Systematic Reviews*, *10*(1), 1–11. https://doi.org/10.1136/bmj.n71

Perkins, S., Winn, S., Murray, J., Murphy, R., & Schmidt, U. (2004). A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: The emotional impact of caring. *International Journal of Eating Disorders*, *36*(3), 256–268. https://doi.org/10.1002/eat.20067

Philipp, J., Truttmann, S., Zeiler, M., Franta, C., Wittek, T., Schöfbeck, G., Mitterer, M., Mairhofer, D., Zanko, A., & Imgart, H. (2020). Reduction of high expressed emotion and treatment outcomes in anorexia nervosa - Caregivers' and adolescents' perspective. *Journal of Clinical Medicine*, *9*(7), 2021. https://doi.org/10.3390/jcm9072021

Qian, J., Wu, Y., Liu, F., Zhu, Y., Jin, H., Zhang, H., Wan, Y., Li, C., & Yu, D. (2022). An update on the prevalence of eating disorders in the general population: A systematic review and meta-analysis. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*, *27*(2), 415–428. https://doi.org/10.1007/s40519-021-01162-z

Raenker, S., Hibbs, R., Goddard, E., Naumann, U., Arcelus, J., Ayton, A., Bamford, B., Boughton, N., Connan, F., Goss, K., Lazlo, B., Morgan, J., Moore, K., Robertson, D., Schreiber-Kounine, C., Sharma, S., Whitehead, L., Beecham, J., Schmidt, U., & Treasure, J. (2013). Caregiving and coping in carers of people with anorexia nervosa admitted for intensive hospital care. *International Journal of Eating Disorders, 46*(4), 346-354.

Reas, D. L. (2017). Public and healthcare professionals' knowledge and attitudes toward binge eating disorder: A narrative review. *Nutrients*, *9*(11), 1267. https://doi.org/10.3390/nu9111267

Rhind, C., Hibbs, R., Goddard, E., Schmidt, U., Micali, N., Gowers, S., Beecham, J., Macdonald, P., Todd, G., Tchanturia, K., & Treasure, J. (2014). Experienced Carers Helping Others (ECHO): Protocol for a pilot randomised controlled trial to examine a psycho-educational intervention for adolescents with anorexia nervosa and their carers. *European Eating Disorders Review*, *22*(4), 267–277. https://doi.org/10.1002/erv.2298

Rhind, C., Salerno, L., Hibbs, R., Micali, N., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., Tchanturia, K., lo Coco, G., & Treasure, J. (2016). The objective and subjective caregiving burden and caregiving behaviours of parents of adolescents with anorexia nervosa. *European Eating Disorders Review*, *24*(4), 310–319. https://doi.org/10.1002/erv.2442

Rhodes, P., Baillie, A., Brown, J., & Madden, S. (2005). Parental efficacy in the family-based treatment of anorexia: Preliminary development of the Parents Versus Anorexia Scale (PVA). *European Eating Disorders Review, 13*(6), 399-405. https://doi.org/10.1002/erv.661

Rienecke, R. D. (2020). Emotional overinvolvement with adolescents: A problematic construct? *Current Treatment Options in Psychiatry*, *7*(2), 162–185. https://doi.org/10.1007/s40501-020-00205-z

Rienecke, R. D., & le Grange, D. (2022). The five tenets of family-based treatment for adolescent eating disorders. *Journal of Eating Disorders*, *10*(1), 1–10. https://doi.org/10.1186/s40337-022-00585-y

Roberts, M. E., Barthel, F. M.-S., Lopez, C., Tchanturia, K., & Treasure, J. L. (2011). Development and validation of the Detail and Flexibility Questionnaire (DFlex) in eating disorders. *Eating Behaviors*, *12*(3), 168–174. https://doi.org/10.1016/j.eatbeh.2011.04.001

Robinson, I., Stoyel, H., & Robinson, P. (2020). 'If she had broken her leg she would not have waited in agony for 9 months': Caregiver's experiences of eating disorder treatment. *European Eating Disorders Review*. https://doi.org/10.1002/erv.2780

Royal College of Psychiatrists. (2022). *Medical emergencies in eating disorders (MEED): Guidance on recognition and management.*

Salerno, L., Rhind, C., Hibbs, R., Micali, N., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., & Coco, G. (2016). An examination of the impact of care giving styles (accommodation and skilful communication and support) on the one year outcome of adolescent anorexia nervosa: Testing the assumptions of the cognitive interpersonal model in anorexia nervosa. *Journal of Affective Disorders*, *191*, 230–236. https://doi.org/10.1016/j.jad.2015.11.016

Santomauro, D. F., Melen, S., Mitchison, D., Vos, T., Whiteford, H., & Ferrari, A. J. (2021). The hidden burden of eating disorders: An extension of estimates from the Global Burden of Disease Study 2019. *The Lancet Psychiatry*, *8*(4), 320–328. https://doi.org/10.1016/S2215-0366(21)00040-7

Scahill, L., Riddle, M. A., McSwiggin-Hardin, M., Ort, S. I., King, R. A., Goodman, W. K., ... & Leckman, J. F. (1997). Children's Yale-Brown obsessive compulsive scale: Reliability and validity. *Journal of the American Academy of Child & Adolescent Psychiatry, 36*(6), 844-852. https://doi.org/10.1097/00004583-199706000-00023

Schmidt, U., & Treasure, J. (2006). Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology*, *45*(3), 343–366. https://doi.org/10.1348/014466505x53902

Schmit, S. E., & Bell, N. J. (2017). Close relationships and disordered eating: Partner perspectives. *Journal of Health Psychology*, *22*(4), 434–445. https://doi.org/10.1177/1359105315603478

Sepulveda, A. R., Kyriacou, O., & Treasure, J. (2009). Development and validation of the Accommodation and Enabling Scale for Eating Disorders (AESED) for caregivers in eating disorders. *BMC Health Services Research*, *9*. https://doi.org/10.1186/1472-6963-9-171

Sepulveda, A. R., Whitney, J., Hankins, M., Treasure, J., AR, S., Whitney, J., Hankins, M., & Treasure, J. (2008). Development and validation of an Eating Disorders Symptom Impact Scale (EDSIS) for carers of people with eating disorders. *Health & Quality of Life Outcomes*, *6*, 28. https://doi.org/10.1186/1477-7525-6-28

Shaw, H., Robertson, S., & Ranceva, N. (2021). What was the impact of a global pandemic (COVID-19) lockdown period on experiences within an eating disorder service? A service evaluation of the views of patients, parents/carers and staff. *Journal of Eating Disorders*, *9*(1), 1–11. https://doi.org/10.1186/s40337-021-00368-x

Snaith, R.P. (2003). The Hospital Anxiety and Depression Scale. *Health Quality Life Outcomes 1*, 29. https://doi.org/10.1186/1477-7525-1-29

Soenens, B., Vansteenkiste, M., Vandereycken, W., Luyten, P., Sierens, E., & Goossens, L. (2008). Perceived parental psychological control and eating-disordered symptoms: Maladaptive perfectionism as a possible intervening variable. *The Journal of Nervous and Mental Disease*, *196*(2), 144–152. https://doi.org/10.1097/NMD.0b013e318162aabf

Stefanini, M. C., Troiani, M. R., Caselli, M., Dirindelli, P., Lucarelli, S., Caini, S., & Martinetti, M. G. (2019). Living with someone with an eating disorder: Factors affecting the caregivers' burden. *Eating and Weight Disorders : EWD*, *24*(6), 1209–1214. https://doi.org/10.1007/s40519-018-0480-7

Stillar, A., Merali, N., Gusella, J., Scarborough, J., Nash, P., Orr, E., Henderson, K., Mayman, S., Files, N., & Lafrance, A. (2022). Caring for a child with an eating disorder: Understanding differences among mothers and fathers of adolescent and adult children. *European Eating Disorders Review*. https://doi.org/10.1002/erv.2935

Stillar, A., Strahan, E., Nash, P., Files, N., Scarborough, J., Mayman, S., Henderson, K., Gusella, J., Connors, L., & Orr, E. S. (2016). The influence of carer fear and self-blame when supporting a loved one with an eating disorder. *Eating Disorders*, *24*(2), 173–185. https://doi.org/10.1080/10640266.2015.1133210

Storch, E. A., Geffken, G. R., Merlo, L. J., Jacob, M. L., Murphy, T. K., Goodman, W. K., Larson, M. J., Fernandez, M., & Grabill, K. (2007). Family accommodation in pediatric obsessive–compulsive disorder. *Journal of Clinical Child and Adolescent Psychology*, *36*(2), 207–216. https://doi.org/10.1080/15374410701277929

Storch, E. A., Merlo, L. J., Larson, M. J., Marien, W. E., Geffken, G. R., Jacob, M. L., Goodman, W. K., & Murphy, T. K. (2008). Clinical features associated with treatment-resistant pediatric obsessive-compulsive disorder. *Comprehensive Psychiatry*, *49*(1), 35–42. https://doi.org/10.1016/j.comppsych.2007.06.009

Szmukler, G. I., Burgess, P., Herrman, H., Bloch, S., Benson, A., & Colusa, S. (1996). Caring for relatives with serious mental illness: The development of the Experience of Caregiving Inventory. *Social Psychiatry and Psychiatric Epidemiology*, *31*(3), 137–148. https://doi.org/10.1007/BF00785760

Tennant, J. P., & Ross-Hellauer, T. (2020). The limitations to our understanding of peer review. *Research Integrity and Peer Review*, *5*(1), 1–14. https://doi.org/10.1186/s41073-020-00092-1

Timko, C. A., Dennis, N. J., Mears, C., Rodriguez, D., Fitzpatrick, K. K., & Peebles, R. (2022). Post-traumatic stress symptoms in parents of adolescents hospitalized with Anorexia nervosa. *Eating Disorders*, 1–13. https://doi.org/10.1080/10640266.2022.2099604

Timko, C. A., & Fitzpatrick, K. K. (2016). Revision of the Accommodation and Enabling Scale for Eating Disorders for use with children and adolescents. Unpublished measure.

Treasure, J., Duarte, T. A., & Schmidt, U. (2020). Eating disorders. *The Lancet*, *395*(10227), 899–911. https://doi.org/10.1016/S0140-6736(20)30059-3

Treasure, J., & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: A summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders*, *1*(1), 13. https://doi.org/10.1186/2050-2974-1-13

Treasure, J., Willmott, D., Ambwani, S., Cardi, V., Clark Bryan, D., Rowlands, K., & Schmidt, U. (2020). Cognitive interpersonal model for anorexia nervosa revisited: The perpetuating factors that contribute to the development of the severe and enduring illness. *Journal of Clinical Medicine*, *9*(3), 630. https://doi.org/10.3390/jcm9030630

Vandereycken, W. (1992). Validity and reliability of the Anorectic Behavior Observation Scale for parents. *Acta Psychiatrica Scandinavica, 85*(2), https://doi.org/163-166. 10.1111/j.1600-0447.1992.tb01462.x

Viljoen, D., King, E., Harris, S., Hollyman, J., Costello, K., Galvin, E., Stock, M., Schmidt, U., Downs, J., & Sekar, M. (2022). *The alarms should no longer be ignored: A survey of the demand, capacity and provision of adult community eating disorder services in England and Scotland*. https://doi.org/10.31234/osf.io/6eszj

Wagner, A. F., Zickgraf, H. F., & Lane-Loney, S. (2020). Caregiver accommodation in adolescents with avoidant/restrictive food intake disorder and anorexia nervosa:

Relationships with distress, eating disorder psychopathology, and symptom change. *European Eating Disorders Review*, *28*(6), 657–670. https://doi.org/10.1002/erv.2786

Wang, S. B., Gray, E. K., Coniglio, K. A., Murray, H. B., Stone, M., Becker, K. R., Thomas, J. J., & Eddy, K. T. (2021). Cognitive rigidity and heightened attention to detail occur transdiagnostically in adolescents with eating disorders. *Eating Disorders*, *29*(4), 408–420. https://doi.org/10.1080/10640266.2019.1656470

Weber, D. M., Fischer, M. S., Baucom, D. H., Baucom, B. R. W., Kirby, J. S., Runfola, C. D., Matherne, C. E., & Bulik, C. M. (2019). The association between symptom accommodation and emotional coregulation in couples with binge eating disorder. *Family Process*, *58*(4), 920–935. https://doi.org/10.1111/famp.12391

Weiss, D. S. (2007). The impact of event scale: Revised. In J. P. Wilson & C. So-Kum Tang (Eds.), *Cross-cultural assessment of psychological trauma and PTSD* (pp. 219-238). Springer New York. https://doi.org/10.1007/978-0-387-70990-1

Whitelaw, M., Lee, K. J., Gilbertson, H., & Sawyer, S. M. (2018). Predictors of complications in anorexia nervosa and atypical anorexia nervosa: Degree of underweight or extent and recency of weight loss? *Journal of Adolescent Health*, *63*(6), 717–723. https://doi.org/10.1016/j.jadohealth.2018.08.019

Whitney, J., & Eisler, I. (2005). Theoretical and empirical models around caring for someone with an eating disorder: The reorganization of family life and inter-personal maintenance factors. *Journal of Mental Health*, *14*(6), 575–585. https://doi.org/10.1080/09638230500347889

Whitney, J., Murray, J., Gavan, K., Todd, G., Whitaker, W., & Treasure, J. (2005). Experience of caring for someone with anorexia nervosa: Qualitative study. *The British Journal of Psychiatry*, *187*(5), 444–449. https://doi.org/10.1192/bjp.187.5.444

Wiedemann, G., Rayki, O., Feinstein, E., & Hahlweg, K. (2002). The Family Questionnaire: Development and validation of a new self-report scale for assessing expressed emotion. *Psychiatry Research*, *109*(3), 265–279. https://doi.org/10.1016/S0165-1781(02)00023-9

Zabala, M. J., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: A systematic review. *European Eating Disorders Review*, *17*(5), 338–349. https://doi.org/10.1002/erv.925

Zickgraf, H. F., & Ellis, J. M. (2018). Initial validation of the Nine Item Avoidant/Restrictive Food Intake disorder screen (NIAS): A measure of three restrictive eating patterns. *Appetite, 123,* 32–42. https://doi.org/10.1016/j.appet.2017.11.111

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x

Tables and Figures

Table 1

General Search Terms Used (Excluding Database Specific Terms)

String	Search Terms
String 1	TI ("Eating Disorder*" OR "Anorexi* " OR "Bulim*" OR "Binge Eat*" OR “OSFED” OR “EDNOS” OR “ARFID” OR “UFED”) OR AB ("Eating Disorder*" OR "Anorexi* " OR "Bulim*" OR "Binge Eat*" OR “OSFED” OR “EDNOS” OR “ARFID” OR “UFED”)
String 2	AND TI ((caregiv* OR carer* OR family* OR partner* OR relative* OR relation* OR sibling* OR spouse OR wife OR wive* OR husband* OR partner* or brother* OR sister* OR aunt* OR uncle* OR grandparent*) N5 (accommodat* OR enabl* OR “recovery-interfering” OR facilitat* OR tolerat* OR reorgani* OR reinforc*) OR TI (“AESED”) OR AB ((caregiv* OR carer* OR family* OR partner* OR relative* OR relation* OR sibling* OR spouse OR wife OR wive* OR husband* OR partner* or brother* OR sister* OR aunt* OR uncle* OR grandparent*) N5 (accommodat* OR enabl* OR “recovery-interfering” OR facilitat* OR tolerat* OR reorgani* OR reinforc*) OR AB (“AESED”)
String 3	AND TI (Determinant* OR factor* OR cause* OR reason* OR predict* OR mediat* OR moderat* OR associate* OR correlat* OR impact OR consequence* OR effect OR influence) OR AB (Determinant* OR factor* OR cause* OR reason* OR predict* OR mediat* OR moderat* OR associat* OR correlat* OR impact OR consequence* OR effect OR influence)

Note. TI refers to title and AB refers to abstract.

Figure 1

Study Selection Flow Diagram

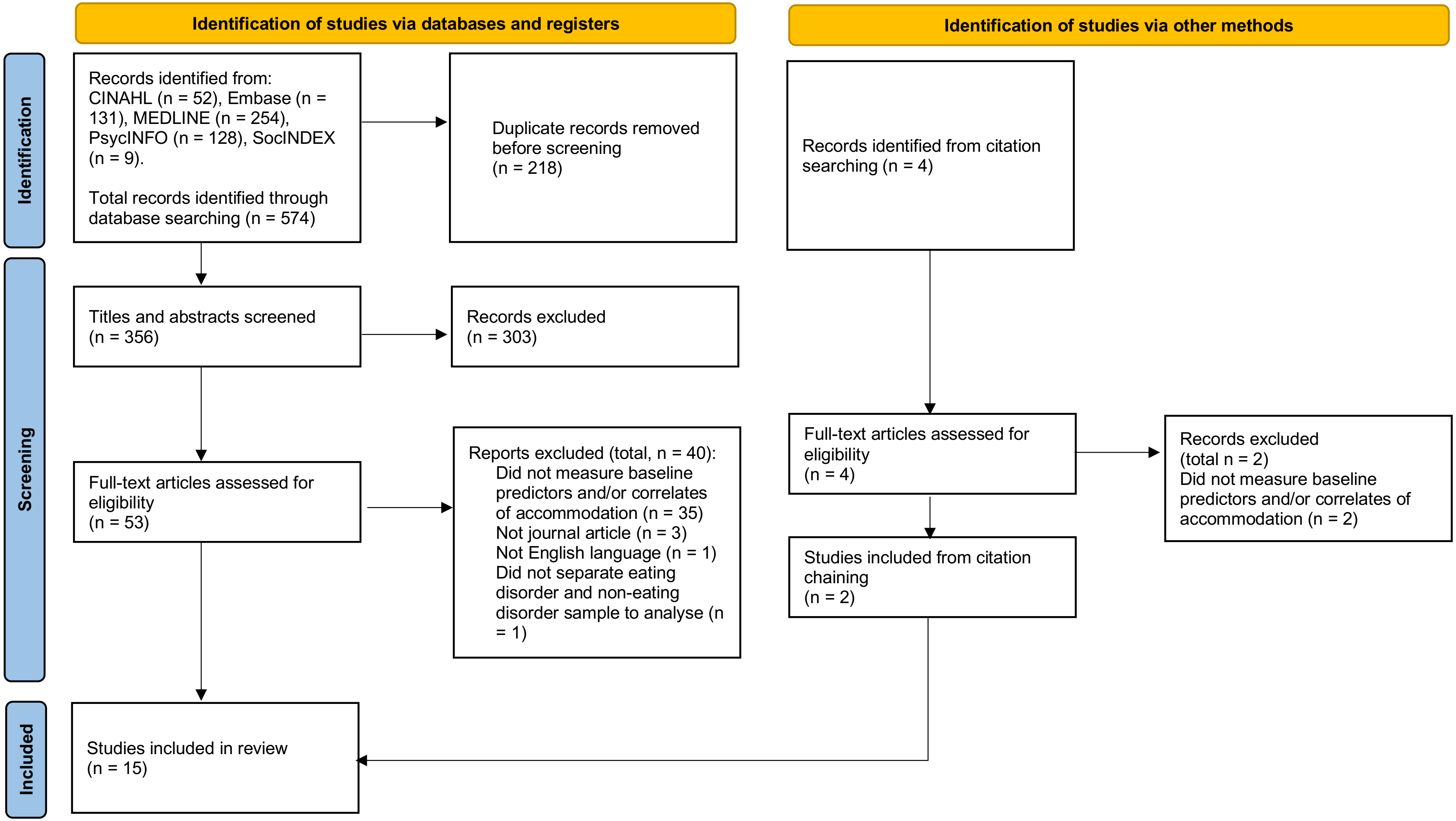


Table 2

Study Characteristics and Findings

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
Cross-sectional design of baseline data						
Goddard et al. (2013) Across England	Secondary data analysis - (Goddard, Raenker, et al., 2013) Examine the cognitive interpersonal maintenance model of anorexia nervosa.	Eating disorder symptoms (EDE-Q) Accommodation (AESED) Expressed emotion (FQ) Caregiver psychological control towards individual affected by eating disorder (PCS) Psychological distress (DASS-21)	Primary caregiver of individuals affected by anorexia nervosa or eating disorder not otherwise specified (EDNOS) with symptoms of anorexia nervosa. *N* = 152 Age (years): *M* = 51.5 (*SD* = 9.9) Gender: 81% female Caregiver type: 79% mothers, 6% fathers, 15% partner/ spouse, 1% other relative. Contact time: 70% living with individual prior to admission, 55% 21 or more hours prior to admission. Own lifetime difficulties with	Individual diagnosed with anorexia nervosa or EDNOS with symptoms of anorexia nervosa, 12 years or over. *N* = 152 Age (years): *M* = 25.4 years (*SD* = 8.5) Gender: 95% female Duration of ED (years): *M* = 6.7 (*SD* = 6.9)	Correlations Structural equation modelling	Accommodation significantly correlated with contact time distress ($r = .411, p < .01$), expressed emotion ($r = .523, p < .01$), psychological control ($r = .340, p < .01$), carer distress ($r = .384, p < .01$), patient distress ($r = .240, p < .01$). Using structural equation models, accommodation was not directly and significantly associated with caregiver distress. Accommodation was significantly associated with caregiver's history of eating difficulties and contact time.

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
			weight/ shape/ eating: 24% Received formal diagnosis of ED: 3.3%			
Hibbs et al. (2015) Across England	Development and validation of CASK	Caregiver skills (CASK) Psychological distress (DASS-21) General health (GHQ) Expressed emotion (FQ) Accommodation (AESED)	Caregivers of individuals affected by an ED. *N* = 325 Age (years): *M* = 49.4 years (*SD* = 7.6) Gender: 76% female, 24% male Caregiver type: Not available for full sample Ethnicity: White (British, Irish, Other): 95% Asian/Asian British/Mixed: 2% Other/missing: 3%	Not reported	Correlation analyses	Accommodation significantly negatively correlated with all CASK subscales, including total CASK (r = -.328, p < .01). Accommodation significantly correlated with expressed emotion (r = .608, p < .01), psychological distress (r = .423, p < .01) and general health (r = .460, p < .01)
Marcos et al. (2016) Alicante, Spain	Examine the Spanish version of the AESED	Accommodation (AESED-S) Anxiety and depression (HADS) Psychological distress (GHQ-12)	Caregivers currently living with the person affected by the eating disorder. *N* = 90 Age (years): *M* = 47.8 (*SD* = 8.1) Gender:	Individuals diagnosed with ED (DSM-4). Age (years): *M* = 18.8 years (*SD* = 6.0) Gender: 91.7% female Diagnosis: 55.7% anorexia nervosa restrictive, 9.8%	Correlational analyses	Positive and significant associations between experience of caregiving subscales and AESED-S subscales, except for meal ritual and the effects on family and loss subscales, and between control of family and need to back up subscales. Significant positive correlation between avoidance and modifying routines and depression (r = .46, p < .01), anxiety (r = .47, p < .01), general health (r = .37, p < .01), critical comments (r = .43, p <

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
		Experience of caregiving (ECI) Expressed emotion (FQ)	61.1% female, 38.9% male Caregiver type: 57.8% mothers, 32.2% fathers, 3.3% partners, 4.4% siblings, 2.2% other connection. Contact time: 48.1% of mothers and 42.9% of fathers were spending 21 or more hours with their loved one.	anorexia nervosa purgative, 6.6% bulimia nervosa purgative, 1.6% bulimia nervosa non-purgative, 13.1% eating disorder not otherwise specified.		.01), and emotional overinvolvement ($r = .52$, $p < .01$). Significant positive correlation between reassurance seeking and depression ($r = .35$, $p < .01$), anxiety ($r = .38$, $p < .01$), general health ($r = .36$, $p < .01$), critical comments ($r = .32$, $p < .01$), and emotional overinvolvement ($r = .49$, $p < .01$). Significant positive correlation between meal ritual and depression ($r = .27$, $p < .05$), critical comments ($r = .47$, $p < .01$), and emotional overinvolvement ($r = .22$, $p < .05$). Significant positive correlation between control of family and depression ($r = .36$, $p < .01$), anxiety ($r = .35$, $p < .01$), general health ($r = .40$, $p < .01$), critical comments ($r = .54$, $p < .01$), and emotional overinvolvement ($r = .47$, $p < .01$). Significant positive correlation between turning a blind eye and critical comments ($r = .37$, $p < .01$).
Rhind et al. (2016) Across England	Secondary data analysis (Rhind et al., 2014). Examination of caregiver burden, distress, accommodation, expressed emotion and skills, in caregivers of adolescents	Objective burden (Care-ED) Subjective burden and psychological distress (DASS-21) Accommodation (AESED) Expressed emotion (FQ)	Parents, living with, individuals newly referred for eating disorder team. $N = 196$ Age (years): $M = 48.4$ years ($SD = 4.9$) for mothers, and 49.5 years ($SD = 5.7$) fathers or stepfathers.	Adolescents (13-21 years) diagnosed with anorexia nervosa or eating disorder not otherwise specified anorexia nervosa subtype (DSM-4). $N = 144$ Age (years): $M = 16.8$ years ($SD = 2.1$) Gender: 91.7% female	Hierarchical linear modelling Spearman's correlation Mediation analysis	Accommodation behaviours lower in fathers, than mothers ($t = -2.535$, $p < .05$). Mothers' time spent caregiving was significantly correlated with their accommodation ($r = .32$, $p < .001$). Levels of accommodation were significantly positively correlated with expressed emotion ($r = .58$, $p < .001$) and caregiver distress ($r = .41$, $p < .001$), and negatively correlated with carer skills ($r = -.44$, $p < .001$) and social support ($r = -.32$, $p < .005$).

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
	affected by anorexia nervosa.	Perceived expressed emotion from individual affected by ED (BDSEE) Social support (OSSS-3) Carer skills (CASK) Obsessive-compulsive symptom severity (CY-BOCS-SR) Social aptitude (SAS) Self-reported eating disorder symptom severity (SEED)	Ethnicity of mothers: 91.8% White British/Other White, 1.5% Asian/ Asian British/ Other Asian, 0.7% Mixed White and Black African Caribbean, 4.4% Missing Ethnicity of fathers: 82% White British/Other White, 3.3% Asian/ Asian British/ Other Asian, 1.6% Mixed White and Black African Caribbean, 13.1% Missing Caregiver type: 68.9% mothers, 31.1% fathers or stepfathers. Contact time: 75% reported spending 21 or more hours face-to-face contact with child (mothers 80%, fathers 68%), and 80% reported up to 7 hours per week in other contact. Eating/ weight problems: 31%	Ethnicity: 88.9% White British/Other White, 2.8% Asian/ Asian British/ Other Asian, 2.1% Mixed White and Black African Caribbean, 6.3% Missing		Social aptitude of the individual affected by the ED was significantly negative correlated with mothers' accommodation ($r = -.33$, $p < .005$) and distress ($r = -.264$, $p < .005$). Mothers: Total time spent caregiving (predictor) significantly related to accommodation (mediator) ($\beta = .32$, $p < .001$). Total time spent caregiving (predictor) significantly associated with caregiver distress ($\beta = .24$, $p < .01$). Mothers and fathers: Accommodation (mediator) significantly related to caregiver distress ($\beta = .38$, $p < .001$ and $\beta = .39$, $p < .01$ respectively).

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
			mothers, 17% fathers.			
Sepulveda et al. (2009) London, UK	Validation of AESED, examine whether accommodation is related to depression and/or anxiety, expressed emotion and negative aspects of caregiving.	Anxiety and depression (HADS) Experience of caregiving (ECI) Expressed emotion (FQ) Accommodation (AESED)	Primary caregivers of individuals affected by an ED. *N* = 193 Age (years): *M* = 49.6 (*SD* = 8.4) Caregiver type: 91.0% parents, 5.2% husband/ partner, 3.8% sibling/friend. 85.5% female Contact time: 78.0% currently living with the individual affected by the eating disorder. 60.6% 21 or more hours contact. Previous eating difficulties (not diagnosed): 24%	Individuals affected by an ED. *N* = 193 Age (years): *M* = 21.3 (*SD* = 6.8) Gender: 98% female Clinical symptoms, based on caregiver reports: 90% restrict food, 49.4% over-exercising, 34.2% vomiting, 26% binge eating, 10.5% stole food/money for binge eating, 45% comorbid impulsive behaviours.	Correlational analyses	Significant correlation between avoidance and reassurance seeking and experience of caregiving (Spearman's rho = .45, *p* < .01), depression (Spearman's rho = .47, *p* < .01), anxiety (Spearman's rho = .48, *p* < .01), critical comments (Spearman's rho = .51, *p* < .01) and emotional overinvolvement (Spearman's rho = .44, *p* < .01). Significant correlation between reassurance seeking and experience of caregiving (Spearman's rho = .33, *p* < .01), depression (Spearman's rho = .17, *p* < .05), anxiety (Spearman's rho = .30, *p* < .01), critical comments (Spearman's rho = .17, *p* < .05). Significant correlation between meal ritual and experience of caregiving (Spearman's rho = .18, *p* < .05), depression (Spearman's rho = .31, *p* < .01), critical comments (Spearman's rho = .18, *p* < .05) and emotional overinvolvement (Spearman's rho = .17, *p* < .05). Significant correlation between control of family and experience of caregiving (Spearman's rho = .24, *p* < .01), depression (Spearman's rho = .34, *p* < .01), anxiety (Spearman's rho = .26, *p* < .01), critical comments (Spearman's rho = .26, *p* < .01) and emotional overinvolvement (Spearman's rho = .18, *p* < .05). Significant correlation between turning a blind eye and experience of caregiving (Spearman's rho = .36, *p* < .01), anxiety (Spearman's rho = .24, *p* <

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
						.01), critical comments (Spearman's rho = .31, $p < .01$) and emotional overinvolvement (Spearman's rho = .21, $p < .05$). Significant correlation between total accommodation and experience of caregiving (Spearman's rho = .43, $p < .01$), depression (Spearman's rho = .45, $p < .01$), anxiety (Spearman's rho = .48, $p < .01$), critical comments (Spearman's rho = .49, $p < .01$) and emotional overinvolvement (Spearman's rho = .40, $p < .01$). Caregivers of those affected by anorexia nervosa had higher control of family ($p = 0.046$) and turning a blind eye ($p = 0.001$) than caregivers of those affected by bulimia nervosa. Caregivers who reported their loved one to experience more co-morbid impulsive behaviours engaged in more reassurance seeking ($p = 0.018$) and turning a blind eye ($p = 0.035$) than those without comorbidities. Caregivers who had contact with their loved one for 21 hours or more experienced more avoidance and modifying behaviours ($p = 0.012$), reassurance seeking ($p = 0.009$), meal rituals ($p = 0.010$), control family ($p = 0.001$) and overall accommodation ($p = 0.005$) compared to those with less than 21 hours contact. Mothers who experienced their own eating problems previously experienced more meal rituals ($p = 0.052$), turning a blind eye ($p = 0.002$) and overall accommodation ($p = 0.032$) compared to mothers who had not.

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
Stillar et al. (2022) Across Canada	Secondary data analysis (Lafrance Robinson et al., 2014) Aimed to investigate 1) whether there are differences in mothers and fathers self-reported levels of treatment-engagement fears and self-efficacy, 2) if emotional responses are related to accommodation, 3) are there differences in parents' emotional experiences to the eating disorder.	Parents' vulnerability to treatment-engagement fears (CTS) Parental self-efficacy (PvA) Accommodation (AESED)	Parents of children affected by an ED. *N* = 143 Caregiver type: 66.4% mothers 33.6% fathers Age of child affected by ED: 57.3% child affected by ED under 18 42.7% child affected by ED an adult	Data taken from reports only. *N* = 143 Age (years): *M* = 18, range 8 – 41 Gender: 100% female Treatment status: 54.5% in treatment for ED, 19.6% waiting list, 17.5% reported "other", (8.4% did not complete). Behaviour duration: *M* = 1.84 years for adolescent children, 5 years for adults. Range 2 months to 20 years. Behaviours: 83.6% reported to engage in food restriction, 41.8% binge eating, 33.6% purging, 48.5% over-exercising, 6.7% laxative use.	Factorial Multivariate Analysis of Variance Mediation via multiple regression	Mothers: First regression model: treatment-engagement fear significantly predicted accommodation F (1, 55) = 20.00, $p < 0.001$, $R^2 = 0.27$, Adjusted $R^2 = 0.25$, treatment- engagement fear b coefficient = 0.65 (SE = 0.15), treatment-engagement fear β (beta) coefficient = 0.52. Third regression model: treatment-engagement fear and self-efficacy significantly predicted accommodation F (2, 53) = 10.06, p < 0.001, R2 = 0.28, Adjusted R2 = 0.25, b coefficient for self-efficacy = 0.71 (SE = 0.87), self-efficacy β (beta) coefficient = 0.10., treatment-engagement fear b coefficient = 0.67 (SE = 0.15), treatment-engagement fear β (beta) coefficient = 0.54. The treatment-engagement fear b coefficient increased from 0.65 to 0.67 and the β (beta) coefficient increased from 0.52 to 0.54, from the first to third regression. Fathers: Neither self-efficacy not treatment-engagement fear predicted accommodation.
Cross-Sectional						
Anastasiadou et al. (2016) Madrid, Spain	Examine whether family functioning and how the family	Disordered eating attitudes and behaviours (EAT-26)	Mothers and fathers of individuals affected by eating disorders.	Individuals aged 12 – 18 years, diagnosis of restrictive or non-	Spearman rank correlation	Non-significant differences in accommodation between mothers and fathers.

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
	respond to the ED are related to treatment outcomes. Explore whether there are differences between the responses from mothers and fathers.	Anxiety and depression (HADS) Experience of caregiving (ECI) Accommodation (AESED) Expressed emotion (FQ) Family adaptability and cohesion (FACES-II)	*N* = 48 mothers, 45 fathers Age (years): Mothers: *M* = 44.9 years (*SD* = 4.6), fathers: *M* = 47.5 years (*SD* = 4.1). Contact time: 90.3% living with their child 85.4% mothers and 68.9% of fathers had 21 or more contact hours per week History of ED: 20.8% mothers and 13.3% fathers And/ or mental health disorder (27.1% and 13.3% respectively).	purging type ED (DSM-4-revised). *N* = 50 Gender: 98% females, 2% male ED duration (months): *M* = 15.7 (*SD* = 12.6). Diagnosis: 78% anorexia nervosa restrictive type, 16% eating disorder not otherwise specified restrictive type, 6% bulimia nervosa non-purging type. 56% comorbid diagnosis of major depressive disorder.	Multiple regression	Accommodation total positively correlated with disordered eating attitudes and behaviours (r_s = 0.36, p < .05) for mothers and fathers. For fathers, anxiety (β = 0.36, p = .014) and accommodation (β = 0.34, p = .021) accounted for 31% of variance in symptom severity.
Anderson et al. (2021) Minneapolis, United States of America	Examination of the relationship between accommodation, caregiver distress, family functioning and treatment outcomes (for cognitive behavioural therapy for	Accommodation (AESED) Anxiety symptoms (PROMIS-A) Family functioning (FAD)	Family members of individuals admitted to speciality residential programme. *N* = 40 Age (years): *M* = 50.38 ± 7.64. Ethnicity: 95% Caucasian	Adolescents and adults admitted to speciality residential treatment for eating disorders, between 2015-2016. *N* = 18 Age (years): *M* = 22.17 ± 5.32, range 15 – 36 Gender:	Pearson bivariate correlation	Higher total accommodation score, and avoidance and modifying routine scores, were significantly correlated to higher anxiety symptoms RROMIS-A scores (*r* = .31 *p* < .01, and .42, *p* < .05, respectively). Higher turning the blind eye scores (accommodation) were significantly correlated with higher family functioning roles and behavioural control (*r* = .41, *p* < .05 and .43, *p* < .01, respectively).

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
	eating disorders).	Self-reported eating disorder symptoms (EDE-Q)	Caregiver type: 72.5% mothers, 15% fathers, 12.5% spouses. Contact time: 75% lived full time with the individual, 90% engaged in family therapy.	66.7% female Ethnicity: 100% Caucasian Diagnosis (DSM-5): 83.3% anorexia nervosa, 5.6% bulimia nervosa, 11.1% other specified feeding and eating disorder.		Baseline accommodation predicts eating disorder symptoms at end of treatment (B = .02, $SE(B)$ = .01, β = .34, *Wald* $\chi2$ = 5.21, p = .023).
Stefanini et al. (2019) Florence and Empoli, Italy	Aimed to identify characteristics of caregivers which expose them to high levels of stress, anxiety, depression and expressed emotion.	Accommodation (AESED) Expressed emotion (FQ) Psychological distress (DASS-21)	Caregivers of individuals diagnosed with any DSM-5 ED. N = 97 Age (years): M = 48.8 years Gender: 57.7% females, 42.3% males Caregiver type: 94.8% parent, 5.2% spouse/ partner Contact time: 82.5% defined as primary caregiver 94.8% lived with individual affected by eating disorder 64.5% spent 21 or more hours with the individual Mental health history:	Individuals diagnosed with any DSM-5 ED, seen between May 2012 – June 2014, in the outpatient or inpatient setting. N = 62 Age (years): M = 17.5 years Gender: 88.1% female ED duration (years): M= 2.8 Comorbidities: no significant reported Treatment type: 52.6% outpatient, 47.4% inpatient	Student's t tests	Caregivers of those affected by anorexia nervosa had higher scores for avoidance and modifying routine, than caregivers of those affected by bulimia nervosa (mean score 16.5 vs. 9.5, p = 0.02), for reassurance seeking (mean score 14.6 vs. 8.1, p = 0.05), and for total accommodation score (mean score 47.0 vs. 29.4, p = 0.03). Accommodation did not differ according to the time spent with the caregiver, nor inpatient and outpatient. Caregivers who had experienced an ED had statistically greater scores around reassurance seeking compared to those who had not (mean score 17.0 vs. 12.2, p = 0.03) and total accommodation score (mean score 52.2 vs. 41.6, p = 0.05). Primary caregivers had higher scores, compared to secondary carers, for avoidance and modifying routine (mean score 16.3 vs. 12.0, p = 0.05) and reassurance seeking (mean score 14.2 vs. 9.6, p = 0.05).

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
			29.7% declared themselves or another family member had experienced a psychiatric disorder (5.5%), an ED (17.6%) or both (6.6%).			
Stillar et al. (2016) Across Canada	Examined the relationship between fear, self-blame, self-efficacy, and accommodation, in caregivers of people affected by EDs.	Caregiver fear (CFS) Caregiver self-blame (CSBS) Caregiver self-efficacy (revised PvA) Accommodation (AESED)	Caregivers who partook in carer intervention. *N* = 137 Caregiver type: 69.0% biological parents, 5.8% stepparents, 1.5% romantic partners, 0.7% relative. Treatment status: 19% loved one waiting for treatment, 56.2% loved one actively involved in treatment, 18.2% families engaged in service, not specifically eating disorders.	Adolescents and adults receiving or waiting for treatment for an eating disorder. Based on caregiver report. *N* = 137 Age (years): *M* = 18 (*SD* = 5.06), range 12-41 Behaviours: 84.7% restricting, 39.4% binge eating, 48.2% over-exercising, 34.3% purging, 7.3% laxatives, 12.4% other symptoms such as self-harm. Duration of behaviours: 56.2% displayed ED symptoms less than one year ago, 14.6% one to two years,	Regression analyses	Caregiver fear positively predicted accommodation – the more fear felt, the greater the accommodation ($b = .36, p < .001$). Accommodation subscales: fear positively predicted control of family accommodation ($b = .22, p = .015$), reassurance seeking accommodation ($b = .24, p = .009$) and avoidance/modifying behaviours ($b = .40, p < .001$). Caregiver self-blame positively predicted accommodation ($b = .25, p = .01$). Caregiver self-blame positively predicted control of family ($b = .19, p = .03$), accommodation of meal rituals ($b = .21, p = .02$) and avoidance/modifying behaviours ($b = .21, p = .04$).

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
				12.4% more than two years (2-20 years).		
Wagner et al. (2020) Pennsylvania, United States of America	Explore accommodation in caregivers of individuals affected by anorexia nervosa or ARFID, and whether this relates to distress and eating psychopathology.	Accommodation (AESED) Self-report assessment of eating disorder symptoms (ChEAT) Distress related to caring for someone affected by an ED (EDSIS) Behavioural outcomes in exposure therapy related to eating disorders (FOFM) Symptoms associated with ARFID (NIAS)	Caregiver currently living with individual with diagnosis of anorexia nervosa or ARFID. *N* = 98 Caregiver type: 78.6% mothers, 16.3% fathers, 3.1% grandparent, 2% stepparent.	Children and adolescents diagnosed with anorexia nervosa restricting subtype, anorexia nervosa binge/purge subtype, or ARFID, who were admitted to partial hospitalisation programme. *N* = 98 Age (years): *M* = 13.74 (*SD* = 2.27*),* range 7.9 – 17.7 Gender: 75.5% female Ethnicity: 82.47% White, 5.1% Hispanic, 5.1% Other, 4.1% Asian, 3.1% Black. Diagnosis: 49% anorexia nervosa restricting, 11.2% anorexia binge/purge, 39.8% ARFID.	Independent samples *t* tests ANOVA analyses MANCOVA analyses Pearson correlation	At baseline, significant difference between accommodation of families of those affected by anorexia nervosa and ARFID (*F*[6, 87] = 2.43 *p* = .03, Wilks' l = 0.86, partial η2 = 0.14). Families of those affected by anorexia nervosa scored significantly higher on reassurance seeking (*M* = 10.26, *SD* = 7.53) than those affected by ARFID (*M* = 5.13, *SD* = 4.88; F[1, 92] = 8.85, *p* = .004). In caregivers of those affected by anorexia nervosa, accommodation avoidance significantly positively correlated with caregiver distress related to nutrition (*r* = .33, *p* < .05), picky eater symptoms associated with ARFID (*r* = .28, *p* < .05), appetite symptoms associated with ARFID (*r* = .29, *p* < .05), eating disorder dieting subscale (*r* = .36, *p* < .01), eating disorder symptoms total score (*r* = .35, *p* < .05). Total accommodation score significantly positively correlated with picky eater symptoms associated with ARFID (*r* = .30, *p* < .05). In caregivers of those affected by ARFID, accommodation avoidance significantly positively correlated with caregiver distress related to nutrition (*r* = .65, *p* < .01), oral control symptoms associated with ARFID (*r* = .33, *p* < .05). Accommodation reassurance seeking significantly positively correlated with eating disorder dieting subscale (*r* = .35, *p* < .05). Accommodation control of family significantly positively correlated with caregiver distress related to nutrition (*r* = .50, *p* < .01), fear symptoms

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
						associated with ARFID ($r = .33, p < .05$). Accommodation turning a blind eye significantly positively correlated with caregiver distress related to nutrition ($r = .38, p < .05$). Total accommodation score significantly positively correlated with caregiver distress related to nutrition ($r = .61, p < .01$), picky eater symptoms associated with ARFID ($r = .34, p < .05$).
Weber et al. (2019) North Carolina, United States of America	Exploration into the association between emotional arousal of individuals affected by binge eating disorder, and their partners, and whether this relates to accommodation.	Emotional arousal (F_0) Binge eating symptom severity (BES) Accommodation (AESED)	Partners who had participated in a couple-based intervention for binge eating disorder and had cohabited for at least six months. $N = 11$ Age (years): $M = 51.18$ ($SD = 14.40$) Gender: 72.7% male, 27.3% female Ethnicity: 91% White	Individuals who met DSM-5 criteria for BED or otherwise-specific feeing or eating disorder binge eating type, who had participated in a couple-based intervention for binge eating disorder. $N = 11$ Age: $M = 48.45$ ($SD = 12.03$) Gender: 72.7% female, 27.3% male	Linear regression Multilevel modelling approach	At baseline, the association between accommodation and binge eating severity was not significant ($B = -0.10, t = -0.50, p = .632$). Pre-treatment accommodation did not predict post-treatment binge eating severity ($F(3, 6) = 1.75, p = .256$), even when pre-treatment severity and gender were controlled ($B = 0.34, t = 1.58, p = .165$). Accommodation explained 17% of the variance in post-treatment severity, beyond the effects of pre-treatment severity and gender. Global levels of accommodation were not associated with emotional arousal in the conversation between partners. Significant cross-level interaction: when partners had high levels of accommodation, the emotional arousal of the individual affected by the eating disorder at any given time predicted the partners' subsequent arousal at the next time point.
Baseline accommodation studied in relation to intervention outcome						
Monteleone et al. (2022)	Secondary data analysis - baseline	Core eating disorder	Primary carers. $N = 149$	Adolescents (13-21 years) diagnosed with anorexia nervosa or	Partial correlational network	Depression of the individual affected by the eating disorder and accommodation were the nodes with

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
Across the United Kingdom	accommodation studied in relation to intervention outcome (from Rhind et al., 2014) Network analysis to predict clinical outcomes in individuals diagnosed with anorexia nervosa.	symptoms (SEED) Eating disorder-related impairment of psychosocial functioning (CIA) Psychological distress (DASS-21) Expressed emotion (FQ) Accommodation (AESED) Caregiver skills (CASK) Social support (OSSS-3)	Age (years): *M* = 48.09 (*SD* = 5.99) Gender: 95.3% female Caregiver type: 93.3% mothers, 4.7% fathers, 0.7% grandmother, 1.3% sibling.	eating disorder not otherwise specified anorexia nervosa subtype (DSM-4). Age (years): *M* = 16.89 (*SD* = 2.13) Gender: 91.9% female Primary diagnosis: 75.2% anorexia nervosa, 24.8% eating disorders not otherwise specified with restricting features. ED duration (months): *M* = 22.35 (*SD* = 22.37)	analysis, regression analyses	the highest bridge expected influence (BEI = 0.07 and 0.05 respectively). Accommodation was connected to depression of the individual affected by the eating disorder, caregiver social support, caregiver depression, emotional overinvolvement, caregiver skills and caregiver criticism. Caregivers' accommodation positively predicted BMI at 1 year.
Salerno et al. (2016) Across England	Secondary data analysis – baseline accommodation studied in relation to intervention outcome (Rhind et al., 2014). Examine parents'	Accommodation (AESED) Caregiver skills (CASK) Self-reported eating disorder symptom severity (SEED)	Parents of individuals newly referred for eating disorder team. Only included in analysis if both parents' data could be analysed. *N* = 108 Age (years): mothers, *M* = 49.2	Adolescents (13-21 years) diagnosed with anorexia nervosa or unspecified eating disorder. Age (years): *M* = 16.7 (*SD* = 2.0) Gender: 94.4% female Diagnosis: 74.1% anorexia nervosa,	Hierarchical linear modelling	Increased level of accommodation in mothers, compared to fathers, but did not reach significance (effects size: *d* = 0.26; *M* = 50.03 (*SD* = 22.70) and M = 44.58 (*SD* = 18.29) for mothers and fathers, respectively; *t* = 1.324, *p* = .189). Neither congruence nor incongruence of accommodating behaviours was related to initial symptoms of anorexia nervosa. Individual's symptoms of anorexia nervosa increase in a quadratic measure when both parents

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
	caregiving skills and accommodation behaviours, and investigate whether the congruence/ incongruence between each parent influences change in their child's symptoms of anorexia nervosa.		($SD = 4.7$), fathers, $M = 50.5$ ($SD = 6.4$) Caregiver type: 54 mothers and 54 fathers/ stepfathers (dyads)	25.9% unspecified eating disorder ED duration (months): $M = 19.8$ months ($SD = 2.1$)		have high baseline accommodation and decrease when both parents have low baseline accommodation. Demonstrates an interaction between congruence of accommodation and quadratic slope for change in anorexia nervosa symptoms ($b = 0.01$, SE = 0.00, $t = 2.125$, $p = 0.040$). Individual's symptoms of anorexia nervosa decreased when one parent had lower baseline accommodation compared to the other parent: significant negative curvature along line of congruence ($b = -0.03$, SE = 0.01, $t = -4.010$, p < .001). The slope along the line of incongruence was not significant.
Timko et al. (2022) Philadelphia, United States of America	Secondary data analysis - baseline accommodation studied in relation to intervention (from Timko et al. 2020, 2018) Examination of trauma symptoms in parents of young people hospitalised for medical stabilisation, with a diagnosis	Perceived post-traumatic stress symptoms (IES-R) Accommodation (AESED-R) Expressed emotion (FQ) Cognitive rigidity, attention to detail (DFlex) Experiential avoidance (AAQ-II)	Parents of a child hospitalised for medical stabilisation due to malnutrition resultant from anorexia nervosa. $N = 47$ Age (years): Mothers, $M = 42.9$ ($SD = 5.9$), fathers, $M = 45.6$ ($SD = 6.8$) Ethnicity: 90% caregivers reported not being Hispanic or Latina/o Caregiver type:	Adolescents (10-20 years) with a diagnosis of anorexia nervosa, hospitalised for medical stabilisation. $N = 37$ Age (years): $M = 14.8 \pm 2.4$, range 10.2-19.	Correlation of study variables at baseline	Mothers: Accommodation significantly correlated with impact of events scale intrusion ($r = .362$, $p < .05$), impact of events scale hyperarousal ($r = .384$, $p < .05$), impact of events scale avoidance ($r = .468$, $p < .01$), impact of events scale total ($r = .476$, $p < .01$), eating disorder symptoms ($r = .584$, $p < .05$), cognitive rigidity ($r = .354$, $p < .05$), attention to detail ($r = .344$, $p < .05$), psychological distress – stress ($r = .386$, $p < .05$), psychological distress – anxiety ($r = .382$, $p < .05$). Fathers: Accommodation significantly correlated with eating disorders symptoms ($r = .599$, $p < .05$), cognitive rigidity ($r = .624$, $p < .05$) and attention to detail ($r = .652$, $p < .05$). Note, accommodation was not significantly correlated with post-traumatic stress symptoms.

Author (Year) / Study Location	Study Aims	Factor(s) investigated / Measure	Carer demographics	Demographics of individual affected by eating disorder	Analysis	Predictors and/ or correlates of accommodation
	of anorexia nervosa.	Psychological distress (DASS-21) Eating disorder symptoms (ABOS)	72.3% mothers, 27.7% fathers (21.3% dyad).			

Note: AAQ-II, Acceptance and Action Questionnaire (Bond et al., 2011); ABOS, Anorectic Behavior Observation Scale (Vandereycken, 1992); AESED, The Accommodation and Enabling Scale for Eating Disorders (Sepulveda et al., 2009); AESED-R, The Accommodation and Enabling Scale for Eating Disorders Revised (Timko & Fitzpatrick, 2016); AESED-S, The Accommodation and Enabling Scale for Eating Disorders Spanish version (Marcos et al., 2016) BDSEE, The Brief Dyadic Scale of Expressed Emotion (Medina-Pradas et al., 2011); BES, Binge Eating Severity (Gormally et al., 1982); BMI, Body Mass Index; Care- ED (Raenker et al., 2013); CASK, Caregiver Skills Scale (Hibbs, Rhind, et al., 2015); CFS, Carer Fear Scale (Lafrance Robinson, 2014); CSBS, Carer Self-Blame Scale (Lafrance Robinson, 2014); ChEAT, Children's Eating Attitudes Test (Maloney et al., 1988); CIA, Clinical Impairment Assessment (Bohn & Fairburn, 2008); CTS, The Caregiver Traps Scale (Lafrance et al., 2021); CY-BOCS-SR, The Children's Yale-Brown Obsessive Compulsive Scale Self Report (Scahill et al., 1997); DASS-21, Depression, Anxiety and Stress Scales (Lovibond & Lovibond, 1993); DFlex, Detail and Flexibility Questionnaire (Roberts et al., 2011); DSM-4, The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994, 2002); DSM-5, The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013); EAT-26, The Eating Attitudes Test (Garner & Garfinkel, 1979); ECI, Experience of Caregiving Inventory (Szmukler et al., 1996); ED, Eating Disorder; EDE-Q, Eating Disorder Examination Questionnaire (Fairburn & Beglin, 1994); EDSIS, Eating Disorders Symptom Impact Scale (Sepulveda et al., 2008); F_0, Fundamental Voice Frequency (Atkinson, 1978); FACES-II, The Family Adaptability and Cohesion Scale (Olson et al., 1983); FAD, Family Assessment Device (Epstein et al., 1983); FOFM, Fear of Food Measure (Levinson & Byrne, 2015); FQ, The Family Questionnaire (Wiedemann et al., 2002); GHQ, General Health Questionnaire (Goldberg & Williams, 1988); HADS, Hospital Anxiety and Depression Scale (Snaith, 2003; Zigmond & Snaith, 1983); IES-R, Impact of Event Scale Revised (Weiss, 2007); NIAS, Nine Item Avoidant/Restrictive Food Intake Disorder Screen (Zickgraf & Ellis, 2018); OSSS-3, Oslo Social Support Scale (Kocalevent et al., 2018); PCS, Psychological Control Scale (Soenens et al., 2008); PROMIS-A, Patient-reported Outcome Measurement Information System Anxiety Short Form 8a (Cella et al., 2007); PvA, Parent Versus Anorexia Scale (Rhodes et al., 2005); SAS, Social Aptitude Scale (Liddle et al., 2009); SEED, Short Evaluation of Eating Disorders (Bauer et al., 2005).

Note: M = Mean, *SD* = Standard Deviation

Table 3

Quality Appraisal Scores Using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet et al., 2004)

Study	Question/ objective sufficiently described	Study design evident and appropriate?	Method of subject/comparison group selection *or* source of information/input variables described and appropriate?	Subject (and comparison group, if applicable) characteristics sufficiently described?	If interventional and random allocation was possible, was it described?	If interventional and blinding of investigators was possible, was it reported?	If interventional and blinding of subjects was possible, was it reported?	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?	Sample size appropriate?	Analytic methods described/justified and appropriate?	Some estimate of variance is reported for the main results?	Controlled for confounding?	Results reported in sufficient detail?	Conclusions supported by the results?	Score
Anastasiadou et al. (2016)	2	2	2	2	N/A	N/A	N/A	2	1	2	1	2	2	2	20/22 90.9%
Anderson et al. (2021)	2	2	2	2	N/A	N/A	N/A	2	1	2	1	2	1	2	19/22 86.4%
Goddard et al. (2013)	2	2	2	2	N/A	N/A	N/A	2	2	2	1	2	2	2	21/22 95.5%

Study	Question/ objective sufficiently described	Study design evident and appropriate?	Method of subject/comparison group selection *or* source of information/input variables described and appropriate?	Subject (and comparison group, if applicable) characteristics sufficiently described?	If interventional and random allocation was possible, was it described?	If interventional and blinding of investigators was possible, was it reported?	If interventional and blinding of subjects was possible, was it reported?	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?	Sample size appropriate?	Analytic methods described/justified and appropriate?	Some estimate of variance is reported for the main results?	Controlled for confounding?	Results reported in sufficient detail?	Conclusions supported by the results?	Score
Hibbs, Rhind et al. (2015)	2	2	2	2	N/A	N/A	N/A	2	2	2	1	1	2	2	20/22 90.9%
Marcos et al. (2016)	2	2	2	2	N/A	N/A	N/A	2	1	2	1	N/A	2	2	18/20 90%
Monteleone et al. (2022)	2	2	2	2	N/A	N/A	N/A	2	2	2	1	2	2	2	21/22 95.5%
Rhind et al. (2016)	2	2	2	2	N/A	N/A	N/A	2	2	2	1	2	2	2	21/22 95.5%
Salerno et al. (2016)	2	2	2	2	N/A	N/A	N/A	2	2	2	2	1	2	2	21/22 95.5%

Study	Question/ objective sufficiently described	Study design evident and appropriate?	Method of subject/comparison group selection *or* source of information/input variables described and appropriate?	Subject (and comparison group, if applicable) characteristics sufficiently described?	If interventional and random allocation was possible, was it described?	If interventional and blinding of investigators was possible, was it reported?	If interventional and blinding of subjects was possible, was it reported?	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?	Sample size appropriate?	Analytic methods described/justified and appropriate?	Some estimate of variance is reported for the main results?	Controlled for confounding?	Results reported in sufficient detail?	Conclusions supported by the results?	Score
Sepulveda et al. (2009)	2	2	2	2	N/A	N/A	N/A	2	2	2	1	N/A	2	2	19/20 95%
Stefanini et al. (2019)	2	2	2	2	N/A	N/A	N/A	2	1	2	0	1	2	2	18/22 81.8%
Stillar et al. (2016)	2	2	2	1	N/A	N/A	N/A	1	2	2	2	1	2	2	19/22 86.4%
Stillar et al. (2022)	2	2	1	2	N/A	N/A	N/A	2	1	2	2	2	2	2	20/22 90.9%
Timko et al. (2022)	2	2	1	1	N/A	N/A	N/A	2	1	2	1	N/A	2	2	16/20 80%

Study	Question/ objective sufficiently described	Study design evident and appropriate?	Method of subject/comparison group selection *or* source of information/input variables described and appropriate?	Subject (and comparison group, if applicable) characteristics sufficiently described?	If interventional and random allocation was possible, was it described?	If interventional and blinding of investigators was possible, was it reported?	If interventional and blinding of subjects was possible, was it reported?	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?	Sample size appropriate?	Analytic methods described/justified and appropriate?	Some estimate of variance is reported for the main results?	Controlled for confounding?	Results reported in sufficient detail?	Conclusions supported by the results?	Score
Wagner et al. (2020)	2	2	2	1	N/A	N/A	N/A	2	1	2	1	2	2	2	19/22 86.4%
Weber et al. (2019)	2	2	2	2	N/A	N/A	N/A	2	1	2	2	2	2	2	21/22 95.5%

Table 4

Caregiver Measures and Their Frequency Throughout the Reviewed Studies

Variable/ Caregiver measure	Number of studies utilising (variations) of this measure	Studies utilising (variations) of this measure
Accommodation		
Accommodation and Enabling Scale for Eating Disorders (AESED; Sepulveda et al., 2009)	15	(Anastasiadou et al., 2016; Anderson et al., 2021; Goddard et al., 2013; Hibbs, Rhind, et al., 2015; Marcos et al., 2016; Monteleone et al., 2022; Rhind et al., 2016; Salerno et al., 2016; Sepulveda et al., 2009; Stefanini et al., 2019; Stillar et al., 2016, 2022; Timko et al., 2022; Wagner et al., 2020; Weber et al., 2019)
Expressed emotion		
Family Questionnaire (FQ; Wiedemann et al., (2002)	9	(Anastasiadou et al., 2016; Goddard et al., 2013; Hibbs, Rhind, et al., 2015; Marcos et al., 2016; Monteleone et al., 2022; Rhind et al., 2016; Sepulveda et al., 2009; Stefanini et al., 2019; Timko et al., 2022)
Caregiver distress		
Depression Anxiety and Stress Scales (DASS-21; Lovibond & Lovibond, 1993)	6	(Goddard et al., 2013; Hibbs, Rhind, et al., 2015; Monteleone et al., 2022; Rhind et al., 2016; Stefanini et al., 2019; Timko et al., 2022)
Hospital Anxiety and Depression Scale (HADS; Snaith, 2003; Zigmond & Snaith, 1983)	3	(Anastasiadou et al., 2016; Marcos et al., 2016; Sepulveda et al., 2009)
Eating Disorder Symptom Impact Scale (EDSIS; Sepulveda et al. 2008)	1	(Wagner et al., 2020)
Patient Reported Outcome Measurement Information System Anxiety Short Form (PROMIS-A; Cella et al., 2007)	1	(Anderson et al., 2021)
Eating disorder symptoms		
Short Evaluation of Eating Disorders	3 (each from the same original study)	(Monteleone et al., 2022; Rhind et al., 2016; Salerno et al., 2016)

(SEED; Bauer et al., 2005)		
Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 1994)	2	(Anderson et al., 2021; Goddard et al., 2013)
Eating Attitudes Test (EAT-26; Garner & Garfinkel, 1979)	1	(Anastasiadou et al., 2016)
Children's Eating Attitudes Test (ChEAT; Maloney et al. 1988)	1	(Wagner et al., 2020)
Nine Item Avoidant/ Restrictive Food Intake Disorder (ARFID) Screen (NIAS; Zickgraf & Ellis, 2018)	1	(Wagner et al., 2020)
Anorectic Behaviour Observation Scale (ABOS; Vandereycken, 1992)	1	(Timko et al., 2022)
Binge Eating Severity (BES; Gormally et al., 1982)	1	(Weber et al., 2019)
Caregiver skills and strengths, in relation to supporting the individual affected by the eating disorder		
Caregiver Skills Scale (CASK; Hibbs et al., 2015)	4	(Hibbs, Rhind, et al., 2015; Monteleone et al., 2022; Rhind et al., 2016; Salerno et al., 2016)
Caregiver health		
General Health Questionnaire (GHQ; Goldberg & Williams, 1988)	3	(Anastasiadou et al., 2016; Hibbs et al., 2015; Marcos et al., 2016)
Caregiver's appraisal of the caregiving experience		
Experience of Caregiving Inventory (ECI; Szmukler et al., 1996)	3	(Anastasiadou et al., 2016; Marcos et al., 2016; Sepulveda et al., 2009)
Social support		
Oslo Social Support Scale (OSSS-3;	2	(Monteleone et al., 2022; Rhind et al., 2016)

Kocalevent et al., 2018)		
Caregiver self-efficacy		
Parent Versus Anorexia Scale (PvA; (Rhodes et al., 2005)	2	(Stillar et al., 2016, 2022)
Caregiver vulnerability to treatment engagement fears		
Caregiver Traps Scale (CTS; Lafrance et al., 2021)	1	(Stillar et al., 2022)
Unpublished Caregiver Fear Scale (CFS; Lafrance Robinson, 2014)	1	(Stillar et al., 2016)
Caregiver self-blame		
Unpublished Carer Self-Blame Scale (CSBS; Lafrance Robinson, 2014)	1	(Stillar et al., 2016)
Psychological control towards the individual affected by the eating disorder		
Psychological Control Scale (PCS; Soenens et al., 2008)	1	(Goddard et al., 2013)
Emotional arousal		
Fundamental Voice Frequency (F0, Atkinson, 1978)	1	(Weber et al., 2019)
Social aptitude		
Social Aptitude Scale (Liddle et al., 2009)	1	(Rhind et al., 2016)
Family functioning		
Family Assessment Device (FAD; Epstein et al., 1983)	1	(Anderson et al., 2021)
Perceived post-traumatic stress symptoms		
Impact of Event Scale Revised (IES-R; Weiss, 2007)	1	(Timko et al., 2022).
Cognitive rigidity and attention to detail		
Detail and Flexibility Questionnaire (DFlex; Roberts et al., 2011)	1	(Timko et al., 2022).

Table 5

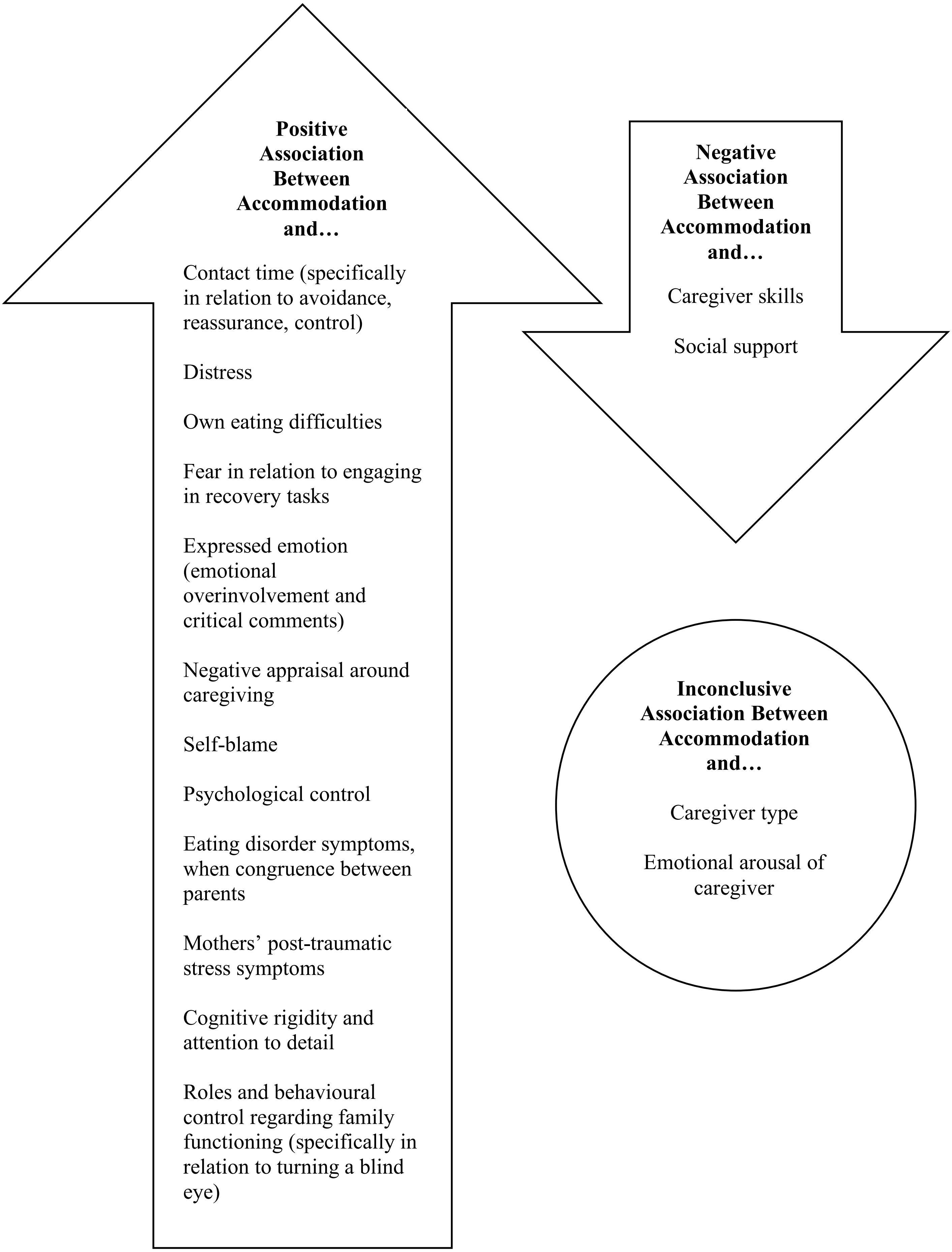
Caregiver Measures of Distress and Their Association with Accommodation Subscales

	Avoidance and modifying routine	Reassurance seeking	Meal rituals	Control of family	Turning a blind eye	Total accommodation
Distress (depression, anxiety and stress not separated)	Not reported	Not reported	Not reported	Not reported	Not reported	Significant positive correlation (Goddard et al., 2013; Hibbs, Rhind, et al., 2015; Rhind et al., 2016) Timko et al. 2022) reported significant positive correlation in relation to mothers only
Global distress (measured by Global Health Questionnaire)	Significant positive correlation (Marcos et al., 2016)	Significant positive correlation (Marcos et al., 2016)	Significant positive correlation (Marcos et al., 2016)	Significant positive correlation (Marcos et al., 2016)	Not significant	Significant positive association (Hibbs, Rhind, et al., 2015)
Depression	Significant positive correlation (Marcos et al., 2016; Sepulveda et al., 2009)	Significant positive correlation (Marcos et al., 2016; Sepulveda et al., 2009)	Significant positive correlation (Marcos et al., 2016; Sepulveda et al., 2009)	Significant positive correlation (Marcos et al., 2016; Sepulveda et al., 2009)	Not significant	Significant positive association (Monteleone et al., 2022; Sepulveda et al., 2009)
Anxiety	Significant positive correlation (Anderson et al., 2021; Marcos et al., 2016; Sepulveda	Significant positive correlation (Marcos et al., 2016; Sepulveda et al., 2009)	Not significant	Significant positive correlation (Marcos et al., 2016; Sepulveda et al., 2009)	Significant positive correlation (Sepulveda et al., 2009)	Significant positive correlation (Anderson et al., 2021; Sepulveda et al., 2009) Significant positive

	et al., 2009)					association for mothers only (Timko et al., 2022)
Distress in relation to health status and nutrition intake of the person affected by the eating disorder	Significant positive correlation in those affected by ARFID and anorexia nervosa (Wagner et al., 2020)	Not significant	Not significant	Significant positive correlation in those affected by ARFID (Wagner et al., 2020)	Significant positive correlation in those affected by ARFID (Wagner et al., 2020)	Significant positive correlation in those affected by ARFID (Wagner et al., 2020)

Figure 2

Infographic Summarising the Predictors and/or Correlates of Accommodation, Relating to Caregiver Factors



Positive Association Between Accommodation and…

- Contact time (specifically in relation to avoidance, reassurance, control)
- Distress
- Own eating difficulties
- Fear in relation to engaging in recovery tasks
- Expressed emotion (emotional overinvolvement and critical comments)
- Negative appraisal around caregiving
- Self-blame
- Psychological control
- Eating disorder symptoms, when congruence between parents
- Mothers' post-traumatic stress symptoms
- Cognitive rigidity and attention to detail
- Roles and behavioural control regarding family functioning (specifically in relation to turning a blind eye)

Negative Association Between Accommodation and…

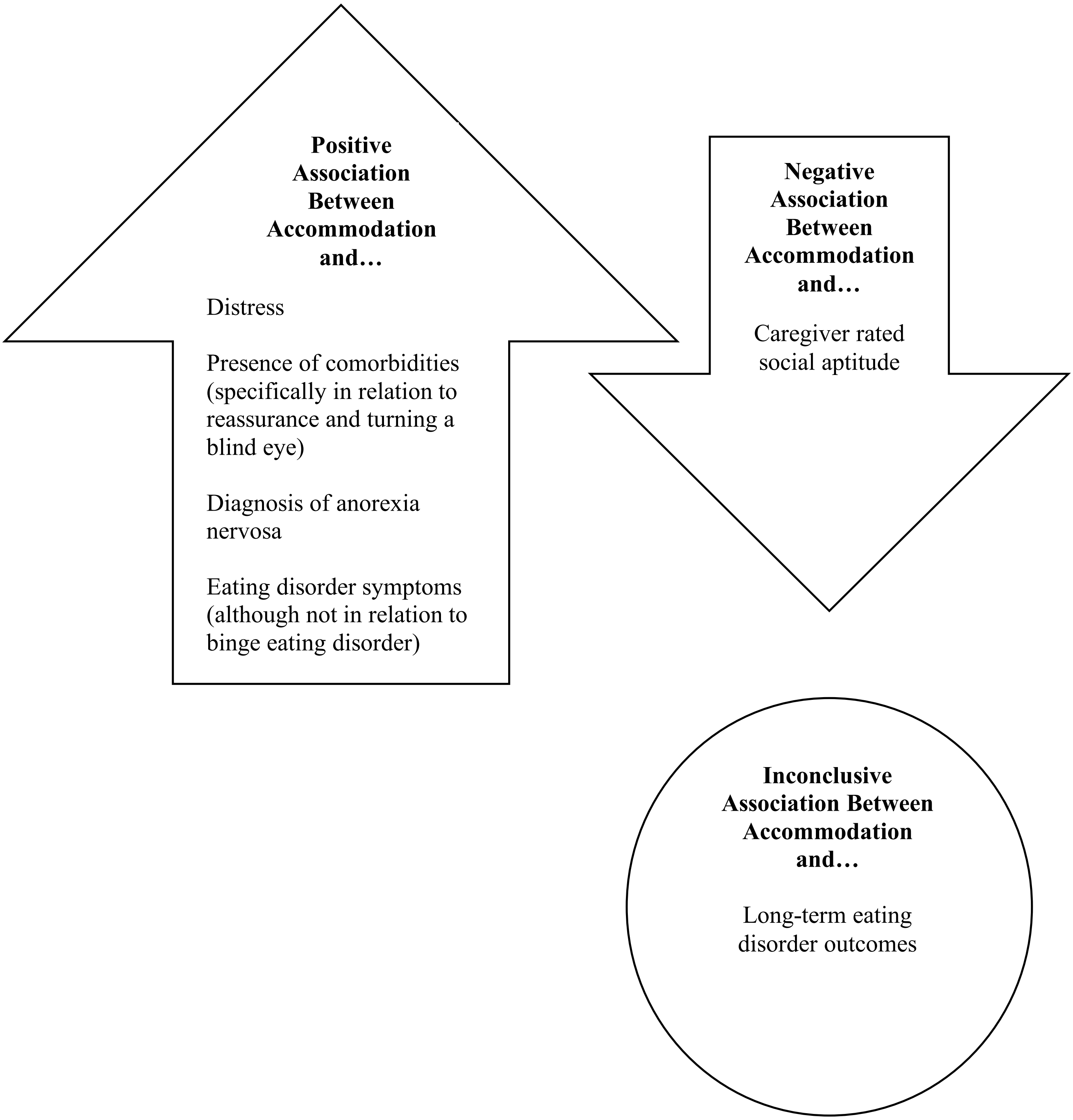
- Caregiver skills
- Social support

Inconclusive Association Between Accommodation and…

- Caregiver type
- Emotional arousal of caregiver

Figure 3

Infographic Summarising the Predictors and/or Correlates of Accommodation, Relating to Factors Associated to the Individual Affected by the Eating Disorder



Appendix A

European Eating Disorders Review Submission Guidelines for Authors

AIMS AND SCOPE

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

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

Authors may submit original theoretical systematic reviews, methodological, or empirical research articles (7000 words or less) or short communications (3000 words or less). The journal also publishes invited conceptual reviews from leading worldwide researchers in the field of Eating Disorders and/or Obesity. The aims of the journal are to offer a channel of communication between researchers, practitioners, administrators and policymakers who need to report and understand developments in the field of eating disorders.

The Journal

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

MANUSCRIPT CATEGORIES AND REQUIREMENTS

Research articles reporting new research of relevance as set out in the aims and scope should not normally exceed 6000 words (excluding abstract, references, tables or figures), with no more than five tables or illustrations. They should conform to the conventional layout: title page, Abstract, Introduction and Aims, Method, Results, Discussion, Acknowledgements and References. Each of these elements should start on a new page.
Word Limit: 6,000 (excluding abstract, references, tables or figures).
Abstract: 200 words.
References: up to 60.

Review articles: Systematic and meta-analytic review papers are welcomed if they critically review the available literature in a topic than will enhance clinical practice. Articles should have clear focus and enough number of studies should be available for a substantive review paper. Studies that only describe or list previous studies without a critical overview of the literature will not be considered.

Word Limit: 5,000 (excluding abstract, references, tables or figures).

Abstract: 200 words.

References: up to 100.

Figures/Tables: 5 maximum, but should be appropriate to the material covered. Additional tables might be included as supplementary information, if needed. Review articles must follow the PRISMA Guidelines. Authors may want to have a look at the review check lists that reviewers when assessing review articles.

…

FREE FORMAT SUBMISSION

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

Before you submit, you will need:

- Your manuscript: this should be an editable file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, conclusions and highlights. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.

- An ORCID ID, freely available at https://orcid.org. (Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)
- The title page of the manuscript, including:
    - Your co-author details, including affiliation and email address.
    - Statements relating to our ethics and integrity policies, which may include any of the following:
        - data availability statement
        - funding statement
        - conflict of interest disclosure
        - ethics approval statement
        - patient consent statement
        - permission to reproduce material from other sources
        - clinical trial registration

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

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

Cover Letters

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

Abstract

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

Graphical TOC/Abstract

The journal's table of contents/abstract will be presented in graphical form with a brief abstract.

The table of contents entry must include the article title, the authors' names (with the corresponding author indicated by an asterisk), no more than 80 words or 3 sentences of text summarizing the key findings presented in the paper and a figure that best represents the scope of the paper.

Table of contents entries should be submitted as 'Supplementary material for review' during the initial manuscript submission process.

The image supplied should fit within the dimensions of 50mm x 60mm and be fully legible at this size.

Guidelines for Table of Contents Graphics

- Concepts illustrated in graphical material must clearly fit with the research discussed in the accompanying text.
- Images featuring depictions or representations of people must not contain any form of objectification, sexualization, stereotyping, or discrimination. We also ask authors to consider community diversity in images containing multiple depictions or representations of people.
- Inappropriate use, representation, or depiction of religious figures or imagery, and iconography should be avoided.

- Use of elements of mythology, legends, and folklore might be acceptable and will be decided on a case-by-case basis. However, these images must comply with the guidelines on human participants when they are present.
- Generally, authors should consider any sensitivities when using images of objects that might have cultural significance or may be inappropriate in the context (for example, religious texts, historical events, and depictions of people).
- Legal requirements:
    - All necessary copyright permission for the reproduction of the graphical elements used in visuals must be obtained prior to publication.
    - Clearance must be obtained from identifiable people before using their image on graphics and such clearance must specify that it will be used on the table of contents. Use within text does not require such clearance unless it discloses sensitive personal information such as medical information. In all situations involving disclosure of such personal information, specific permission must be obtained and images of individuals should not be used in a false manner.

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

Highlights

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

Keywords

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

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends

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

Figures

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

Additional Files

Appendices

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

Supporting Information

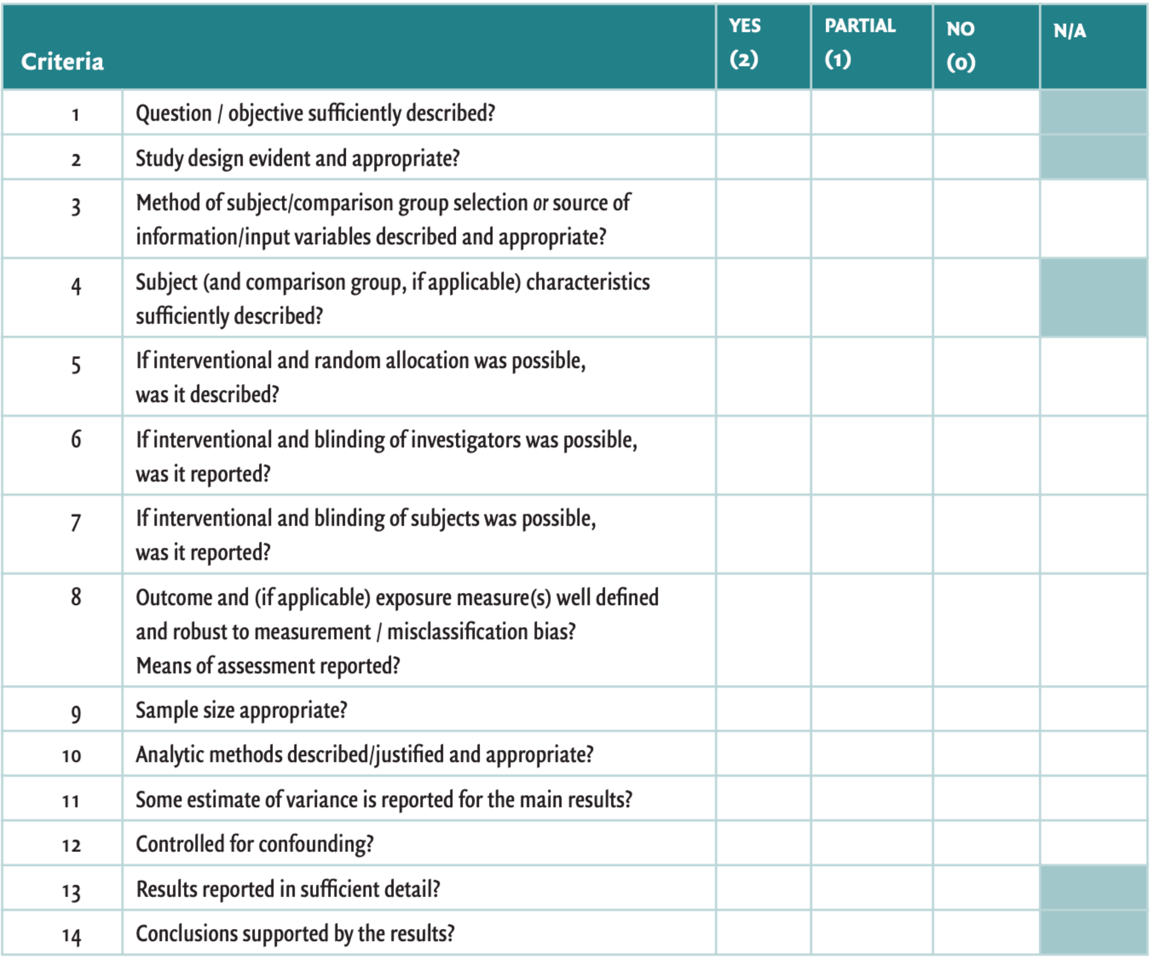
Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc. **Click here** for Wiley's FAQs on supporting information.

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

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

Appendix B

Quality Appraisal Tool (Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields, Kmet et al., 2004)



Criteria		YES (2)	PARTIAL (1)	NO (0)	N/A
1	Question / objective sufficiently described?				▨
2	Study design evident and appropriate?				▨
3	Method of subject/comparison group selection *or* source of information/input variables described and appropriate?				
4	Subject (and comparison group, if applicable) characteristics sufficiently described?				▨
5	If interventional and random allocation was possible, was it described?				
6	If interventional and blinding of investigators was possible, was it reported?				
7	If interventional and blinding of subjects was possible, was it reported?				
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?				
9	Sample size appropriate?				
10	Analytic methods described/justified and appropriate?				
11	Some estimate of variance is reported for the main results?				
12	Controlled for confounding?				
13	Results reported in sufficient detail?				▨
14	Conclusions supported by the results?				▨

Section Two - Empirical Paper

The Role of Self-compassion on Expressed Emotion in Caregivers of People Affected by Eating Disorders

Word count (excluding references, tables and appendices): 7805

Abstract: 196

Emily Rothwell
Doctorate in Clinical Psychology
Division of Health Research, Lancaster University

Prepared in accordance with *European Eating Disorders Review*[2] submission guidelines for authors.

All correspondence should be sent to:

Emily Rothwell
Doctorate in Clinical Psychology Lancaster University
Furness College
United Kingdom
LA1 4GY

Email: e.rothwell@lancaster.ac.uk

Declarations of interest: None

---

[2] See Appendix A for submission guidelines

Abstract

Objective: The poor prognosis of eating disorders illustrates the need to enhance treatment efficacy. Family *expressed emotion* (EE) is a modifiable factor which has been associated with worse treatment outcomes in those affected by eating disorders and increased caregiver distress. Identifying the drivers of EE could support clinical outcomes and enhance caregiver wellbeing.

Method: 154 caregivers of individuals affected by an eating disorder completed an online self-report survey measuring: two components of EE – emotional overinvolvement (EOI) and critical comments (CC); self-compassion; guilt, shame and blame in relation to caregiving. The relationships between EE, guilt, shame, blame and self-compassion were explored.

Results: EOI had a significant positive association with guilt and shame, and significant negative association with self-compassion; guilt was the only significant predictor of EOI once other factors had been accounted for. CC had a significant positive association with guilt, shame and blame; blame was the only significant predictor once other factors had been accounted for. Self-compassion did not moderate the relationship between guilt/shame/blame and EE.

Conclusions: Guilt and blame are potential targets for caregiver interventions, to reduce EOI and CC (respectively). Future studies should investigate whether these findings hold in broader, more representative samples.

Keywords: eating disorders; expressed emotion; guilt; shame; self-compassion

Highlights

- Caregivers of individuals affected by eating disorders commonly express high levels of emotional overinvolvement (EOI). EOI is higher when levels of guilt and shame are higher and self-compassion lower, however, the direction of these associations cannot be inferred. Guilt predicts higher levels of EOI.
- Caregivers of individuals affected by eating disorders commonly express high levels of critical comments (CC). CC is higher when levels of guilt, shame and blame are higher, however, the direction of these associations cannot be inferred. Blame predicts higher levels of CC.
- Guilt and blame are potential targets of intervention, to empower and support caregivers and reduce levels of EE. This could have a beneficial impact on both the wellbeing of the caregiver and the individual affected by the eating disorder.

The Role of Self-Compassion on Expressed Emotion in Caregivers of People Affected by Eating Disorders

Eating disorders are disabling and potentially fatal (Treasure, Duarte, et al., 2020); they are associated with an increased risk of mortality (Arcelus et al., 2011). Their prevalence is rising worldwide (Galmiche et al., 2019). Eating disorders are noted to be "notoriously difficult to treat" (Aspen et al., 2014, p. 32); long-term outcomes suggest that about two-thirds of those affected by anorexia nervosa or bulimia nervosa meet the criteria for recovered after twenty to thirty years (Dobrescu et al., 2020; Eddy et al., 2017). Historically parents, namely mothers, were viewed negatively in relation to the development of an eating disorder (vander Ven & vander Ven, 2003), however, this position has been refuted (le Grange et al., 2010). The way in which families respond to the eating disorder, may however influence outcomes.

Expressed Emotion

Family *expressed emotion* (EE) has been associated with treatment outcomes (Duclos et al., 2012; Gorrell et al., 2022; Rienecke, 2018). EE refers to the behaviours and attitudes which caregivers express towards the individual they are supporting. It can be mapped onto five domains; emotional overinvolvement (EOI), critical comments (CC), hostility, positive remarks and warmth (Brown & Rutter, 1966; Leff & Vaughn, 1984). High EE ratings reflect scoring above a pre-specified cut-off for CC and/or hostility, and/or EOI (Hooley & Gotlib, 2000). Low EE reflects scores which do not score above the cut-off for any of these measures. The role of familial EE has been explored in an array of physical and mental health problems and is widely accepted to influence prognosis generally (Hooley, 2007; Wearden et al., 2000).

Rather than being blaming or pathological, EE attitudes and behaviours have been suggested as “ordinary” (Brown, 1985, p. 22). Whitney and Eisler (2005) suggested that there is family “reorganisation” (p. 583) due to factors such as the distress of caring for a loved one and the fear of the physical consequences of the eating disorder. This may result in internal resources being depleted, and individuals engaging in unhelpful interactions which maintain the eating disorder. This is expanded in the cognitive interpersonal model of anorexia nervosa (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013; Treasure, Willmott, et al., 2020), which suggests that caregivers’ own vulnerabilities may become heightened by the eating disorder. This may lead to high criticism, hostility and over-protection, thus high EE, which then fuels eating disorder symptoms. Although the rates of high EE have been found to be lower than in studies of families affected by a diagnosis of schizophrenia (Rienecke, 2018), a systematic review reported that up to 73.2% of caregivers of those affected by an eating disorder demonstrated high levels of CC and 89.3% high levels of EOI (Anastasiadou et al., 2014). This reflects the widely supported conclusion that EOI is more likely to be elevated than CC in families affected by EDs (e.g. Blondin et al., 2019; Zabala et al., 2009).

This difference in the proportion of caregivers with high EOI and high CC, may reflect caregivers’ attributions of their loved ones difficulties and behaviours. Research from families affected by a schizophrenia diagnosis found that relatives with high CC tend to view their loved one as having greater control over their difficulties, thus increased attribution of responsibility, compared to relatives with low CC or those who are high only in EOI (Barrowclough & Hooley, 2003). Similarly, the blaming attributions made by high EOI relatives were found to be either no different (Yang et al., 2004) or less likely (Barrowclough et al., 1994) compared to low EE families. If this model also applies to those affected by eating disorders, the greater rates of EOI compared to CC, suggest caregivers are more likely to attribute behaviours to the eating disorder and outside of the control of their loved one.

High levels of EE, particularly levels of CC, have been associated with poor treatment engagement in those affected by anorexia nervosa (Rienecke, Accurso, et al., 2016; Szmukler et al., 1985), as well as treatment outcomes. For example, Allan et al. (2018) reported that for adolescents affected by anorexia nervosa, individuals were less likely to be in remission at end-of-treatment when maternal EE increased or remained high throughout treatment, compared to when it decreased or remained low. Similar results have been found in adults affected by bulimia nervosa; interview scores suggested that individuals from high EE environments had significantly greater eating disorder cognitions/behaviours throughout treatment and after six years, compared to those from low EE environments (Hedlund et al., 2003). Although the authors highlighted that the small sample size limited the study, this suggests the role of EE is transdiagnostic.

However, there are inconsistent findings. The relationship between EE and treatment outcomes at end-of-treatment, 12-month follow-up and 4-year follow-up, was explored in adolescents affected by anorexia nervosa (Rienecke et al., 2021). Contrary to hypotheses, EE did not predict weight restoration or eating disorder psychopathology at any time point. The authors questioned whether this may be due to the relatively young age of those affected and the shorter duration of eating disorder. They also hypothesised that having one parent low in EE may be protective, as in only three pairs of parents did both score high on EE. This is consistent with distress being higher for the individual affected by the eating disorder, when both maternal and paternal accommodation is high (Salerno et al., 2016). Further research is needed to explore whether there is a potential interaction in families with two parents present. Future research must also address the notable prioritisation of parents of individuals affected by anorexia nervosa (Rienecke, 2018), meaning less is known about other eating disorder diagnoses or caregiver types.

High EOI has also been suggested to be beneficial to treatment outcomes. High maternal EOI has been associated with lower eating disorder severity and fewer re-hospitalisations after 18-months, for adolescents affected by anorexia nervosa (Duclos et al., 2018). Similarly, a network analysis revealed a positive association between caregivers' accommodation and patient BMI at follow-up (Monteleone et al., 2022). This supports the idea that maternal EOI may be adaptive and necessary, and that rather than indicating the degree to which caregivers are *over*involved, it may be a measure of involvement in care more generally (Rienecke, 2020a). Duclos et al. (2018) noted that conflicting results may be due to the measure of EE utilised. For example, high maternal EOI is linked with poorer outcomes one-year following treatment (van Furth et al., 1996) when using the Camberwell Family Interview (the gold standard assessment measure for EE), in which EOI has a negative connotation. This contrasted with results when the Five-Minute Speech Sample was used (Duclos et al., 2018), which includes more positive elements.

Guilt, Shame and Blame

Caregivers have been reported to experience guilt, shame and self-blame regarding eating disorders (Fletcher et al., 2021; Fox et al., 2017; Highet et al., 2005; Sepulveda et al., 2008; Stillar et al., 2016). Although guilt and shame are commonly grouped together as self-critical, self-conscious emotions, they are distinguishable. Miceli and Castelfranchi (2018) postulated that guilt suggests a moral self-evaluation, thus is concerned with the behaviours, goals and beliefs that individuals view themselves as responsible for. Contrastingly, they proposed that shame is "nonmoral" (p. 711), thus is not focused on the responsibility of issues, but the perceived differences between an individual's actual and ideal self. This supports Gilbert's suggestion that the evolutionary roots of guilt and shame differ (Gilbert, 2003). Guilt is described as evolving from a system of "avoiding doing harm to others"

(Gilbert, 2003, p. 1205), whilst shame is focused on oneself, and has evolved based on our social threat system, to support us to outcompete those around us. In relation to caregivers of those affected by eating disorders, guilt and shame have been suggested as interpersonal interactions, which alongside EE, may maintain the eating disorder (Treasure et al., 2008). Guilt has also been correlated with caregivers' anxiety and depression (Sepulveda et al., 2012).

Although yet to be explored within caregivers of those affected by eating disorders, guilt and shame have been found to be associated with EE in caregivers of long-term mental health difficulties (Cherry et al., 2017). In a systematic review, EOI was positively associated with guilt, when measures of care-specific guilt were used. The authors therefore hypothesised that for guilt to impact upon EOI, it must relate either to caregiving or to having a relative who is affected by mental health difficulties (Cherry et al., 2017). EOI was also found to have a strong positive association with shame, regardless of whether this was in relation to shame-proneness or caregiver-specific shame. This was maintained after controlling for the effects of guilt. Additionally, shame-proneness and caregiver-specific shame was associated with CC/hostility, when self-report measures were used, but no association with guilt was found. The authors noted that it was not possible to decipher the causality of these associations, nor the mechanisms behind the drivers of these constructs. However, it was suggested that the attributions underlying these emotional states also drive EOI and CC. In addition, they suggested that utilising principles of compassion focused therapy (CFT), which is designed to support individuals with high levels of shame and self-criticism (Gilbert & Procter, 2006), could enhance support for families experiencing high EE.

Limited research has also explored the potential association between blame and EE, both in relation to self-blame and blame towards others (Besharat, 1997; Besharat & Eisler, 1996; Besharat et al., 2001). In line with the previously described attributional model of EE (Barrowclough et al., 1994), preliminary evidence utilising the Self- and Other-Blame Scale (SOBS) found mothers with high EE (≥ 2 CC) were more likely to blame themselves and their daughter affected by the eating disorder, compared to mothers with low EE. Fathers' blame towards their daughter was also greater in families with higher paternal CC. The interlinked nature of these associations with self- and other-blame from the individual affected by the eating disorder was also noted. Blame towards the individual affected by the eating disorder has also been described based upon interviews from caregivers. For instance, one caregiver shared "It is appalling because she has chosen it" in relation to anorexia nervosa (Whitney et al., 2005, p. 446), which may be accompanied by later feelings of guilt (Whitney & Eisler, 2005).

Self-compassion

Self-compassion, defined as "a basic kindness, with deep awareness of the suffering of oneself and of other living things, coupled with the wish and effort to relieve it" (Gilbert, 2009, p. xiii), has been suggested as a "shield" (Sedighimornani et al., 2019, p. 2) against difficult emotions. A recent study explored caregiver self-compassion, EE and quality of life in primary caregivers of children and adolescents diagnosed with an eating disorder (Coleman et al., 2022). They found a significant indirect relationship between caregiver self-compassion and eating disorder psychopathology, via EE; lower EE was associated with lower eating disorder psychopathology. There was a direct relationship between caregiver self-compassion and EE, with higher self-compassion being associated with lower EE. Although the authors highlighted that the cross-sectional design prevents causal inferences being made, the results provide preliminary support that is consistent with the cognitive interpersonal model (Schmidt & Treasure, 2006) and suggests that enhancing self-compassion may reduce EE and benefit eating disorder psychopathology.

Research Hypotheses

This study aimed to determine whether there is an association between guilt, shame, blame (to others), self-compassion and EE in caregivers of those affected by eating disorders. It was hypothesised that guilt, shame and blame would have a positive association with EE, whilst self-compassion would have a negative association with EE. Secondly, it aimed to explore whether self-compassion moderates the potential relationship between guilt/shame/blame (hypothesised independent variables) and EE (hypothesised dependent variable). It was hypothesised that self-compassion would be a moderator variable.

Method

Design

Participants

Participants were recruited between 24th November 2021 and 27th October 2022. Participants were eligible if they self-reported as: English-speaking adults; 18 years or over; able to complete an online survey; and a family member, partner or friend currently caring for someone affected by an eating disorder. No exclusions were made based on location, the specific eating disorder diagnosis, the relationship type of the caregiver or the time they spend caring for the individual.

Procedure

Ethical approval from Lancaster University's Faculty of Health and Medicine Ethics Committee was received on 3rd November 2021. Experts by experience, introduced via Beat (a UK eating disorder charity), were consulted on the accessibility and wording of the information sheet, consent form, online advert and demographics questions. They were also asked to feedback about the potential time burden of participating and the use of standardised questionnaires. The feedback was positive; the final design included minimal changes to aspects of the wording.

Participants responded to an anonymous online survey, which was promoted using an online advert via social media (Facebook and Twitter). Key stakeholders were also asked to circulate the advert; these included Beat (https://www.beateatingdisorders.org.uk), other eating disorder charities and organisations, academic researchers and clinicians who work in eating disorders, eating disorder campaigners, and public ambassadors with lived experience of an eating disorder or of caring for someone affected. Participants were not directly asked to share the advert; however, some participants may have been recruited via snowball sampling.

Participants were required to complete a consent form prior to the survey, indicating that they had read and understood the participant information sheet. This informed participants that the study aimed to understand whether certain attitudes and emotions have an impact on responses to caregiving. It also outlined what participation would involve, including any potential risks, and that it was the participant’s choice to proceed. Following the completion of the survey, a participant debrief sheet was shown which noted that difficult thoughts and feelings may have been evoked, and therefore outlined support sources. Participants were also given the opportunity to email the principal researcher if they wished to be informed about the survey findings. This information was obtained separately to ensure participants remained anonymous. The full study documentation and ethical approval are included in Section 4 of this thesis.

Demographic Questions

Prior to beginning the survey, participants were asked to confirm their eligibility, including that they identify as a family member, partner or friend who currently provides care for someone affected by an eating disorder. The survey ended if this was not confirmed. Those who confirmed their eligibility, were asked to report on sociodemographic information about themselves and the individual they were caring for. A mixture of drop-down menus and free text responses were used, including having the option of ‘prefer not to say’.

Measures

Family Questionnaire (**FQ;** Wiedemann et al., 2002). The FQ was designed to measure self-reported EE in caregivers. It is a 20-item measure, where items are scored across 4-point Likert scales (ranging from 1 = *never/very rarely* to 4 = *very often*). Ten items comprise the critical comments (CC) subscale and ten items comprise the emotional overinvolvement (EOI) subscale. Higher scores indicate higher levels of EE. The original authors proposed a cut-off of 23 and 27 to indicate high CC and EOI respectively. They found the subscales had good internal consistency (CC: Cronbach’s α = .92, EOI: Cronbach’s α = .80). In the present study, the Cronbach’s α for the CC scale was α = .84 and for the EOI scale was α = .73.

Self-Compassion Scale (**SCS;** Neff, 2003). The SCS was designed to measure compassion towards oneself. It is a 26-item measure, where items are scored across 5-point Likert scales (ranging from 1 = *almost never*, 5 = *almost always*). The original author reported the SCS had good internal consistency (Cronbach’s α = .92), which was replicated for the Cronbach’s α for this sample = .94. Noting concerns about the validity of self-compassion as a single global factor (Brenner et al., 2017; Kumlander et al., 2018), the two-factor model was utilised in this study (Brenner et al., 2017). Here, self-compassion consists of self-kindness, common humanity and mindfulness, whilst self-coldness consists of self-judgement, isolation and over-identification. Only the self-compassion scale will be reported on. In the present study, Cronbach's α for self-compassion α = .90.

Caring and Related Emotions (CARE) Questionnaire: (**CARE;** Noir, 2023 – see Appendix B). The CARE questionnaire was designed to measure guilt, shame and blame in specific caregiving situations. At the time of the study, the questionnaire consisted of 12 scenarios. Since validation, this has been updated to 10 scenarios, each of which is measured in relation to three subscales: blame, guilt and shame. Responses are scored across 5-point Likert scales (ranging from 1 = *not likely,* 5 = *very* likely). Higher scores indicate higher levels of blame, guilt and shame. Only the validated 10 scenarios were included in the analyses. High internal consistencies have been reported for each subscale: blame Cronbach's α = .87; guilt Cronbach's α = .89; shame Cronbach's α = .85 (Noir, 2023). Across the 10 scenarios in the present study, blame Cronbach's α = .87; guilt Cronbach's α = .87; shame Cronbach's α = .89. As described in the subsequent missing data section, one scenario was removed; the internal consistency remained high for the three subscales, across nine scenarios: blame Cronbach's α = .86; guilt Cronbach's α = .87; shame Cronbach's α = .88.

Data Analysis

Data analysis was conducted using Statistical Package for the Social Sciences (SPSS; version 28).

Missing Data

As is common in psychological research (Dong & Peng, 2013), there was substantial drop off throughout the survey, leading to high levels of missing data. Multiple Imputation was therefore deemed not suitable on the full dataset (Dong & Peng, 2013). The FQ and SCS were designed so the individual had to complete the full questionnaire, prior to continuing with the rest of the survey. Missing data for FQ and SCS was therefore handled by omitting listwise on an analysis-by-analysis basis (Jakobsen et al., 2017), which has the benefit of maximising the validity of the results (Scheffer, 2002). Each analysis therefore specifies the number of participants.

The CARE questionnaire had limited missing data (0.67% data points across 23 respondents). After the removal of data from those who did not complete the FQ or SCS, Little's Missing Completely at Random Test for the CARE questionnaire did not find data were missing at random (*p* = .013). On closer inspection, every missing response was in relation to scenario 9: "Your relative has been struggling to take care of their own basic needs such as; eating properly, washing themselves and/or doing their laundry and so on…" These data were missing across each of the three subscales, guilt, shame and blame. Considering the scenario was in relation to "eating properly", it was hypothesised that individuals felt unsure how to complete this question due to the impact of the eating disorder on their loved one's eating. The impact of removing this on the internal consistency of the subscales was minimal, thus this scenario and therefore the missing data were removed from analyses.

Statistical Analysis Strategy

Firstly, descriptive statistics of the demographics of both the caregiver and person affected by the eating disorder were examined, in order to understand the characteristics of the sample. Kolmogorov-Smirnov test of normality was conducted to check for normal distributions of questionnaire data. This found that EOI, guilt and blame were not normally distributed. Data transformations were conducted as recommended by Field (2018), however, these did not result in normal distributions, thus non-parametric tests were used on the original data. All analyses were two-tailed and statistical significance was set at $p < .05$.

Meaningful univariate analysis in relation to gender, ethnicity, country based, and caregiver type could not be conducted due to the small sample size of the non-dominant groups. Mann-Whitney U tests, Pearson's Product-Moment Correlation and Spearman's rank correlation analyses were undertaken to explore the relationships between EE, self-compassion, guilt, shame and blame. Due to respondents being able to report multiple diagnoses, it was not possible to analyse diagnosis in relation to the variables in a way which would provide meaningful results. To confirm the use of the two-factor model (rather than the global model) of the SCS, correlation analyses were undertaken with both models. However, no differences of significance were noted, thus, the rest of the analyses utilised only the two-factor model, and only this has been reported on.

Subsequently, a hierarchical regression analysis was conducted to explore the relationship between EE (both EOI and CC separately), and the predictor variables (guilt, shame, blame and self-compassion). An *a priori* sample size calculation using G*power (Faul et al., 2007) indicated a sample size of $N = 98$ was required, in order to have appropriate power to detect a medium effect size of .15, with a power level of .80, for a multiple regression with six predictors. The control variables were first entered into the model, followed by the predictor variables (guilt, shame, blame and self-compassion).

Lastly, moderation analyses were undertaken to investigate whether self-compassion moderated the relationship between guilt/shame/blame and EE (both EOI and CC separately). An *a priori* sample size calculation suggested that in order to detect a small effect size with a power level of .80, a sample of 439 was required. The moderation analyses were conducted using the PROCESS tool plug in (Hayes, 2012) for SPSS (version 3.5). Bootstrapping with

5,000 replications was utilised, and predictor variables were centred to improve their interpretation (Field, 2018).

Assumptions

The assumptions of regression analyses were tested prior to conducting the analyses. For both regression analyses, there was no evidence of multicollinearity, as indicated by the variance inflation factors all being below 10 (Myers, 1990). A scatterplot of the residuals indicated homoscedasticity, normally distrusted residuals, and linearity (Appendix C). There was independence of the residuals, as indicated by the Durbin-Watson (Durbin & Watson, 1950) test value of 1.789 and 1.977 (in relation to EOI and CC respectively). The value for Cook's distance was .055 and .106 (in relation to EOI and CC respectively), indicating no residual outliers.

Results

Participant Characteristics

A total of 294 responses were recorded. After consenting and agreeing to proceed, 22 people did not continue. A further seven did not identify themselves as a friend, partner or family member currently providing care for an individual affected by an eating disorder, therefore the survey did not allow them to progress any further. Two further participants' data were removed as their answers displayed an unusual response pattern (e.g., scoring "prefer not to say" on all the demographic questions or writing "." on compulsory questions, and "never/very rarely" on all the FQ, or "almost never" on all the SCS). One further participant's data were removed as although they identified as an individual caring for someone affected by an eating disorder, they noted that the person they were caring for was "myself" (Figure 1).

[INSERT FIGURE 1]

As seen in Table 1, participants' mean age was 47.52 years (*SD* = 8.26), ranging from 18 to 66 years. 246 people identified as female (93.89%), 235 people identified as White English/Welsh/Scottish/Northern Irish/British (89.69%) and 222 (84.73%) were currently based in England. A further 37 respondents did not continue after responding to where they are currently based; 225 respondents remained. Of these, 189 (84.00%) identified as the mother of someone affected by an eating disorder, 192 (85.33%) respondents reported living with the person affected and 47 (20.89%) reported that they were also currently caring for another individual with a mental health diagnosis. The average time spent per week providing face-to-face care was estimated as 41.80 hours (*SD* = 33.84) and providing virtual care 8.04 hours (*SD* = 16.24). 130 respondents (57.78%) reported that they had received formal support in relation to their caring role; 89 respondents (68.46%) reported this included NHS support. For those who indicated they had received support outside of the NHS, private or charity sector, this included support from social services, eating disorder forums, Facebook, friends, health professionals and an inpatient unit.

[INSERT TABLE 1]

Demographics of the Individual Affected by the Eating Disorder

As seen in Table 2, the mean age of the individual affected by the eating disorder was 17.47 years (*SD* = 5.81), ranging from 4.5 years to 64 years, with 210 individuals reported to identify as female (95.02%). The average time that someone had experienced or been diagnosed with an eating disorder was 33.62 months (*SD* = 40.49), ranging from 0.25 months to 26 years. Respondents were able to report more than one diagnosis, to acknowledge that individuals may have received multiple eating disorder diagnoses. Eight respondents (3.62%) did not know the diagnosis. Of the remaining 213 respondents, 196 (92.02%) reported the individual had experienced or been diagnosed with anorexia nervosa. Additionally, 159 (71.95%) respondents reported that the person affected by the eating disorder was currently receiving treatment, 58 (26.24%) reported that they were not currently receiving treatment and four (1.81%) reported that they were unsure. Of those currently receiving treatment, 20 (12.58%) individuals were reported as currently receiving inpatient treatment. Respondents reported that 140 (63.35%) individuals also had other physical or mental health difficulties (Appendix C). The most commonly reported difficulty was anxiety, following by autism and depression.

[INSERT TABLE 2]

Descriptive Statistics

Descriptive statistics of study variables are reported in Table 3. Based upon Wiedemann et al.'s (2002) suggested cut-off points, 199 (93.87%) caregivers were rated as high EE. With respect to each component, 198 (93.40%) caregivers scored above the cut-off point for high EOI, and 136 (64.15%) scored above the cut-off point for high CC; 135 (63.68%) individuals scored highly on both EOI and CC. Only one individual scored highly on CC, who did not score highly on EOI.

Depending on whether the necessary assumptions were met, Pearson's Product-Moment Correlation and Spearman's rank correlation were conducted to assess the relationships between EE, self-compassion, guilt, shame and blame (Table 3). There were significant positive correlations between EOI and CC ($r_s(210) = .31, p < .001$); EOI and guilt ($r_s(152) = .31, p < .001$); EOI and shame ($r_s(152) = .25, p = .002$); CC and guilt ($r_s(152) = .18, p = .025$); CC and shame ($r(152) = .25, p = .002$); CC and blame ($r_s(152) = .37, p < .001$); shame and blame ($r_s(152) = .24, p = .003$); guilt and shame ($r_s(152) = .75, p < .001$). There were significant negative correlations between EOI and self-compassion (r_s (210) = -

.21, $p = .008$); guilt and self-compassion ($r_s(152) = -.38$, $p < .001$); shame and self-compassion ($r(152) = -.46$, $p < .001$).

EOI was significantly greater in those who engaged in 21 or more caregiving hours a week (mean rank = 85.30) compared to caregivers who engaged in less than 21 hours (mean rank = 61.34), $U = 1820$, $z = -3.200$, $p = .001$. No significant differences were found in relation to hours spent virtual caregiving, whether the caregiver had received support, or whether the person affected by the eating disorder was receiving support.

[INSERT TABLE 3]

Regression Analyses

Variables Associated with EOI.

The control variables (time spent face-to-face caring and CC) were first entered into the model. They were collectively found to be significant predictors; adjusted $R^2 = .23$, $F(2, 150) = 23.88$, $p < .001$ (Table 4). The independent variables of guilt, shame, blame and self-compassion were then entered into Step 2. They were collectively found to be significant predictors; adjusted $R^2 = .33$, $F(6, 146) = 13.64$, $p < .001$. The final model explained 33.3% of the variance in EOI ($p < .001$). The significant positive beta value of guilt ($\beta = .32$, $p = .003$) indicates guilt was the most influential predictor. Self-compassion was the next most influential predictor ($\beta = -.14$, $p = .066$), however this did not reach significance. These findings indicate that CC and time spent caregiving independently predict EOI. When controlling for these, the only significant predictor to remain is guilt. Higher guilt predicts greater levels of EOI.

[INSERT TABLE 4]

Variables Associated with CC.

The control variable (EOI) was first entered into the model, and was found to be a significant predictor; adjusted $R^2 = .14$, $F(1, 152) = 25.94$, $p < .001$ (Table 5). The independent variables of guilt, shame, blame and self-compassion were then entered into Step 2. They were collectively found to be significant predictors; adjusted $R^2 = .30$, $F(5, 148) = 12.58$, $p < .001$. The final model explained 27.4% of the variance in CC ($p < .001$). The significant positive beta value of blame ($\beta = .36$, $p < .001$) indicates blame was the most influential predictor. Neither self-compassion, guilt or shame were significant predictors of CC. These findings indicate that when controlling for EOI, the only significant predictor to remain is blame. Higher blame predicts greater levels of CC.

[INSERT TABLE 5]

Moderation:

Moderation analyses indicated that self-compassion did not significantly moderate the relationships between the explored emotions and components of EE, as outlined in Table 6.

[INSERT TABLE 6]

Discussion

Key Findings

The overarching aim of this observational, cross-sectional study was to determine whether there was an association between guilt, shame, blame, self-compassion and EE in caregivers of those affected by eating disorders, and the nature of these potential relationships. Correlational analyses, hierarchical regression analyses and moderation analyses were undertaken to explore this. EE was explored specifically in relation to the components of EOI and CC. EOI had a significant positive association with CC, guilt and shame, and significant negative association with self-compassion. CC had a significant positive association with EOI, guilt, shame and blame. However, it was noted that the effect size between CC and guilt was small, explaining just 3.2% of the variance. Additionally, there were significant positive associations between guilt and shame, and shame and blame, as well as significant negative associations between guilt and self-compassion, and shame and self-compassion (the latter nearing a large effect size). These findings suggest that EOI is higher when levels of guilt and shame are higher and self-compassion lower, whilst CC is higher when levels of guilt, shame and blame are higher. When controlling for time spent face-to-face caregiving and CC, guilt, shame, blame and self-compassion accounted for over 30% of the variance of EOI. Guilt was the only significant predictor of this, suggesting greater guilt predicts higher levels of EOI. When controlling for EOI, guilt, shame, blame and self-compassion accounted for nearly 30% of the variances in CC. The only significant predictor of this was blame, suggesting greater blame predicts higher levels of CC. Self-compassion was not found to moderate any of the relationships between the explored emotions and EE.

Beginning with EOI, the current study partially supports the conclusion from a systematic review exploring EE in caregivers of those affected by long-term mental health difficulties (Cherry et al., 2017). Whilst EOI was found to be positively associated with both guilt and shame, only guilt predicted EOI. Taken alongside the attribution model of EE (Barrowclough et al., 1994), this may suggest that when the eating disorder and associated behaviours are perceived as outside of the individual’s control, caregivers question their own perceived involvement in the eating disorder. Given the outdated narrative that problematic family dynamics played a role in the aetiology of the eating disorder (Minuchin et al., 1975), this may provide a basis for this guilt. This is reflected widely as caregivers commonly express personal culpability regarding the eating disorder, thus feelings of guilt and self-blame (Fox et al., 2017). This may drive levels of EOI higher as an attempt to protect and appease the individual (Figure 2). The feelings of guilt may also interact with feelings of anxiety, since anxiety has been reported to account for 57% of the variance in EOI (Kyriacou et al., 2008). This could become a vicious cycle, particularly if caregivers view their responses as potentially maintaining the eating disorder (Philipp et al., 2020; Simic et al., 2021).

Although self-compassion was not found to be a moderator of EOI, there was a negative association between self-compassion and EOI, as also noted by Coleman et al. (2022). Whilst the direction of this association cannot be inferred, it is consistent with the hypothesis that self-compassion is a “shield” (Sedighimornani et al., 2019, p. 2) for difficult emotions. One hypothesis may therefore be that self-compassion does not moderate the relationship between guilt/shame and EOI, since it has already protected caregivers from feeling these self-conscious emotions, thus it influences without moderating. Alternatively, self-compassion has also been suggested as an antidote to shame (Gilbert, 2005), suggesting the components of kindness, common humanity and mindfulness usurp the feelings associated with shame, such as self-blame (Braehler & Neff, 2020). In relation to caregivers of those affected by eating disorders, this would mean that caregivers are more able to respond to their emotions compassionately, thus reduced likelihood of critical comments or the drive to self-sacrifice. However, caregivers still score highly on guilt, supporting the differing functions behind guilt and shame (Gilbert, 2003).

Additionally, it has been suggested that EOI is developmentally appropriate for adolescents affected by mental health difficulties (Peris & Miklowitz, 2015; Rienecke, 2020a), unlike the adult sample the construct was originally developed in relation to (Brown et al., 1958). High EOI may reflect that the average age of the sample being cared for is late adolescence, therefore increased support is consequently required. It could also be indicative of the high proportion of individuals receiving outpatient care, which has been associated with increased CC (Philipp et al., 2020). This is likely to coincide with the high levels of caregiver contact time reported (Goddard et al., 2013), with caregivers spending an average of six hours a day face-to-face with their loved one. This skew of the sample with regards to the lack of variance around EOI and CC may also explain the non-significant result, as the statistical power for detecting moderators is significantly reduced when the sample variance is less than the variance of the population (Aguinis & Stone-Romero, 1997).

[INSERT FIGURE 2]

Following on, CC is higher when levels of guilt, shame and blame are higher, which differs from the finding that CC in caregivers of individuals affected by long-term health conditions is associated with shame, but not guilt (Cherry et al., 2017). The current study supports preliminary findings that high EE families of those affected by eating disorders demonstrate greater blame for both themselves and the service user (Besharat, 1997; Besharat & Eisler, 1996; Besharat et al., 2001). Considering the key predictor of CC was blame, this supports the association between increased blaming attributions and greater CC, as described in relation to the diagnosis of schizophrenia (Barrowclough & Hooley, 2003). Therefore, when an individual engages in a behaviour, such as hiding food or binge eating, if the caregiver views them as having control over this, it may lead to feelings of annoyance and blame, and result in CC (Figure 2). The self-conscious emotions of guilt and shame are also associated with CC. The way in which caregivers manage these may be through again placing blame on the individual, thus increasing CC. Since shame has been associated with self-blame (Tangney et al., 1992) and how people judge themselves and perceive others to view them is correlated (Goss et al., 1994), it supports the notion that blaming others is protective (Gilbert & Miles, 2000).

Considering caregivers' perception of negative/difficult behaviours accounted for 52% of the variance in parental CC (Kyriacou et al., 2008), this suggests blame is associated with CC, when the individual is blamed for engaging in difficult behaviours. Some studies have suggested that maternal and paternal CC is higher in caregivers of those affected by bulimia nervosa, compared to anorexia nervosa (Rienecke, Sim, et al., 2016). One hypothesis accounting for this is that caregivers place more blame on their loved one's egodystonic behaviours, such as binge eating and purging, compared to the egosyntonic behaviours such as restriction, which are more commonly associated with anorexia nervosa (Rienecke, 2020b). This is aligned with the fatphobic society we live in, and the impact of this on those affected by eating disorders (Rothwell & Coopey, 2021). However, given the study participants were mainly caregivers of those affected by anorexia nervosa and the nature of the CARE questionnaire, this illustrates that egosyntonic behaviours also evoke blame. This may reflect the question of "why won't you just eat?" (Phillipou et al., 2018, p. 13) and support the frustration that caregivers may feel both in response to their own feelings of inadequacy (Whitney & Eisler, 2005), and if they perceive their loved one as being in control of these behaviours. Unlike Coleman et al.'s (2022) hypothesis that self-compassion is protective, self-compassion was not found to moderate the relationship between guilt, shame, blame and CC, nor was it associated with CC. This may reflect the limitations of the sample, as described below. Additionally, whilst this study only measured one flow of compassion, self-compassion, it would be interesting to explore the compassion we experience towards others (Gilbert et al., 2017), as here high compassion for others may be protective of CC and evoke warmth.

Implications for Practice and Policy

The current study presents potential targets for interventions to help support caregivers of those affected by eating disorders. Whilst the consequences of high EOI are inconsistent (Rienecke, 2020a), the associations between high EOI and both high caregiver distress/psychological difficulties and accommodating behaviours (Marcos et al., 2016; Schwarte et al., 2017) suggest it is important that caregivers are offered support around these emotional and behavioural responses. This seems particularly important considering guilt is often associated with difficult emotions such as sadness and sorrow (Gilbert, 2022). However, it should be noted that EOI is in part defined by strong emotional reactions, thus the associated psychological difficulties are likely not to be distinct. Additionally, from the perspective of the individual affected by the eating disorder, perceived EOI has been found to be stressful (Medina-Pradas et al., 2011) and is often perceived as criticism (Domínguez-Martínez & Medina-Pradas, 2020). This suggests that at least certain behaviours and responses evoked as part of the construct of EOI have negative associations for both the caregiver and the person affected by the eating disorder. Interventions and psychoeducation designed to support caregivers with their feelings of guilt may therefore be helpful to reduce the difficult thoughts, feelings and responses associated with high EOI. Attention should be paid to the language used when offering these, to ensure that families do not perceive this to mean they are responsible, thus potentially evoking further guilt.

Similarly, since CC has been associated with negative treatment outcomes (Duclos et al., 2012), interventions that are designed to reduce CC, through targeting blame, are likely to be advantageous to both the caregiver and person affected by the eating disorder (Hibbs et al., 2015). It is therefore important to emphasise one of the key principles of family-based treatment, that neither the person nor the caregiver are to blame (Rienecke & le Grange, 2022). The use of externalisation is one way in which caregivers can be encouraged to view the behaviours in relation to the eating disorder, rather than attribution of blame to the individual, and can support caregivers to contain and tolerate the behaviour (Lock & Nicholls, 2020). Increasing support and empowering caregivers is particularly important considering the recent call to both explore new treatments and enhance the efficacy of current treatments, due to the poor prognosis of eating disorders and the emerging notion of terminal eating disorders, which can lead to the withdrawal of evidence-based care (Downs et al., 2023).

Limitations and Future Research

The high level of attrition was a limitation of the study. Although 262 eligible respondents began the survey, less than 60% completed the full survey. Of those who were eligible who began the survey, about 15% dropped out before completing all the demographics questions regarding the individual affected by the eating disorder. A further 4% dropped out before completing the full FQ, 7% prior to completing the full SCS and 21% prior to completing the CARE questionnaire. There are several potential reasons for this drop-out. One explanation may be that individuals felt participant burden was too high, since the proportion of those who dropped out increased as the survey progressed. This may be particularly relevant since many participants highlighted the lengthy period of time they were caring for their loved one throughout the day, with up to 140 hours of face-to-face support per week being reported. This also may have meant that they were interrupted during completing the survey, and unable to finish this. The attrition was greatest in relation to the CARE questionnaire. Whilst this may reflect this being the final survey, another explanation may also be a potential technological issue around the storage of questionnaire results. Across a consecutive six-day period, although 67 respondents began the survey, none of these individuals began the CARE questionnaire. Although enquires were made with Qualtrics as to any difficulties with the platform or storage of data at this time, no explanations for this could be found.

The lack of diversity in the sample may have also affected the findings, as well as their generalisability. Although the study was adequately powered and significant results were noted, the demographics of the sample were limited. The majority of the sample were White mothers, based in England, who were supporting females who had experienced or were experiencing a diagnosis of anorexia nervosa. This is consistent with previous research (Rienecke, 2018), and highlights that research fails to represent the experiences of a large proportion of caregivers of those affected by eating disorders. The homogeneity around this sample (including with respect to EE factors) did not allow for meaningful analyses of relationships such as differences in relation to ethnicity, caregiver type and diagnosis, which is important considering some evidence suggests EE may differ across these groups. Several studies have reported that mothers often have higher levels of EOI compared to fathers (e.g. Schwarte et al., 2017), whilst caregiver type does not appear to affect levels of CC as consistently (e.g. Rienecke & Richmond, 2017). These differences across EOI may suggest that there are distinct predictors related to caregiver type and/or gender, which future research could explore. This may be particularly true of the potential role of self-compassion, considering males have been reported to experience higher levels of self-compassion than females (Yarnell et al., 2019).

Whilst the high proportion (over 90%) of individuals rated as high EE fits with the general pattern of caregivers of those affected by eating disorders, the current sample had a somewhat greater proportion of caregivers scoring high on EE (Anastasiadou et al., 2014). This may be due to several reasons, such as the high proportion of mothers, since maternal EOI tends to be greater than paternal EOI (e.g. Anastasiadou et al., 2016; Blondin et al., 2019; Hoste & le Grange, 2008; Schwarte et al., 2017). The self-selecting recruitment method may also have attracted caregivers who were more motivated to engage in research, which may be associated with features associated with high levels of EOI and CC. It may also reflect the context regarding COVID-19. Recruitment began at a time when the consequences of COVID-control measures such as social distancing and public lockdowns are reported to have a negative impact on both the physical and mental health of those affected by eating disorders (Devoe et al., 2022) and the support eating disorder services were able to provide (Ayton et al., 2022; Linardon et al., 2022). Caregivers commonly reported feeling that COVID-19 was impacting their ability to provide support to the individual affected by the eating disorder and that their own mental health was being impacted (Parsons et al., 2021). Thus, it is likely this also impacted upon levels of EE.

Although EE ratings from different countries, cultures and ethnicities have been found to be broadly homogenous (Domínguez-Martínez & Medina-Pradas, 2020; Hoste et al., 2012; Hoste & le Grange, 2008), some differences regarding specific components of EE have been noted. In families of those affected by anorexia nervosa, when mothers' and fathers' EE scores were averaged, White families scored significantly higher on the warmth subscale, and tended to make more positive remarks, compared to ethnic minority families (Hoste et al., 2012). This reflects the pattern found in families affected by bulimia nervosa, although these differences did not reach significance (Hoste & le Grange, 2008). The present study was unable to explore potential cultural and ethnic nuances around the factors associated with EE due to the homogeneity of the sample. Future research therefore needs work to recruit more individuals who are not White, to explore whether cultural background affects caregivers' responses to the eating disorder. It is also important that people of ethnic minority groups are not just grouped into one, therefore attempts should be made to have large enough samples of individuals from several ethnicities.

Future research could explore the positive dimensions of EE (warmth and positive remarks) which, as in other research (Gorrell & le Grange, 2020), this study did not include. Parental warmth has been reported as being related to good outcomes at end-of-treatment in adolescents affected by anorexia nervosa engaged in family-based treatment (le Grange et al., 2011). Perceived warmth has also been suggested to be protective, as has been found to be negatively related to the stress of the individual affected by the eating disorder (Medina-Pradas et al., 2011). This is consistent with wider mental health research in which some evidence, particularly in the early phase of the diagnosis psychosis, suggests a positive association between warmth and outcomes, including protection of relapse up to nine months (Butler et al., 2019). It is also important to expand beyond cross-sectional approaches, which prevent causal inference. As well as longitudinal research utilising the objective measures of EE, future research should also include perceived EE, from the perspective of the individual affected by the eating disorder. This has been found to be important regarding both wellbeing and the individual's eating disorder psychopathology (di Paola et al., 2010; Medina-Pradas et al., 2011). Thus, future research is needed to explore this likely bidirectional relationship. Finally, whilst self-compassion was not found to moderate the relationship between guilt, shame, blame and EE, it was negatively associated with EOI. This supports the notion that CFT could support caregivers and reduce levels of EE (Cherry et al., 2017; Coleman et al., 2022), therefore it would be of value to further explore this with genuinely representative samples.

Conclusion

In summary, the present study explored the association between guilt, shame, blame, self-compassion and EE in caregivers of those affected by eating disorders. Specifically, most of the sample identified as mothers of individuals affected by anorexia nervosa. EOI was found to be positively associated with guilt and shame, and negatively associated with self-compassion; guilt was the only significant predictor of EOI. CC was found to be positively associated with guilt, shame and blame; blame significantly predicted levels of CC. These results have important implications for clinical practice, and suggest new targets for caregiver interventions.

References

Aguinis, H., & Stone-Romero, E. F. (1997). Methodological artifacts in moderated multiple regression and their effects on statistical power. *Journal of Applied Psychology*, *82*(1), 192.

Allan, E., le Grange, D., Sawyer, S. M., McLean, L. A., & Hughes, E. K. (2018). Parental expressed emotion during two forms of family-based treatment for adolescent anorexia nervosa. *European Eating Disorders Review*, *26*(1), 46–52. https://doi.org/10.1002/erv.2564

Anastasiadou, D., Medina-Pradas, C., Sepulveda, A. R., & Treasure, J. (2014). A systematic review of family caregiving in eating disorders. *Eating Behaviors*, *15*(3), 464–477. https://doi.org/10.1016/j.eatbeh.2014.06.001

Anastasiadou, D., Sepulveda, A. R., Parks, M., Cuellar-Flores, I., & Graell, M. (2016). The relationship between dysfunctional family patterns and symptom severity among adolescent patients with eating disorders: A gender-specific approach. *Women & Health*, *56*(6), 695–712. https://doi.org/10.1080/03630242.2015.1118728

Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry*, *68*(7), 724–731. https://doi.org/10.1001/archgenpsychiatry.2011.74

Aspen, V., Darcy, A. M., & Lock, J. (2014). Patient resistance in eating disorders. *Psychiatric Times*, *31*(9), 32.

Ayton, A., Viljoen, D., Ryan, S., Ibrahim, A., & Ford, D. (2022). Risk, demand, capacity and outcomes in adult specialist eating disorder services in South-East of England before and since COVID-19. *BJPsych Bulletin*, *46*(2), 89–95. https://doi.org/10.1192/bjb.2021.73

Barrowclough, C., & Hooley, J. M. (2003). Attributions and expressed emotion: A review. *Clinical Psychology Review*, *23*(6), 849–880. https://doi.org/10.1016/s0272-7358(03)00075-8

Barrowclough, C., Johnston, M., & Tarrier, N. (1994). Attributions, expressed emotion, and patient relapse: An attributional model of relatives' response to schizophrenic illness. *Behavior Therapy*, *25*(1), 67–88. https://doi.org/doi.org/10.1016/S0005-7894(05)80146-7

Besharat, M. A. (1997). *An investigation of the relationship between personality-family factors and response to treatment in young adult anorexic and bulimic patients*. [Doctoral thesis, UCL]. UCL Discovery.

Besharat, M. A., & Eisler, I. (1996). The self and other-blame scales (SOBS). *European Psychiatry*, *11*(S4), 363s–363s.

Besharat, M. A., Eisler, I., & Dare, C. (2001). The Self-and Other-Blame Scale (SOBS). The background and presentation of a new instrument for measuring blame in families. *Journal of Family Therapy*, *23*(2), 208–223. https://doi.org/doi.org/10.1111/1467-6427.00179

Blondin, S., Meilleur, D., Taddeo, D., & Frappier, J.-Y. (2019). Caregiving experience and expressed emotion among parents of adolescents suffering from anorexia nervosa following illness onset. *Eating Disorders*, *27*(5), 453–470. https://doi.org/10.1080/10640266.2018.1553431

Braehler, C., & Neff, K. (2020). Self-compassion in PTSD. In M. Tull & N. Kimbrel (Eds.), *Emotion in posttraumatic stress disorder* (pp. 567–596). Elsevier.

Brenner, R. E., Heath, P. J., Vogel, D. L., & Credé, M. (2017). Two is more valid than one: Examining the factor structure of the Self-Compassion Scale (SCS). *Journal of Counseling Psychology*, *64*(6), 696. https://doi.org/10.1037/cou0000211

Brown, G. (1985). The discovery of expressed emotion: Induction or deduction. *Expressed Emotion in Families*, 7–25.

Brown, G., Carstairs, G., & Topping, G. (1958). Post-hospital adjustment of chronic mental patients. *The Lancet*, *272*(7048), 685–689. https://doi.org/10.1016/s0140-6736(58)92279-7

Brown, G., & Rutter, M. (1966). The measurement of family activities and relationships: A methodological study. *Human Relations*, *19*(3), 241–263. https://doi.org/10.1177/001872676601900301

Butler, R., Berry, K., Varese, F., & Bucci, S. (2019). Are family warmth and positive remarks related to outcomes in psychosis? A systematic review. *Psychological Medicine*, *49*(8), 1250–1265.

Cherry, M. G., Taylor, P. J., Brown, S. L., Rigby, J. W., & Sellwood, W. (2017). Guilt, shame and expressed emotion in carers of people with long-term mental health difficulties: A systematic review. *Psychiatry Research*, *249*, 139–151. https://doi.org/10.1016/j.psychres.2016.12.056

Coleman, M., Jones, E. J., Hoiles, K. J., & McEvoy, P. M. (2022). The association between carer self-compassion, expressed emotion, quality of life, and paediatric eating disorder symptoms. *Eating Behaviors*, *45*, 101628. https://doi.org/10.1016/j.eatbeh.2022.101628

Devoe, D. J., Han, A., Anderson, A., Katzman, D. K., Patten, S. B., Soumbasis, A., Flanagan, J., Paslakis, G., Vyver, E., & Marcoux, G. (2022). The impact of the COVID-19 pandemic on eating disorders: A systematic review. *International Journal of Eating Disorders*. https://doi.org/10.1002/eat.23704

di Paola, F., Faravelli, C., & Ricca, V. (2010). Perceived expressed emotion in anorexia nervosa, bulimia nervosa, and binge-eating disorder. *Comprehensive Psychiatry*, *51*(4), 401–405. https://doi.org/10.1016/j.comppsych.2009.10.002

Dobrescu, S. R., Dinkler, L., Gillberg, C., Råstam, M., Gillberg, C., & Wentz, E. (2020). Anorexia nervosa: 30-year outcome. *The British Journal of Psychiatry*, *216*(2), 97–104. https://doi.org/10.1192/bjp.2019.113

Domínguez-Martínez, T., & Medina-Pradas, C. (2020). Cultural differences in expressed emotion. *Eating Disorders and Expressed Emotion*, 129–155. https://doi.org/doi.org/10.4324/9780429429484-8

Dong, Y., & Peng, C.-Y. J. (2013). Principled missing data methods for researchers. *SpringerPlus*, *2*(1), 1–17. https://doi.org/doi.org/10.1186/2193-1801-2-222

Downs, J., Ayton, A., Collins, L., Baker, S., Missen, H., & Ibrahim, A. (2023). Untreatable or unable to treat? Creating more effective and accessible treatment for long-standing and severe eating disorders. *The Lancet Psychiatry*, *10*(2), 146–154. https://doi.org/10.1016/S2215-0366(22)00400-X

Duclos, J., Dorard, G., Cook-Darzens, S., Curt, F., Faucher, S., Berthoz, S., Falissard, B., & Godart, N. (2018). Predictive factors for outcome in adolescents with anorexia nervosa: To what extent does parental expressed emotion play a role? *PLoS ONE*, *13*(7). https://doi.org/10.1371/journal.pone.0196820

Duclos, J., Vibert, S., Mattar, L., & Godart, N. (2012). Expressed emotion in families of patients with eating disorders: A review of the literature. *Current Psychiatry Reviews*, *8*(3), 183–202. https://doi.org/10.2174/157340012800792975

Durbin, J., & Watson, G. S. (1950). Testing for serial correlation in least squares regression: I. *Biometrika*, *37*(3/4), 409–428.

Eddy, K. T., Tabri, N., Thomas, J. J., Murray, H. B., Keshaviah, A., Hastings, E., Edkins, K., Krishna, M., Herzog, D. B., & Keel, P. K. (2017). Recovery from anorexia nervosa and bulimia nervosa at 22-year follow-up. *The Journal of Clinical Psychiatry*, *78*(2), 17085. https://doi.org/10.4088/JCP.15m10393

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*(2), 175–191. https://doi.org/10.3758/bf03193146

Field, A. (2018). *Discovering statistics using IBM SPSS statistics (5th ed.)*. Sage.

Fletcher, L., Trip, H., Lawson, R., Wilson, N., & Jordan, J. (2021). Life is different now - impacts of eating disorders on carers in New Zealand: A qualitative study. *Journal of Eating Disorders*, *9*(1), 91. https://doi.org/10.1186/s40337-021-00447-z

Fox, J. R. E., Dean, M., & Whittlesea, A. (2017). The experience of caring for or living with an individual with an eating disorder: A meta-synthesis of qualitative studies. *Clinical Psychology & Psychotherapy*, *24*(1), 103–125. https://doi.org/10.1002/cpp.1984

Galmiche, M., Déchelotte, P., Lambert, G., & Tavolacci, M. P. (2019). Prevalence of eating disorders over the 2000–2018 period: A systematic literature review. *The American Journal of Clinical Nutrition*, *109*(5), 1402–1413. https://doi.org/10.1093/ajcn/nqy342

Gilbert, P. (2003). Evolution, social roles, and the differences in shame and guilt. *Social Research: An International Quarterly*, *70*(4), 1205–1230. https://doi.org/10.1353/sor.2003.0013

Gilbert, P. (2005). *Compassion: Conceptualisations, research and use in psychotherapy*. Routledge.

Gilbert, P. (2009). *The compassionate mind*. Robinson.

Gilbert, P. (2022). Shame, humiliation, guilt, and social status: The distress and harms of social disconnection. In P. Gilbert & G. Simos (Eds.), *Compassion focused therapy* (pp. 122–163). Routledge.

Gilbert, P., Catarino, F., Duarte, C., Matos, M., Kolts, R., Stubbs, J., Ceresatto, L., Duarte, J., Pinto-Gouveia, J., & Basran, J. (2017). The development of compassionate engagement and action scales for self and others. *Journal of Compassionate Health Care*, *4*(1), 1–24. https://doi.org/doi.org/10.1186/s40639-017-0033-3

Gilbert, P., & Miles, J. (2000). Sensitivity to social put-down: It's relationship to perceptions of social rank, shame, social anxiety, depression, anger and self-other blame. *Personality and Individual Differences*, *29*(4), 757–774. https://doi.org/10.1016/S0191-8869(99)00230-5

Gilbert, P., & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: Overview and pilot study of a group therapy approach. *Clinical Psychology & Psychotherapy: An International Journal of Theory & Practice*, *13*(6), 353–379. https://doi.org/10.1002/cpp.507

Goddard, E., Salerno, L., Hibbs, R., Raenker, S., Naumann, U., Arcelus, J., Ayton, A., Boughton, N., Connan, F., Goss, K., Lacey, H., Laszlo, B., Morgan, J., Moore, K., Robertson, D., Schreiber-Kounine, C., Sharma, S., Whitehead, L., Schmidt, U., & Treasure, J. (2013). Empirical examination of the interpersonal maintenance model of anorexia nervosa. *International Journal of Eating Disorders*, *46*(8), 867–874. https://doi.org/10.1002/eat.22172

Gorrell, S., Byrne, C. E., Trojanowski, P. J., Fischer, S., & le Grange, D. (2022). A scoping review of non-specific predictors, moderators, and mediators of family-based treatment for adolescent anorexia and bulimia nervosa: A summary of the current research findings. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*, 1–20. https://doi.org/10.1007/s40519-022-01367

Gorrell, S., & le Grange, D. (2020). Expressed emotion and anorexia nervosa. In R. Rienecke & D. le Grange (Eds.), *Eating disorders and expressed emotion* (pp. 76–100). Routledge. https://doi.org/10.4324/9780429429484-3

Goss, K., Gilbert, P., & Allan, S. (1994). An exploration of shame measures - I: The other as shamer scale. *Personality and Individual Differences*, *17*(5), 713–717. https://doi.org/10.1016/0191-8869(94)90149-X

Hayes, A. F. (2012). *PROCESS: A versatile computational tool for observed variable mediation, moderation, and conditional process modeling*. University of Kansas, KS.

Hedlund, S., Fichter, M. M., Quadflieg, N., & Brandl, C. (2003). Expressed emotion, family environment, and parental bonding in bulimia nervosa: A 6-year investigation. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*, *8*(1), 26–35. https://doi.org/10.1007/BF03324986

Hibbs, R., Rhind, C., Leppanen, J., & Treasure, J. (2015). Interventions for caregivers of someone with an eating disorder: A meta-analysis. *International Journal of Eating Disorders*, *48*(4), 349–361. https://doi.org/10.1002/eat.22298

Highet, N., Thompson, M., & King, R. M. (2005). The experience of living with a person with an eating disorder: The impact on the carers. *Eating Disorders*, *13*(4), 327–344. https://doi.org/10.1080/10640260591005227

Hooley, J. M. (2007). Expressed emotion and relapse of psychopathology. *Annual Review of Clinical Psychology*, *3*, 329–352. https://doi.org/10.1146/annurev.clinpsy.2.022305.095236

Hooley, J. M., & Gotlib, I. H. (2000). A diathesis-stress conceptualization of expressed emotion and clinical outcome. *Applied and Preventive Psychology*, *9*(3), 135–151. https://doi.org/10.1016/S0962-1849(05)80001-0

Hoste, R. R., Labuschagne, Z., Lock, J., & le Grange, D. (2012). Cultural variability in expressed emotion among families of adolescents with anorexia nervosa. *International Journal of Eating Disorders*, *45*(1), 142–145. https://doi.org/10.1002/eat.20888

Hoste, R. R., & le Grange, D. (2008). Expressed emotion among white and ethnic minority families of adolescents with bulimia nervosa. *European Eating Disorders Review*, *16*(5), 395–400. https://doi.org/10.1002/erv.856

Jakobsen, J. C., Gluud, C., Wetterslev, J., & Winkel, P. (2017). When and how should multiple imputation be used for handling missing data in randomised clinical trials–a practical guide with flowcharts. *BMC Medical Research Methodology*, *17*(1), 1–10. https://doi.org/doi.org/10.1186/s12874-017-0442-1

Kumlander, S., Lahtinen, O., Turunen, T., & Salmivalli, C. (2018). Two is more valid than one, but is six even better? The factor structure of the Self-Compassion Scale (SCS). *PLoS One*, *13*(12), e0207706. https://doi.org/10.1371/journal.pone.0207706

Kyriacou, O., Treasure, J., & Schmidt, U. (2008). Expressed emotion in eating disorders assessed via self-report: An examination of factors associated with expressed emotion in carers of people with anorexia nervosa in comparison to control families. *International Journal of Eating Disorders*, *41*(1), 37–46. https://doi.org/10.1002/eat.20469

Leff, J., & Vaughn, C. (1984). *Expressed emotion in families: Its significance for mental illness*. Guilford Press. https://doi.org/10.1176/ps.37.7.741-a

le Grange, D., Hoste, R. R., Lock, J., & Bryson, S. W. (2011). Parental expressed emotion of adolescents with anorexia nervosa: Outcome in family-based treatment. *International Journal of Eating Disorders*, *44*(8), 731–734. https://doi.org/10.1002/eat.20877 le Grange, D., Lock, J., Loeb, K., & Nicholls, D. (2010). Academy for eating disorders position paper: The role of the family in eating disorders. *International Journal of Eating Disorders*, *43*(1), 1–5. https://doi.org/10.1002/eat.20751

Linardon, J., Messer, M., Rodgers, R. F., & Fuller-Tyszkiewicz, M. (2022). A systematic scoping review of research on COVID-19 impacts on eating disorders: A critical appraisal of the evidence and recommendations for the field. *International Journal of Eating Disorders*, *55*(1), 3–38. https://doi.org/10.1002/eat.23640

Lock, J., & Nicholls, D. (2020). Toward a greater understanding of the ways family-based treatment addresses the full range of psychopathology of adolescent anorexia nervosa. *Frontiers in Psychiatry*, *10*, 968. https://doi.org/10.3389/fpsyt.2019.00968

Marcos, Y. Q., Quiles Sebastián, M. J., Aubalat, L. P., Sepúlveda García, A. R., & Treasure, J. (2016). The Spanish validation of the Accommodation and Enabling Scale for Eating Disorders among carers: A pilot study. *European Eating Disorders Review*, *24*(1), 62–68. https://doi.org/10.1002/erv.2378

Medina-Pradas, C., Navarro, J. B., López, S. R., Grau, A., & Obiols, J. E. (2011). Dyadic view of expressed emotion, stress, and eating disorder psychopathology. *Appetite*, *57*(3), 743–748. https://doi.org/10.1016/j.appet.2011.08.016

Miceli, M., & Castelfranchi, C. (2018). Reconsidering the differences between shame and guilt. *Europe's Journal of Psychology*, *14*(3), 710. https://doi.org/10.5964/ejop.v14i3.1564

Minuchin, S., Baker, L., Rosman, B. L., Liebman, R., Milman, L., & Todd, T. C. (1975). A conceptual model of psychosomatic illness in children: Family organization and family therapy. *Archives of General Psychiatry*, *32*(8), 1031–1038. https://doi.org/10.1001/archpsyc.1975.01760260095008

Monteleone, A. M., Cascino, G., Salerno, L., Schmidt, U., Micali, N., Cardi, V., & Treasure, J. (2022). A network analysis in adolescent anorexia nervosa exploring the connection between both patient and carer reactions and outcome. *European Eating Disorders Review*.

Myers, R. H. (1990). *Classical and modern regression with applications* (Vol. 2). Duxbury Press Belmont, CA.

Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and Identity*, *2*(3), 223–250. https://doi.org/10.1080/15298860390209035

Noir, L. (2023). *Caregivers expressed emotion: Validating a measure of guilt and shame in a caregiving context [Manuscript in preparation]*. Lancaster University.

Parsons, H., Murphy, B., Malone, D., & Holme, I. (2021). Review of Ireland's first year of the COVID-19 pandemic impact on people affected by eating disorders: 'Behind every screen there was a family supporting a person with an eating disorder'. *Journal of Clinical Medicine*, *10*(15), 3385. https://doi.org/10.3390/jcm10153385

Peris, T. S., & Miklowitz, D. J. (2015). Parental expressed emotion and youth psychopathology: New directions for an old construct. *Child Psychiatry & Human Development*, *46*(6), 863–873. https://doi.org/10.1007/s10578-014-0526-7

Philipp, J., Truttmann, S., Zeiler, M., Franta, C., Wittek, T., Schöfbeck, G., Mitterer, M., Mairhofer, D., Zanko, A., & Imgart, H. (2020). Reduction of high expressed emotion and treatment outcomes in anorexia nervosa - Caregivers' and adolescents' perspective. *Journal of Clinical Medicine*, *9*(7), 2021. https://doi.org/10.3390/jcm9072021

Phillipou, A., Castle, D. J., & Rossell, S. L. (2018). Anorexia nervosa: Eating disorder or body image disorder?. *The Australian and New Zealand Journal of Psychiatry, 52*(1), 13–14. https://doi.org/10.1177/0004867417722640

Rienecke, R. D. (2018). Expressed emotion and eating disorders: An updated review. *Current Psychiatry Reviews*, *14*(2), 84–98. https://doi.org/10.2174/1573400514666180808115637

Rienecke, R. D. (2020a). Emotional overinvolvement with adolescents: A problematic construct? *Current Treatment Options in Psychiatry*, *7*(2), 162–185. https://doi.org/10.1007/s40501-020-00205-z

Rienecke, R. D. (2020b). Expressed emotion and bulimia nervosa. In R. Rienecke & D. le Grange (Eds.), *Eating disorders and expressed emotion* (pp. 101–114). Routledge. https://doi.org/10.4324/9780429429484-3

Rienecke, R. D., Accurso, E. C., Lock, J., & le Grange, D. (2016). Expressed emotion, family functioning, and treatment outcome for adolescents with anorexia nervosa. *European Eating Disorders Review*, *24*(1), 43–51. https://doi.org/10.1002/erv.2389

Rienecke, R. D., Gorrell, S., Blalock, D. V., Smith, K., Lock, J., & le Grange, D. (2021). Expressed emotion and long-term outcome among adolescents with anorexia nervosa. *International Journal of Eating Disorders*, *54*(11), 2019–2024. https://doi.org/10.1002/eat.23613

Rienecke, R. D., & le Grange, D. (2022). The five tenets of family-based treatment for adolescent eating disorders. *Journal of Eating Disorders*, *10*(1), 1–10. https://doi.org/10.1186/s40337-022-00585-y

Rienecke, R. D., & Richmond, R. L. (2017). Psychopathology and expressed emotion in parents of patients with eating disorders: Relation to patient symptom severity. *Eating Disorders: The Journal of Treatment & Prevention*, *25*(4), 318–329. https://doi.org/10.1080/10640266.2017.1289795

Rienecke, R. D., Sim, L., Lock, J., & le Grange, D. (2016). Patterns of expressed emotion in adolescent eating disorders. *Journal of Child Psychology and Psychiatry*, *57*(12), 1407–1413. https://doi.org/10.1111/jcpp.12594

Rothwell, E., & Coopey, E. (2021). The impact of living in a 'fatphobic' society. *Clinical Psychology Forum*, *343*.

Salerno, L., Rhind, C., Hibbs, R., Micali, N., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., & Lo Coco, G. (2016). An examination of the impact of care giving styles (accommodation and skilful communication and support) on the one year outcome of adolescent anorexia nervosa: Testing the assumptions of the cognitive interpersonal model in anorexia nervosa. *Journal of Affective Disorders*, *191*, 230–236. https://doi.org/10.1016/j.jad.2015.11.016

Scheffer, J. (2002). Dealing with missing data. *Research Letters in the Information and Mathematical Sciences*, *3*, 153–160.

Schmidt, U., & Treasure, J. (2006). Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology*, *45*(3), 343–366. https://doi.org/10.1348/014466505x53902

Schwarte, R., Timmesfeld, N., Dempfle, A., Krei, M., Egberts, K., Jaite, C., Fleischhaker, C., Wewetzer, C., Herpertz-Dahlmann, B., Seitz, J., & Bühren, K. (2017). Expressed emotions and depressive symptoms in caregivers of adolescents with first-onset anorexia nervosa—A long-term investigation over 2.5 years. *European Eating Disorders Review*, *25*(1), 44–51. https://doi.org/10.1002/erv.2490

Sedighimornani, N., Rimes, K. A., & Verplanken, B. (2019). Exploring the relationships between mindfulness, self-compassion, and shame. *Sage Open*, *9*(3), 2158244019866294. https://doi.org/10.1177/2158244019866294

Sepulveda, A. R., Graell, M., Berbel, E., Anastasiadou, D., Botella, J., Carrobles, J. A., & Morandé, G. (2012). Factors associated with emotional well-being in primary and secondary caregivers of patients with eating disorders. *European Eating Disorders Review*, *20*(1), e78–e84. https://doi.org/10.1002/erv.1118

Sepulveda, A. R., Whitney, J., Hankins, M., Treasure, J., AR, S., Whitney, J., Hankins, M., & Treasure, J. (2008). Development and validation of an Eating Disorders Symptom Impact Scale (EDSIS) for carers of people with eating disorders. *Health & Quality of Life Outcomes*, *6*, 28. https://doi.org/10.1186/1477-7525-6-28

Simic, M., Jewell, T., & Eisler, I. (2021). Beneath the surface of expressed emotion (EE): The clinical relevance of possible mechanisms underlying EE in eating disorders. In In R. Rienecke & D. le Grange (Eds.), *Eating disorders and expressed emotion* (pp. 33–57). Routledge. https://doi.org/10.4324/9780429429484-3

Stillar, A., Strahan, E., Nash, P., Files, N., Scarborough, J., Mayman, S., Henderson, K., Gusella, J., Connors, L., & Orr, E. S. (2016). The influence of carer fear and self-blame when supporting a loved one with an eating disorder. *Eating Disorders*, *24*(2), 173–185. https://doi.org/10.1080/10640266.2015.1133210

Szmukler, G., Eisler, I., Russell, G., & Dare, C. (1985). Anorexia nervosa, parental 'expressed emotion' and dropping out of treatment. *The British Journal of Psychiatry*, *147*, 265–271. https://doi.org/10.1192/bjp.147.3.265

Tangney, J. P., Wagner, P., & Gramzow, R. (1992). Proneness to shame, proneness to guilt, and psychopathology. *Journal of Abnormal Psychology*, *101*(3), 469. https://doi.org/10.1037/0021-843X.101.3.469

Treasure, J., Duarte, T. A., & Schmidt, U. (2020). Eating disorders. *The Lancet*, *395*(10227), 899–911. https://doi.org/10.1016/S0140-6736(20)30059-3

Treasure, J., & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: A summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders*, *1*(1), 13. https://doi.org/10.1186/2050-2974-1-13

Treasure, J., Sepulveda, A. R., MacDonald, P., Whitaker, W., Lopez, C., Zabala, M., Kyriacou, O., & Todd, G. (2008). Interpersonal maintaining factors in eating disorder: Skill sharing interventions for carers. *International Journal of Child and Adolescent Health*, *1*(4), 331–338. https://doi.org/10.1007/978-3-319-32742-6_9

Treasure, J., Willmott, D., Ambwani, S., Cardi, V., Clark Bryan, D., Rowlands, K., & Schmidt, U. (2020). Cognitive interpersonal model for anorexia nervosa revisited: The perpetuating factors that contribute to the development of the severe and enduring illness. *Journal of Clinical Medicine*, *9*(3), 630. https://doi.org/10.3390/jcm9030630

van Furth, E., van Strien, D., Martina, L., van Son, M., Hendrickx, J., & van Engeland, H. (1996). Expressed emotion and the prediction of outcome in adolescent eating disorders. *International Journal of Eating Disorders*, *20*(1), 19–31. https://doi.org/10.1002/(SICI)1098-108X(199607)20:1<19::AID-EAT3>3.0.CO;2-7

vander Ven, T., & vander Ven, M. (2003). Exploring patterns of mother-blaming in anorexia scholarship: A study in the sociology of knowledge. *Human Studies*, *26*(1), 97–119. https://doi.org/https://doi.org/10.1023/A:1022527631743

Wearden, A. J., Tarrier, N., Barrowclough, C., Zastowny, T. R., & Rahill, A. A. (2000). A review of expressed emotion research in health care. *Clinical Psychology Review*, *20*(5), 633–666. https://doi.org/10.1016/s0272-7358(99)00008-2

Whitney, J., & Eisler, I. (2005). Theoretical and empirical models around caring for someone with an eating disorder: The reorganization of family life and inter-personal maintenance factors. *Journal of Mental Health*, *14*(6), 575–585. https://doi.org/10.1080/09638230500347889

Whitney, J., Murray, J., Gavan, K., Todd, G., Whitaker, W., & Treasure, J. (2005). Experience of caring for someone with anorexia nervosa: Qualitative study. *The British Journal of Psychiatry*, *187*(5), 444–449. https://doi.org/10.1192/bjp.187.5.444

Wiedemann, G., Rayki, O., Feinstein, E., & Hahlweg, K. (2002). The Family Questionnaire: Development and validation of a new self-report scale for assessing expressed emotion. *Psychiatry Research*, *109*(3), 265–279. https://doi.org/10.1016/S0165-1781(02)00023-9

Yang, L. H., Phillips, M. R., Licht, D. M., & Hooley, J. M. (2004). Causal attributions about schizophrenia in families in China: Expressed emotion and patient relapse. *Journal of Abnormal Psychology*, *113*(4), 592. https://doi.org/10.1037/0021-843X.113.4.592

Yarnell, L. M., Neff, K. D., Davidson, O. A., & Mullarkey, M. (2019). Gender differences in self-compassion: Examining the role of gender role orientation. *Mindfulness*, *10*(6), 1136–1152. https://doi.org/10.1007/s12671-018-1066-1

Zabala, M. J., Macdonald, P., Treasure, J., MJ, Z., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: A systematic review. *European Eating Disorders Review*, *17*(5), 338–349. https://doi.org/10.1002/erv.925

Tables and Figures

Figure 1

Participant Inclusion Flow Diagram

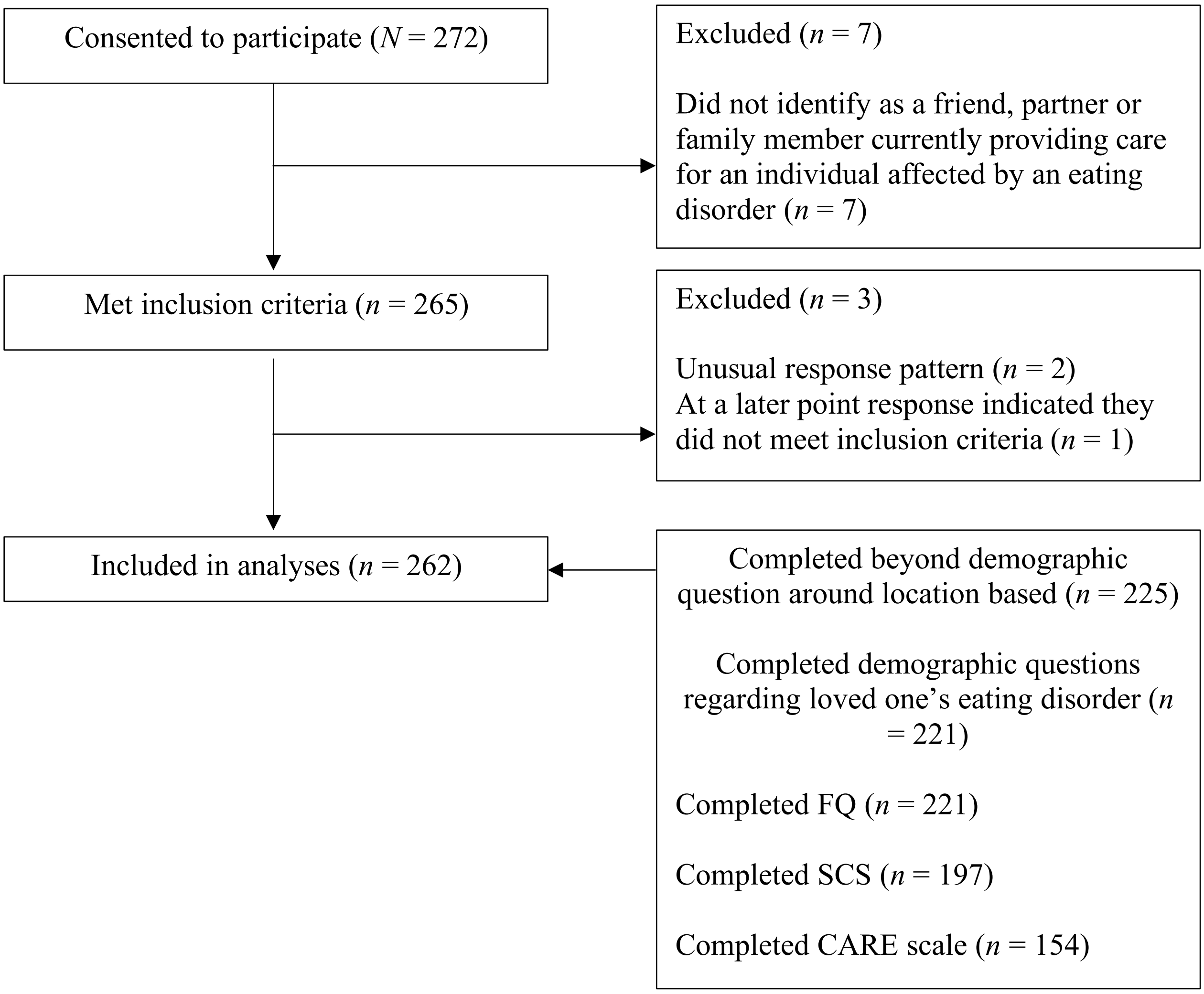


Table 1

Participant Characteristics

Characteristic		Mean (Min – Max)	Standard Deviation
Age (years) (*N* = 261)		47.52 (18-66)	8.26
Time spent providing face-to-face support (hours per week) (*N* = 223)		41.8 (0-140)	33.84
Time spent providing virtual support (hours per week) (*N* = 221)		8.04 (0-126)	16.24

Characteristic		N	Percentage
Gender (*N* = 262)	Female	246	93.89%
	Male	15	5.73%
	Non-binary	1	0.38%
Ethnicity	White – English/ Welsh/ Scottish/ Northern Irish/ British	235	89.69%

(*N* = 262)	White Irish	5	1.91%
	Another Other White Background	10	3.82%
	Asian/ Asian British – Indian	1	0.38%
	Asian/ Asian Pakistani	2	0.76%
	Any Other Asian Background	3	1.15%
	Any Other Mixed/ Multiple Ethnic Background	2	0.76%
	Any Other Ethnic Background	1	0.38%
	Prefer Not to Say	3	1.14%
Country Based In	England	222	84.73%
(*N* = 262)	Wales	10	3.82%
	Scotland	24	9.16%
	Northern Ireland	1	0.38%
	Outside of the UK – Republic of Ireland	1	0.38%
	Outside of the UK – Spain	1	0.38%

	Outside of the UK – United States	2	0.76%
	Outside of the UK – New Zealand	1	0.38%
Relationship Type (*N* = 225)	Mother	189	84%
	Father	8	3.56%
	Friend	2	0.89%
	Partner	3	1.33%
	Sibling	4	1.78%
	Child	15	6.67%
	Grandparent	3	1.33%
	Prefer not to say	1	0.44%
Currently Live with the Person Affected by ED (*N* = 225)	Yes	192	85.33%
	No	14	6.22%
	Sometimes	18	8%
	Prefer not to say	1	0.44%
	Yes	47	20.89%
	No	174	77.33%

Caring for Someone Else with Mental Health Difficulties (*N* = 225)	Prefer not to say	4	1.78%
Received Formal Support for Self (in Relation to the Eating Disorder) (*N* = 225)	Yes	130	57.78%
	No	81	36%
	Unsure	13	5.78%
	Prefer not to say	1	0.44%
Type of formal support received (*N* = 130)	NHS	89	68.46%
	Private	21	16.15%
	Charity	19	14.62%
	Other	10	7.69%

Table 2

Characteristics of the Person Affected by the Eating Disorder

Characteristic		Mean (Min – Max)	Standard Deviation
Age (years)		17.47	5.81
($N = 221$)		4.5 - 64	
Duration experienced/ diagnosed with eating disorder (months)		33.62 0.25 - 312	40.49
($N = 219$)			
Characteristic		**N**	**Percentage**
Gender	Female	210	95.02%
($N = 221$)	Male	7	3.17%
	Non-binary	3	1.36%
	Prefer not to say	1	0.45%
Diagnosis	Anorexia Nervosa	196	88.69%
($N = 221$)	Bulimia Nervosa	10	4.52%
	Binge Eating Disorder	7	3.17%
	Avoidant/ Restrictive Food Intake Disorder	10	4.52%
	Otherwise Specified Feeding and Eating Disorder	9	4.07%
	Atypical Anorexia	5	2.26%

	Not known	8	3.62%
Currently receiving treatment (*N* = 221)	Yes	159	71.95%
	No	58	26.24%
	Not known	4	1.81%
Currently receiving inpatient treatment (*N* = 221)	Yes	20	9.05%
	No	200	90.50%
	Not known	1	0.45%
Other physical or mental health difficulties (*N* = 221)	Yes	140	63.35%
	No	61	27.60%
	Not known	15	6.79%
	Prefer not to say	5	2.26%

Table 3

Descriptive and Bivariate Statistics

Variable (N)		M (*SD*)	Range	1	2	3	4	5
1	EOI (*N* = 212)	32.9 (3.8)	20 (20-40)	-				
2	CC (*N* =212)	24.3 (5.00)	29 (11-40)	*.31***	-			
3	Self-compassion (*N* = 197)	37.2 (9.4)	45 (17-62)	*-.21***	-.06	-		
4	Guilt (*N* = 154)	31.5 (7.8)	34 (11-45)	*.31***	*.18**	*-.38***	-	
5	Shame (*N* = 154)	26.2 (8.7)	36 (9-45)	*.25***	.25**	-.46**	*.75***	-
6	Blame (*N* = 154)	18.8 (7.0)	30 (9-39)	*.00*	*.37***	*.01*	*.05*	*.24***

Note. Italicised values indicate Spearman's Rho values, non-italicised values indicate Pearson's product-moment correlation co-efficient.

Table 4

Predictors of EOI

Step	Predictors	B	SE B	*β*	Sig.	Adjusted *R* Square	*R* Square Change	F Change	Sig. F. Change
1.	CC	.24	.05	.34	<.001				
	Time spent caregiving	.03	.01	.32	<.001	.23	.24	23.88	<.001
2.	CC	.23	.05	.32	<.001				
	Time spent caregiving	.03	.01	.28	<.001				
	Blame	-.05	.04	-.09	.252				
	Self-Compassion	-.05	.03	-.14	.066				
	Guilt	.15	.05	.32	.003				
	Shame	-.03	.05	-.07	.532	.33	.12	6.70	<.001

Note. CC critical comments, EOI emotional overinvolvement

Table 5

Predictors of CC

Step	Predictors	B	SE B	*β*	Sig.	Adjusted *R* Square	*R* Square Change	F Change	Sig. F. Change
1.	EOI	.54	.11	.38	<.001	.14	.15	25.94	<.001
2.	EOI	.52	.11	.37	<.001				
	Blame	.27	.05	.36	<.001				
	Self-Compassion	.03	.04	.06	.438				
	Guilt	-.01	.08	-.02	.859				
	Shame	.06	.07	.10	.806	.27	.15	8.03	<.001

Note. CC critical comments, EOI emotional overinvolvement

Table 6

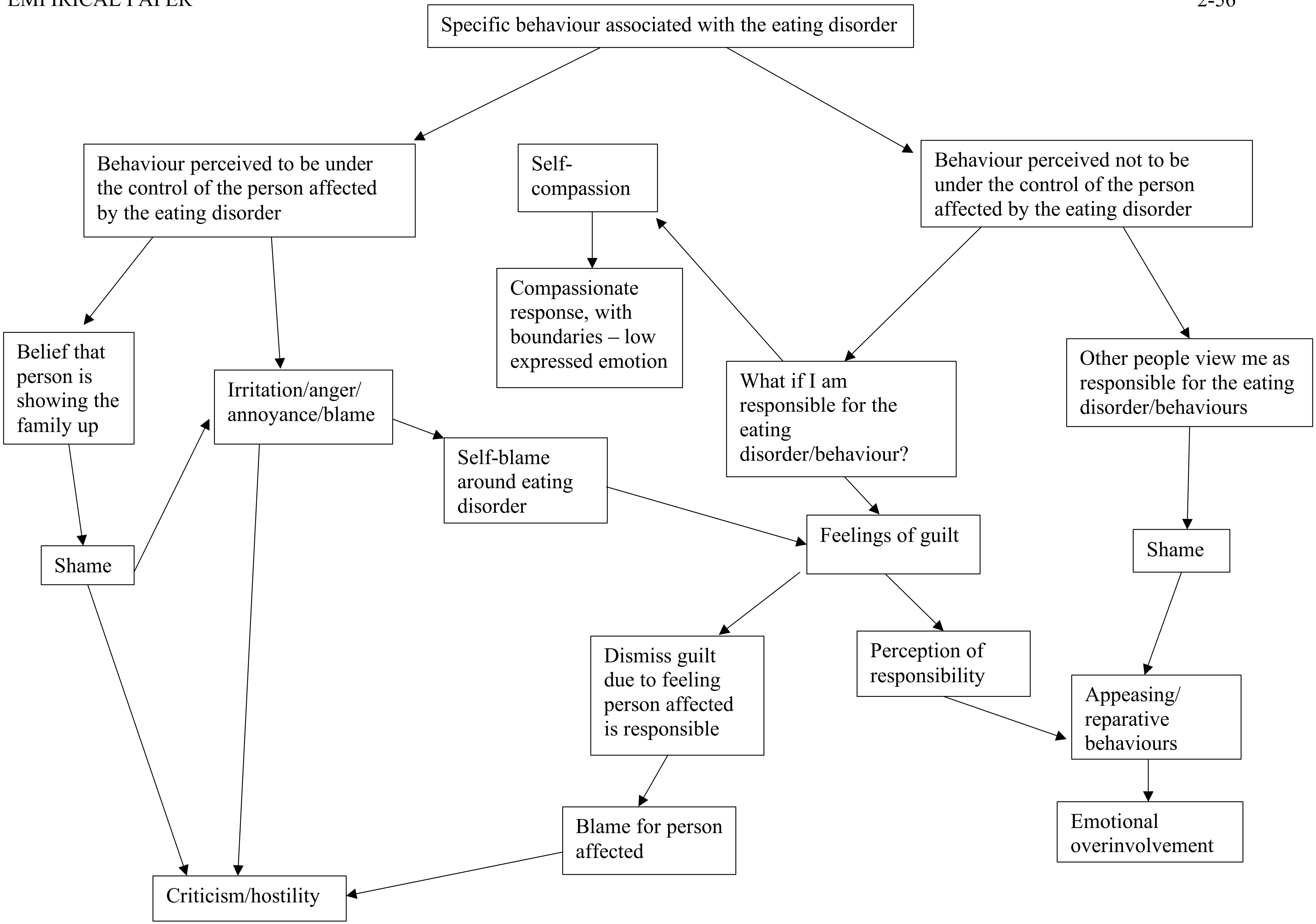
Moderation Analyses Results

Self-compassion as a moderator between…	Results
Guilt and EOI	($F[1, 150] = .31$, $p = .581$, R^2 *Change* = .002, $b = .002$, $t = .55$)
Shame and EOI	($F[1, 150] = .24$, $p = .63$, R^2 *Change* = .001, $b = -.002$, $t = -.49$)
Blame and EOI	($F[1, 150] = .01$, $p = .921$, R^2 *Change* = .001, $b = .004$, $t = .10$)
Guilt and CC	($F[1, 150] = .24$, $p = .623$, R^2 *Change* = .002, $b = .003$, $t = .49$)
Shame and CC	($F[1, 150] = 1.16$, $p = .283$, R^2 *Change* = .007, $b = .005$, $t = 1.08$)
Blame and CC	$F[1, 150] = .37$, $p = .546$, R^2 *Change* = .002, $b = -.004$, $t = -61$)

Note. CC critical comments, EOI emotional overinvolvement

Figure 2

Hypothetical Formulation Accounting for EE


Specific behaviour associated with the eating disorder
Behaviour perceived to be under the control of the person affected by the eating disorder
Self-compassion
Behaviour perceived not to be under the control of the person affected by the eating disorder
Compassionate response, with boundaries – low expressed emotion
Belief that person is showing the family up
Irritation/anger/annoyance/blame
What if I am responsible for the eating disorder/behaviour?
Other people view me as responsible for the eating disorder/behaviours
Self-blame around eating disorder
Shame
Feelings of guilt
Shame
Dismiss guilt due to feeling person affected is responsible
Perception of responsibility
Appeasing/reparative behaviours
Blame for person affected
Emotional overinvolvement
Criticism/hostility

Appendix A

European Eating Disorders Review Submission Guidelines for Authors

AIMS AND SCOPE

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

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

Authors may submit original theoretical systematic reviews, methodological, or empirical research articles (7000 words or less) or short communications (3000 words or less). The journal also publishes invited conceptual reviews from leading worldwide researchers in the field of Eating Disorders and/or Obesity. The aims of the journal are to offer a channel of communication between researchers, practitioners, administrators and policymakers who need to report and understand developments in the field of eating disorders.

The Journal

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

MANUSCRIPT CATEGORIES AND REQUIREMENTS

Research articles reporting new research of relevance as set out in the aims and scope should not normally exceed 6000 words (excluding abstract, references, tables or figures), with no more than five tables or illustrations. They should conform to the conventional layout: title page, Abstract, Introduction and Aims, Method, Results, Discussion, Acknowledgements and References. Each of these elements should start on a new page.
Word Limit: 6,000 (excluding abstract, references, tables or figures).
Abstract: 200 words.
References: up to 60.

Review articles: Systematic and meta-analytic review papers are welcomed if they critically review the available literature in a topic than will enhance clinical practice. Articles should have clear focus and enough number of studies should be available for a substantive review paper. Studies that only describe or list previous studies without a critical overview of the literature will not be considered.

Word Limit: 5,000 (excluding abstract, references, tables or figures).

Abstract: 200 words.

References: up to 100.

Figures/Tables: 5 maximum, but should be appropriate to the material covered. Additional tables might be included as supplementary information, if needed. Review articles must follow the PRISMA Guidelines. Authors may want to have a look at the review check lists that reviewers when assessing review articles.

…

FREE FORMAT SUBMISSION

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

Before you submit, you will need:

- Your manuscript: this should be an editable file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, conclusions and highlights. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.

- An ORCID ID, freely available at https://orcid.org. (Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)
- The title page of the manuscript, including:
    - Your co-author details, including affiliation and email address.
    - Statements relating to our ethics and integrity policies, which may include any of the following:
        - data availability statement
        - funding statement
        - conflict of interest disclosure
        - ethics approval statement
        - patient consent statement
        - permission to reproduce material from other sources
        - clinical trial registration

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

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

Cover Letters

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

Abstract

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

Graphical TOC/Abstract

The journal's table of contents/abstract will be presented in graphical form with a brief abstract.

The table of contents entry must include the article title, the authors' names (with the corresponding author indicated by an asterisk), no more than 80 words or 3 sentences of text summarizing the key findings presented in the paper and a figure that best represents the scope of the paper.

Table of contents entries should be submitted as 'Supplementary material for review' during the initial manuscript submission process.

The image supplied should fit within the dimensions of 50mm x 60mm and be fully legible at this size.

Guidelines for Table of Contents Graphics

- Concepts illustrated in graphical material must clearly fit with the research discussed in the accompanying text.
- Images featuring depictions or representations of people must not contain any form of objectification, sexualization, stereotyping, or discrimination. We also ask authors to consider community diversity in images containing multiple depictions or representations of people.
- Inappropriate use, representation, or depiction of religious figures or imagery, and iconography should be avoided.

- Use of elements of mythology, legends, and folklore might be acceptable and will be decided on a case-by-case basis. However, these images must comply with the guidelines on human participants when they are present.
- Generally, authors should consider any sensitivities when using images of objects that might have cultural significance or may be inappropriate in the context (for example, religious texts, historical events, and depictions of people).
- Legal requirements:
    - All necessary copyright permission for the reproduction of the graphical elements used in visuals must be obtained prior to publication.
    - Clearance must be obtained from identifiable people before using their image on graphics and such clearance must specify that it will be used on the table of contents. Use within text does not require such clearance unless it discloses sensitive personal information such as medical information. In all situations involving disclosure of such personal information, specific permission must be obtained and images of individuals should not be used in a false manner.

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

Highlights

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

Keywords

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

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends

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

Figures

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

Additional Files

Appendices

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

Supporting Information

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

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

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

Appendix B

CARE Scales

Instructions

- Below is a list of situations relatives tell us they have experienced. They may or may not have happened during the time you have cared for your relative.
- For each situation we have listed four possible responses. Please indicate how likely it is you would have this response *if the situation occurred today.*
- You may think or feel multiple responses to each circumstance so please tell us how likely it is that There are no right or wrong answers, we are just looking to understand how relatives in a caring role think and feel about these kind of events.
- All your scores are anonymous.
- Please complete all ratings for the responses a) to d), for all questions.

In the following scenarios, how likely is it you would think or feel the following responses *(if the situation occurred today)*…						
1) Your relative doesn’t attend an appointment with mental health services (psychiatrist, psychologist, nurse or other mental health professional)…		Not likely				Very likely
	a) I would worry if this was down to something I did as I haven't supported them as much as I had intended.	1	2	3	4	5
	b) I would think about how my relative should be taking more responsibility for their treatment so that they can be as well as possible.	1	2	3	4	5
	c) I would think about how many people miss appointments, my relative may have a lot to manage at the moment.	1	2	3	4	5
	d) I would worry people think I am not doing a good job as a carer for my relative.	1	2	3	4	5
2) Your relative experiences a period of relapse…		Not likely				Very likely

DRAFT

	a) I would feel like I’m a failure.	1	2	3	4	5
	b) I would think how good weeks and bad weeks are to be expected.	1	2	3	4	5
	c) I would feel bad about the times I might have helped more but didn’t and think about ways I could make up for this.	1	2	3	4	5
	d) I would think about how they could have avoided this if they had just learned to look after themselves better.	1	2	3	4	5
3) You have other commitments (such as with work or to other people or hobbies) alongside caring for your relative, and their mental health deteriorates…		Not likely				Very likely
	a) I would think about how I can’t always be there to help stop this from happening, and I may not have been able to prevent it anyway.	1	2	3	4	5
	b) I would feel like a bad person.	1	2	3	4	5
	c) I would feel bad that I prioritised other commitments and would try to make amends.	1	2	3	4	5
	d) I would think about how they need to learn to look after themselves better.	1	2	3	4	5
4) You encourage your relative to go for a walk with you but while you’re out in public your relative appears distressed (e.g uncooperative, crying, shouting, responding to voices, acting agitated)…		Not likely				Very likely
	a) I would worry about what people think of me.	1	2	3	4	5
	b) I would think they should be able to control their own actions.	1	2	3	4	5
	c) I would think they have a lot going on so it’s understandable for them to be acting this way.	1	2	3	4	5
	d) I would feel bad for encouraging them to join me and try to think of ways to be more helpful.	1	2	3	4	5
5) You attend an appointment with your relative’s psychiatrist, psychologist, nurse or other professional.		Not likely				Very likely

DRAFT

In the appointment your relative discusses how they have been feeling worse recently…						
	a) I would think about how my relative didn't help themselves as much as they could have.	1	2	3	4	5
	b) I would think about how a lot is going on for my relative, it's reasonable for them to have ups and downs.	1	2	3	4	5
	c) I would feel bad about my role in this and think about what I could do to help them.	1	2	3	4	5
	d) I would feel like all eyes are on me.	1	2	3	4	5
6) Your relative shares their intention to do something to harm themselves or set back their recovery in some way…		Not likely				Very likely
	a) I would wonder if there was something I missed or did wrong and try to make up for it.	1	2	3	4	5
	b) I would feel as if I have failed.	1	2	3	4	5
	c) I would think this can happen when people are really distressed and services/professionals are well placed to help if this happens.	1	2	3	4	5
	d) I would think they should have asked for help earlier if they were becoming this distressed.	1	2	3	4	5
7) Your relative blames you or your family for their mental health difficulties…		Not likely				Very likely
	a) I would think about how they might be right, I could have done things differently and will try and change how I do things in future.	1	2	3	4	5
	b) I would think they should look at their own role in their mental health difficulties.	1	2	3	4	5
	c) I would feel like I'm not good enough and want to end the conversation.	1	2	3	4	5
	d) I would think they are just expressing their frustration at their situation.	1	2	3	4	5

DRAFT

8) Your relative is experiencing a period of relapse at a time when you have not been providing your usual level of support. When talking to your friend, your relative's mental health difficulties come into the conversation…	Not likely				Very likely
a) I would raise the things that my relative is not doing to improve their situation.	1	2	3	4	5
b) I would feel like I'm not good enough and avoid the topic.	1	2	3	4	5
c) I would go over what I should do differently in order to prevent my relative's distress.	1	2	3	4	5
d) I would think how it is good to be able to discuss it because it's not talked about enough.	1	2	3	4	5
9) During a conversation with your relative they became angry/upset…	Not likely				Very likely
a) I would think they shouldn't be so sensitive and have better control over their emotions.	1	2	3	4	5
b) I would think other families seem to manage without having these problems, why can't we?	1	2	3	4	5
c) I would think about how they can quite easily become distressed because there are many things going on for them.	1	2	3	4	5
d) I would think about where I went wrong and show I am sorry for what I said/did.	1	2	3	4	5
10) You notice that you've been less patient with your relative's mental health difficulties recently…	Not likely				Very likely
a) I would think it's reasonable to find it hard, and I need time off from this sometimes.	1	2	3	4	5
b) I would think if they hadn't behaved this way then I wouldn't have become impatient.	1	2	3	4	5
c) I would feel not good enough so avoid thinking about it or start overthinking it.	1	2	3	4	5
d) I would feel bad about this and would like to do something to make them feel better about it.	1	2	3	4	5

DRAFT

11) Your relative has been struggling to take care of their own basic needs such as; eating properly or washing themselves or doing their laundry or cleaning their space, and so on…	Not likely				Very likely
a) I would feel responsible for not supporting their independence more and think about how I could make up for it.	1	2	3	4	5
b) I would think about how other people will judge me because of this.	1	2	3	4	5
c) I would think about how their mental health problems can make even quite simple things rather difficult.	1	2	3	4	5
d) I would think they can do these things for themselves; they are just not doing what they should.	1	2	3	4	5
12) Your relative's symptoms deteriorate and you decide to ring services (e.g. the local mental health team, emergency services). You feel like it is the right thing to phone services but you feel bad because you hadn't directly asked for your relative's permission to make the phone call…	Not likely				Very likely
a) I would worry if this had damaged the trust in our relationship and think about how to repair this.	1	2	3	4	5
b) I would think my relative could have prevented this from happening and then I wouldn't have had to call.	1	2	3	4	5
c) I would feel bad that I couldn't handle this on my own.	1	2	3	4	5
d) I would think that this can happen when people are unwell and services are better placed to help if this happens.	1	2	3	4	5

Note. Only the validated questions were analysed as part of the results.

DRAFT

Appendix C

Tests of Normality

Figure C1

Histogram of SCS Compassion Subscale

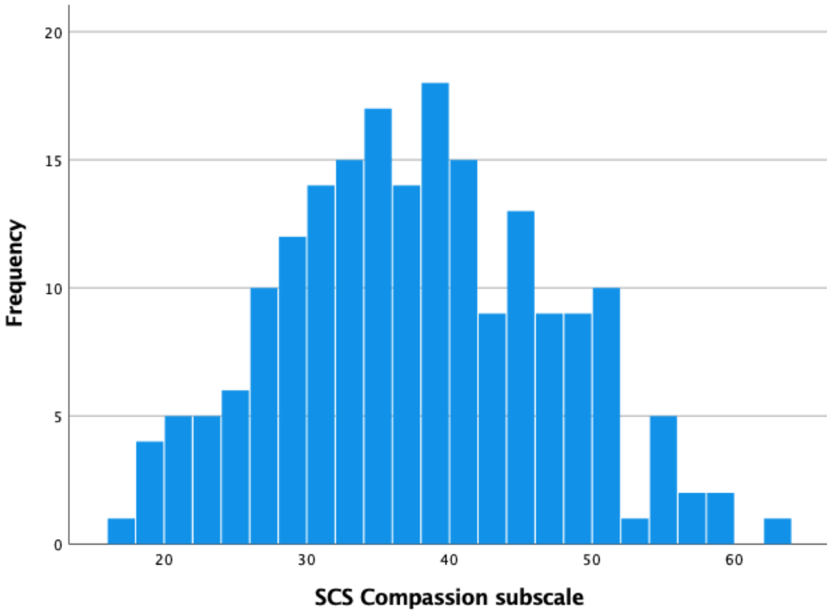


Figure C2

Q-Q Plot of SCS Compassion Subscale

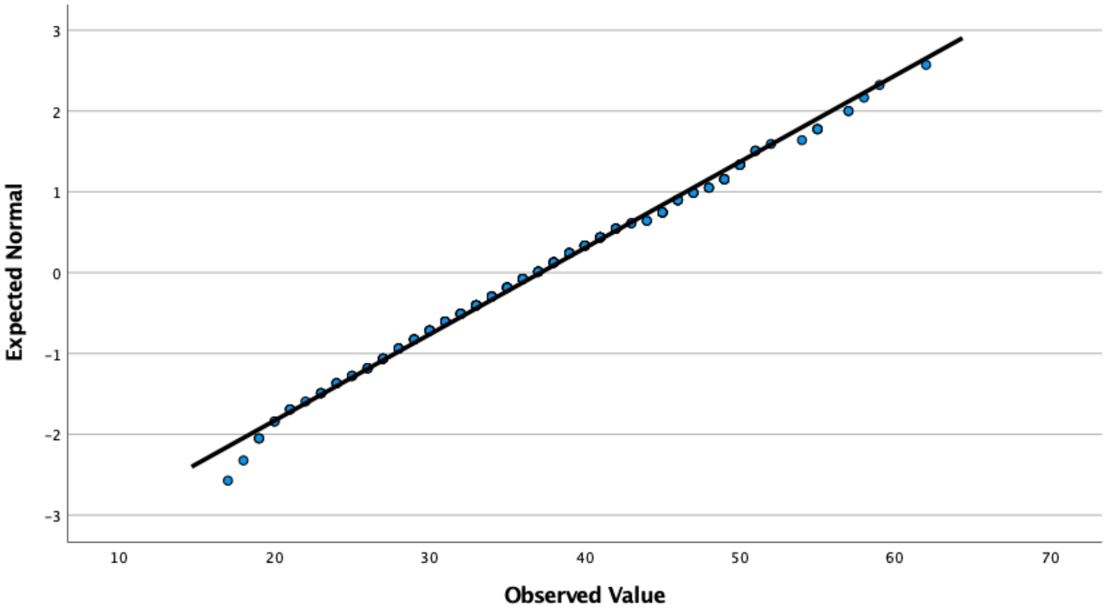


Figure C3

Histogram of Guilt Subscale

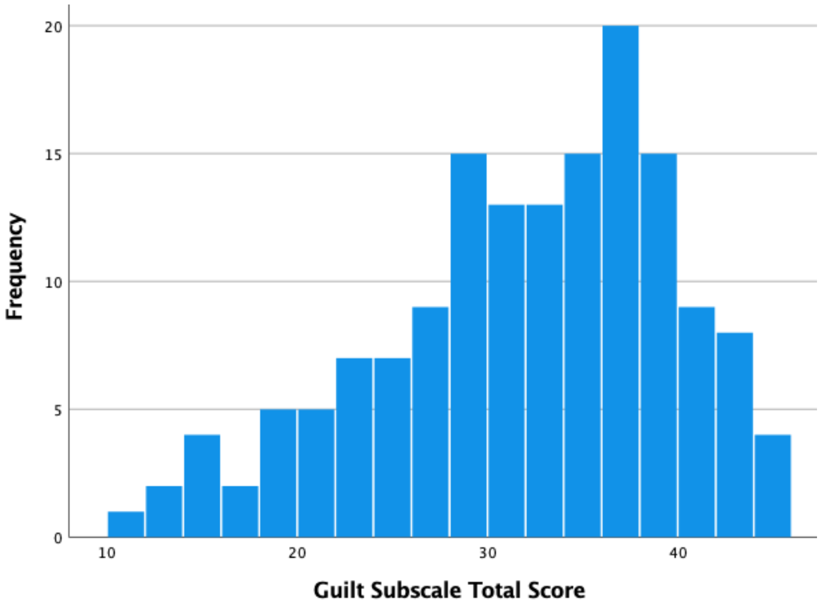


Figure C4

Q-Q Plot of Guilt Subscale

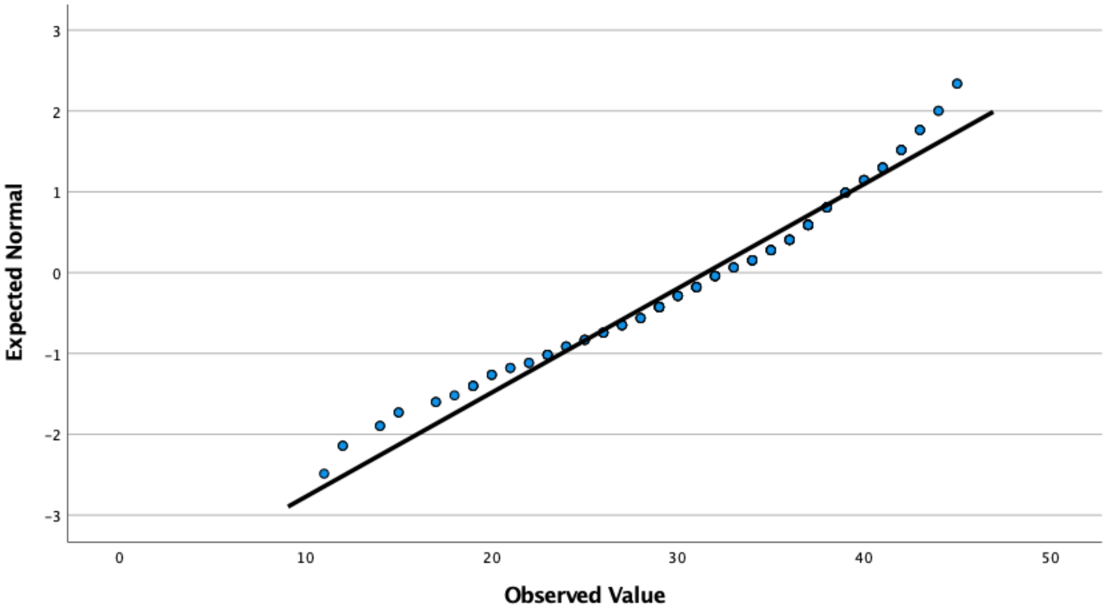


Figure C5

Histogram of Shame Subscale

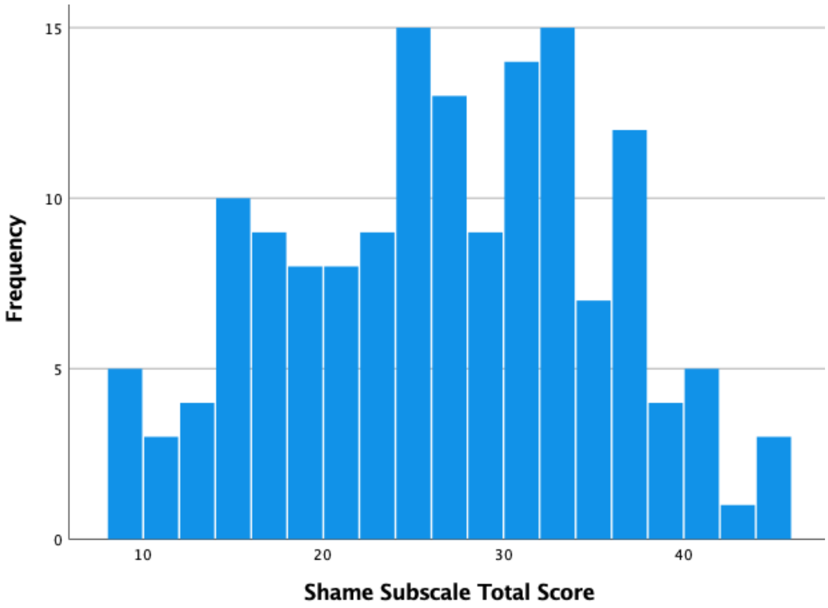


Figure C6

Q-Q Plot of Shame Subscale

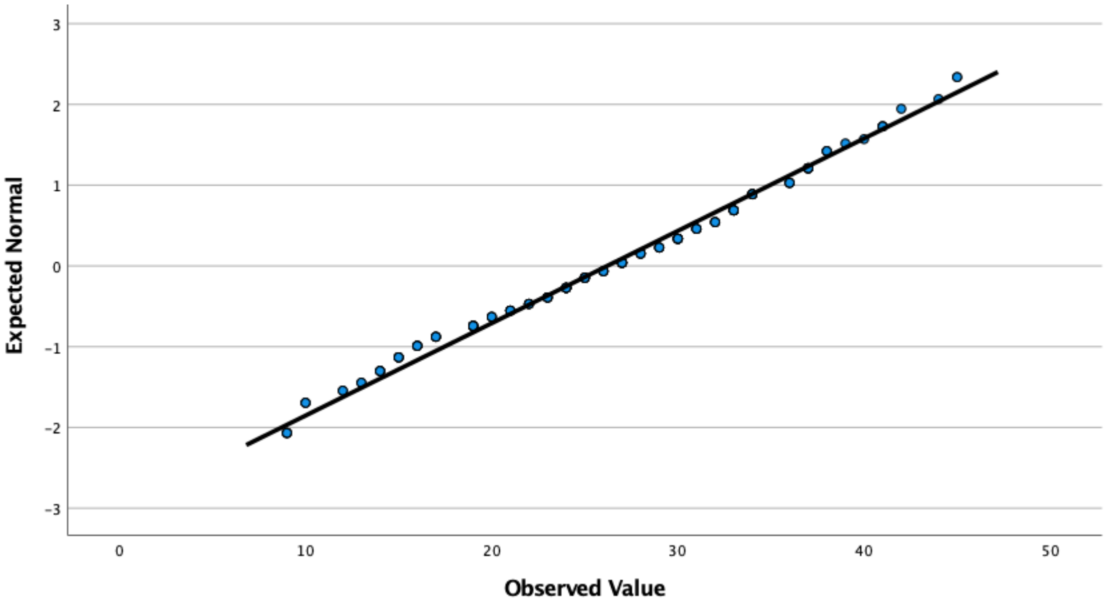


Figure C7

Histogram of Blame Subscale

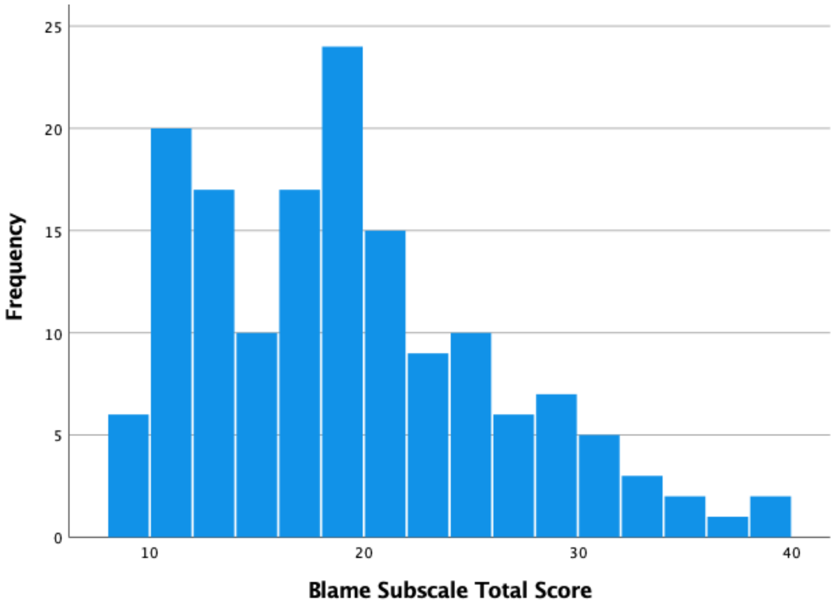


Figure C8

Q-Q Plot of Blame Subscale

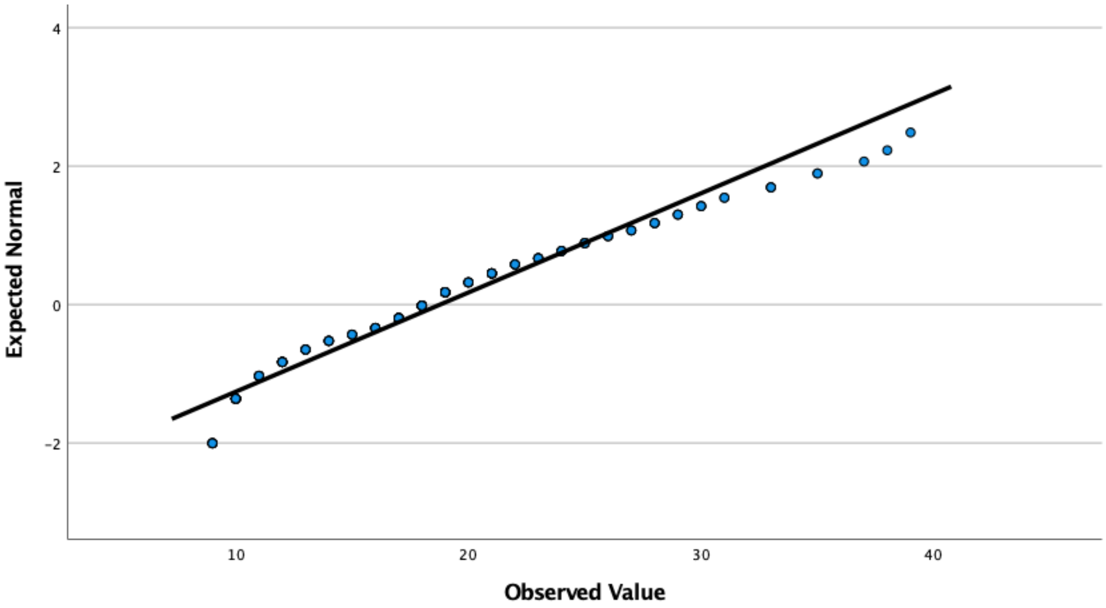


Figure C9

Histogram of Emotional Overinvolvement Subscale

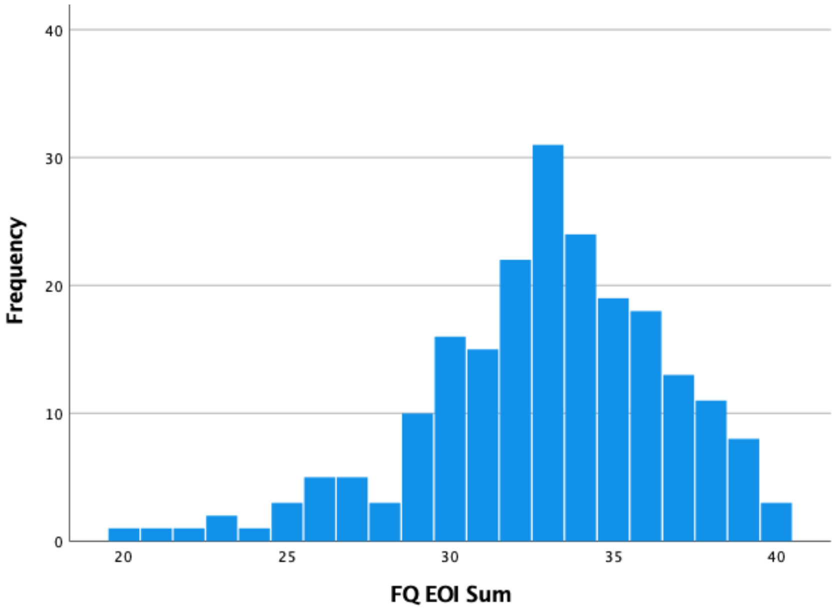


Figure C10

Q-Q Plot of Emotional Overinvolvement Subscale

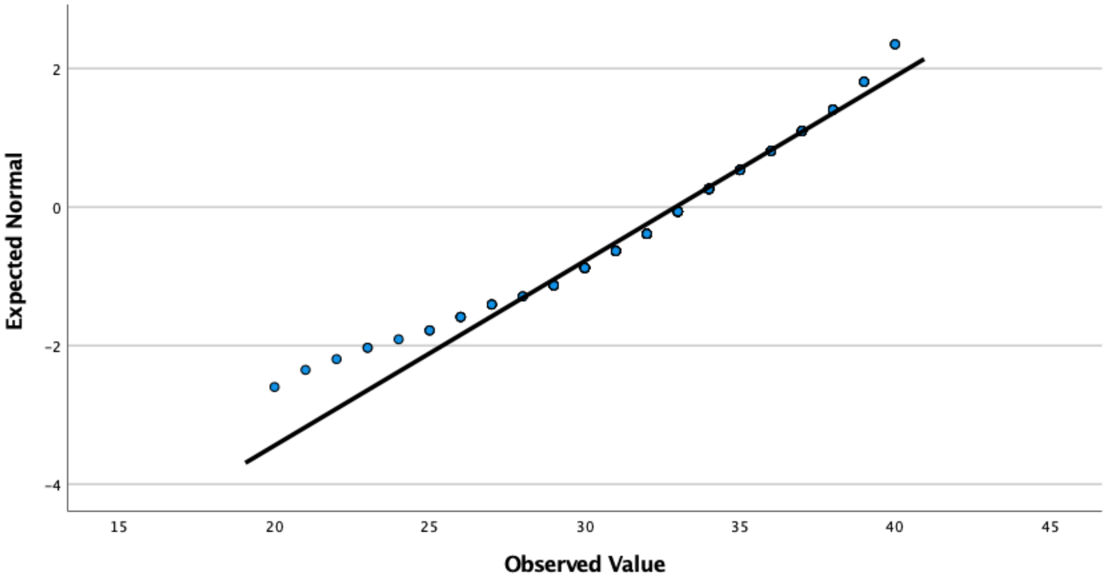


Figure C11

Histogram of Critical Comments Subscale

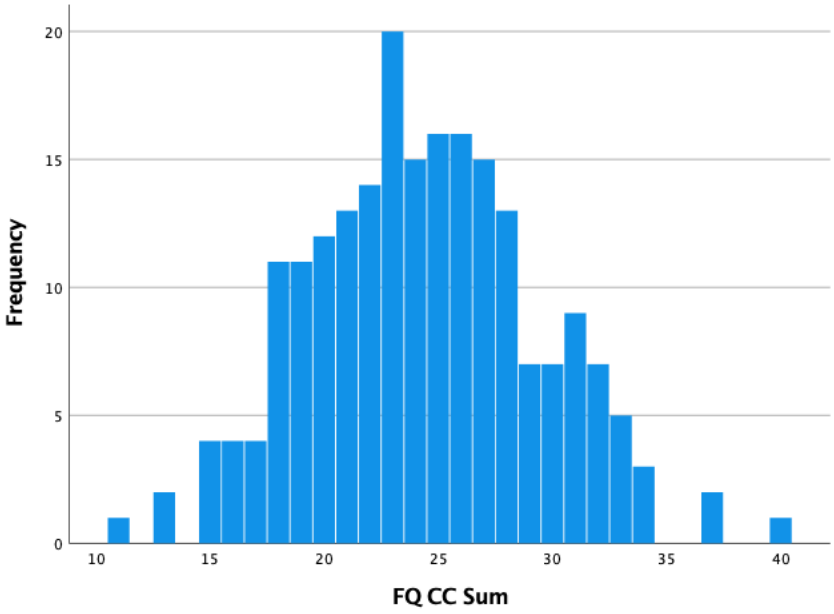
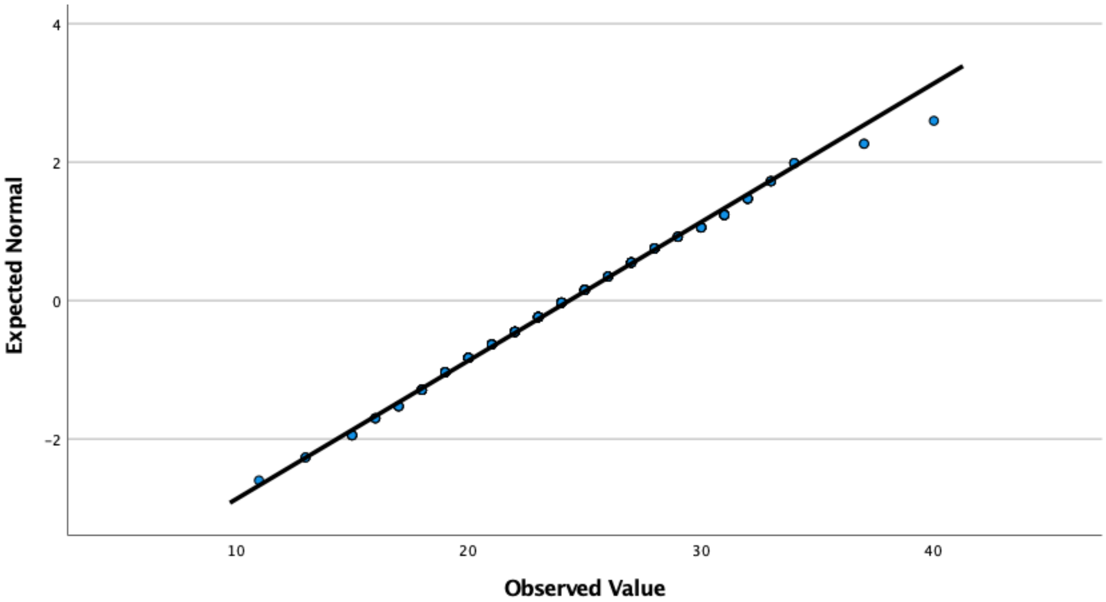


Figure C12

Q-Q Plot of Critical Comments Subscale



Appendix D

Table D1

Additional Physical or Mental Health Difficulties Experienced by Those Affected by an Eating Disorder, as Reported by Ten or More Caregivers

Physical or Mental Health Difficulty	Number of Times Reported
Anxiety	74
Autism	47
Attention-Deficit Hyperactivity Disorder	10
Depression	45
Obsessive Compulsive Disorder	24
Self-Harm	12

Note. There were no limits of the number of physical or mental health difficulties caregivers could report, thus, the proportion of the sample affected has not been reported.

Note. Only difficulties experienced by ten or more caregivers have been reported.

Section Three - Critical Appraisal

Word count (excluding references, tables, and appendices): 4,000

Emily Rothwell

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

All correspondence should be sent to:

Emily Rothwell
Doctorate in Clinical Psychology
Lancaster University
Furness College
United Kingdom
LA1 4GY

Email: e.rothwell@lancaster.ac.uk

Critical Appraisal

This final section of the thesis will firstly explore how the systematic literature review and empirical paper sit alongside each other. I will then explore the decisions I made throughout the thesis and reflect upon the main challenges I encountered. Finally, I will consider the language used throughout, and highlight the need to explore this with caregivers of those affected by eating disorders.

Overview of Research

This thesis has explored caregivers' responses to those affected by an eating disorder, in particular, the concepts of accommodating and enabling behaviours (accommodation) (Sepulveda et al., 2009) and expressed emotion (EE; Leff & Vaughn, 1984). The findings and clinical implications of these papers are complementary. Accommodation refers to the way in which families change their behaviours in an attempt to reduce the conflict caused by the eating disorder, for example, allowing individuals to weigh out exact portions of food (Sepulveda et al., 2009). EE is a construct which captures the attitudes and behaviours caregivers express towards the individual affected by the eating disorder. The cognitive interpersonal maintenance model of anorexia nervosa identifies both accommodation and high familial EE as responses which maintain eating disorder behaviours (Treasure & Schmidt, 2013). The model suggests that caregivers' own vulnerabilities, such as insecure attachment and sensitivity to stress, predispose the caregiver to increased anxiety and frustration in response to the eating disorder. These traits are associated with increased high criticism (Cherry et al., 2018), emotional overinvolvement and accommodation, and reduced warmth, thus maintain the behaviours and feelings of distress. The work in this thesis potentially expands this model.

Whilst a hypothesised formulation was developed as part of the empirical paper, findings from the review can also be included (Figure 1). Here, the association between accommodation and EE (e.g. Marcos et al., 2016; Sepulveda et al., 2009) has been speculatively included. Additionally, factors affecting accommodation such as caregiver distress (e.g. Rhind et al., 2016), caregivers' own eating difficulties (e.g. Stefanini et al., 2019) and fear of engaging in recovery tasks (Stillar et al., 2016) have been incorporated. It must be noted that commonly the direction between factors related to the caregiver/person affected by the eating disorder and accommodation cannot be inferred. Therefore, the developed formulation is a series of hypotheses based upon clinical and research knowledge, and which may be tested. A key issue relates to the apparent dichotomy of blaming oneself as a caregiver and blaming the individual affected by the eating disorder, evoking criticism and overinvolvement regarding the same individual. This can be explained by reference to Figure 1, whereby specific behaviours are what attributions are concerned with, rather than the overall disorder.

Although the cognitive interpersonal maintenance model of anorexia nervosa has been suggested to be transdiagnostic (Goddard et al., 2011), most of the samples drawn upon to develop the aforementioned formulation (Figure 1) are mothers of those affected by anorexia nervosa. Considering differences in levels of accommodation and EE across eating disorder diagnoses have been reported, the generalisability of the model is unclear and requires research from more diverse samples. Compared to caregivers of individuals affected by bulimia nervosa, caregivers of those affected by anorexia nervosa have been found to have greater levels of accommodation (Sepulveda et al., 2009; Stefanini et al., 2019). Perhaps conversely considering the positive association between accommodation and EE (e.g. Marcos et al., 2016; Sepulveda et al., 2009), critical comments have been reported to be greater in caregivers of those affected by bulimia nervosa compared to anorexia nervosa (Rienecke et al., 2016). This may suggest that there are some distinct drivers of accommodation and EE.

One explanation for this could relate to the difference between egosyntonic behaviours, such as weight loss, which are valued by the individual (Gregertsen et al., 2017), and egodystonic behaviours such as binge eating, which are incongruent with the individual's beliefs (Winkler et al., 2017). The "valued and visible" (Schmidt & Treasure, 2006, p. 343) egosyntonic nature of anorexia nervosa may invite increased anxiety, thus draw caregivers into attempting to reduce this via accommodating behaviours. This may be at odds with egodystonic behaviours such as binge eating or vomiting, which may have more blame attributed to them, and therefore critical comments (Barrowclough et al., 1994). It may also mirror the value society places on thinness, and the "fatphobic moralizing of food" (Atherton, 2021, p. 1) which occurs. Findings from a study measuring "fat talk" (Lydecker et al., 2018, p. 527) illustrate the way in which caregivers' critical comments around weight may be associated with egodystonic behaviours. The Fat Talk Questionnaire (Royal et al., 2013) was utilised, which uses words such as "criticize", "hate" and "disgusting", thus taking a negative stance towards weight. Fat talk was common, with 76% of parents of pre-adolescents and adolescents engaging in fat talk about themselves and 43.6% about their child. Fat talk towards the child was significantly associated with binge eating, overeating, secretive eating and greater rates of children living with obesity (Lydecker et al., 2018). Whilst the sample was not recruited based upon a diagnosis of an eating disorder and results are cross-sectional, therefore causation cannot be implied, it highlights the association between egodystonic eating behaviours and critical comments, thus the potential interaction with EE.

An Exploration of Decisions Made, Including Reflections from Personal and Professional Experience

Research Area and Design

Whilst reflexivity is common practice in qualitative research as a means of enhancing rigour (Darawsheh, 2014), it is less prevalent in quantitative research, which is rooted in positivism (Park et al., 2020). However, Greiffenhagen et al. (2011) noted that “Models do not build themselves any more than they interpret themselves… choices still have to be made, and these are frequently based on intuitions, hunches and ideas of what is needed that have not yet been fully rationalized” (p. 103). I have therefore chosen to reflect upon my own personal and professional experiences of eating disorders, which are likely to have shaped the decisions I have made in conducting this research.

My personal experience of having had a diagnosis of an eating disorder and professional experience of working alongside those affected influenced my choice of research topic. I was familiar with the devastation eating disorders can bring to both the person affected and those around them, having engaged in both family and individual therapy myself, and having experienced extremely difficult family dynamics throughout this. I was also aware of the lack of research funding eating disorders receive (MQ, 2019). An All-Party Parliamentary Group commissioned inquiry reported that between 2009 and 2019, the total UK investment into research funding for eating disorders resulted in £1.13 per person affected (Beat, 2021). I therefore wished to contribute to the research surrounding eating disorders, in the hope that this will support those affected by eating disorders, as well as helping to break the cycle which maintains low funding for eating disorder research (Beat, 2021).

I held several privileges in my own difficulties which meant that the eating disorder was recognised, and I received treatment earlier than others. I received a diagnosis of anorexia nervosa, I was diagnosed as an adolescent and I am a White female. This is supported by a systematic review which reported the duration of untreated eating disorder (weighted by sample size), as 29.9 months for those affected by anorexia nervosa, 53.0 months for those affected by bulimia nervosa, and 67.4 months for those affected by binge eating disorder (Austin et al., 2020). Younger individuals tended to have a shorter duration of untreated eating disorder (Austin et al., 2020). Furthermore, research has found that clinicians underdiagnose eating disorders in females from African American backgrounds (Gordon et al., 2006) and in males (Murray et al., 2017). This discrepancy in recognition and treatment also reflects my clinical experience of working with individuals affected by binge eating disorder, who are commonly unable to access the recommended support (e.g. NICE, 2017). Considering this inequality and recognising my own privilege, I wished to ensure that the research was as inclusive as possible. I therefore did not exclude participants or included studies based on eating disorder diagnosis, duration of eating disorder, ethnicity or caregiver type.

My success surrounding diversity was limited. Participants in the empirical research were mainly White British mothers, who supported individuals affected by anorexia nervosa. This is reflective of the samples of the included studies I reviewed and highlights a wider issue around recruitment in eating disorder research (American Psychiatric Association, 2023). Whilst research surrounding cultural and ethnic differences regarding the way in which caregivers respond to the eating disorder is scarce (Domínguez-Martínez & Medina-Pradas, 2020), evidence suggests there are likely to be cultural differences in the response and understanding around mental health difficulties (Gopalkrishnan, 2018). This is reflected in the limited research on EE across White and ethnic minority families (Hoste et al., 2012). I could have sought responses from a broader range of ethnicities more directly, for example, through naming this in my social media promotion and engaging with groups such as a Black, Indigenous, and People of Colour support group run by the National Association of Anorexia

Nervosa and Associated Disorders. My future work will include a focus on this issue and studies will recruit from a wider range of sources.

In an attempt to diversify the study sample, I targeted the accounts I engaged with on social media to try to include more fathers and/or partners, and included comments around seeking caregivers of those affected by diagnoses other than anorexia nervosa. I also considered posting on Reddit, a social media platform which is more commonly utilised by men (Dixon, 2022) to try to enhance engagement from men, and those supporting people who identify as male. However, I felt there were a lack of appropriate subreddits where promoting this research would fit and based on what I saw about eating disorders on the site, I felt it could attract negative pro-eating disorder comments, which would outweigh any potential benefits. Another option to expand my sample could have been to position myself in an eating disorder service and routinely invite all caregivers of those referred to the service to participate. This may have increased diversity around caregiver type, levels of EE and diagnosis. However, this was not deemed to be appropriate due to the high pressure that eating disorder services are under, following a raise of referrals after COVID-19 (Ayton et al., 2022; Linardon et al., 2022). It would also have only captured information from those who feel able to seek treatment and are referred for this, which is estimated to exclude the majority of those affected (Hart et al., 2011).

I made the decision not to include disordered eating or eating difficulties (rather than a diagnosable eating disorder) throughout my thesis. I recognise this limited the research to those who had been able to receive a diagnosis or self-identified as being affected by an eating disorder, thus fails to recognise the nuances around individuals’ difficulties and distress. I made this decision as felt the research would be too broad and may limit the conclusions that could be drawn if I explored eating difficulties more generally, considering the time restraints of a doctorate thesis. I believe it is important for future research to consider how the research questions explored throughout this thesis would fit with people who are experiencing difficulties in relation to their eating, who would not identify this as an eating disorder. This may also increase the shortcomings around diversity of the sample. Exploring eating difficulties could also provide valuable knowledge around the prevention and early intervention of eating disorders, through increasing understanding of how best to support family and friends with their own understandable responses and behaviours. This is particularly important considering disordered eating may evolve to a diagnosable eating disorder (Toni et al., 2017), and a recent systematic review and meta-analysis of 32 studies, which identified 22% of children and adolescents experience disordered eating (López-Gil et al., 2023).

Methods and Analysis

As part of the empirical research, a small number of caregivers of those affected by eating disorders were consulted in relation to the recruitment process and methodology. These were individuals I knew from my time working for Beat, the eating disorder charity, so may be more likely to be reflective of people who seek support and engage in research. This may have reinforced the difficulties I experienced in terms of the diversity of the sample, particularly around the high proportion of individuals with high emotional overinvolvement. Although collaborating with a wider range of individuals could have resulted in disagreements and an increased time cost (Oliver et al., 2019), it may have allowed for more diversity in the views expressed and reduced the homogeneity of the research sample.

I chose to utilise the Family Questionnaire (FQ; Wiedemann et al., 2002) as this is an efficient self-report measure of EE, which has been utilised in several studies with caregivers of those affected by eating disorders (Rienecke, 2018). It separately reports levels of critical comments (CC) and emotional overinvolvement (EOI), which was important based upon previous findings that noted individual differences in EOI and CC, such as maternal EOI being reported as greater than paternal EOI (Rhind et al., 2016). In relation to the measure of guilt, shame and blame, I made the decision to use the CARE scale (Noir, 2023). This was developed to address the limitations of previous scales measuring guilt and shame in those providing care for individuals affected by long-term mental health conditions (Cherry et al., 2017); frequently measures were not peer-reviewed or evaluated in terms of their reliability and validity (Noir, 2023). Evaluation of the CARE scale utilised the COSMIN (Consensus-based standards for the selection of health measurement instruments) guidelines, and reported acceptable structural, convergent and discrimination validity, and adequate internal consistency and reliability (Noir, 2023). However, utilising a scale which was being concurrently developed raised challenges. The necessary factor analysis for the scale was completed after the online survey was published, thus there was a delay to being able to score the survey. Additionally, as described in the empirical paper, all the missing data from the CARE scale arose from a specific scenario which referred to the caregiver's relative being able to manage their basic needs such as "eating properly". Although caregivers of those affected by eating disorders were included in the scale validation study (Noir, 2023), it was the first time the scale had been used exclusively with those affected by eating disorders. This may have influenced how this question was answered. These observations have been shared with the scale developer, in order to support further development. With hindsight, I recognise that it would have been helpful for me to have further considered these potential issues when deciding to utilise the scale. I would also check that data were being collected and saved more frequently, considering the consecutive six-day period where data were not saved for the CARE questionnaire.

In relation to self-compassion, the SCS has also been widely utilised in research around self-compassion and is reported to have been translated and validated in at least 17 countries (Muris & Otgaar, 2020). Whilst I recognise there is a large ongoing debate around its validity (Ferrari et al., 2022; Muris & Otgaar, 2020), I felt that utilising Brenner et al.'s (2017) two-factor structure would negate some of the concerns surrounding the reversal of items measuring self-judgement, isolation and over-identification. The two-factor model has been found to be valid across a range of population samples (e.g. Coroiu et al., 2018; Costa et al., 2016; Kumlander et al., 2018), although I recognise this has also been disputed (Neff et al., 2019). In order to crosscheck my decision, I ran a separate correlation analysis between EOI, CC, guilt, shame, blame and the total SCS score. No differences in significance were noted, thus, I continued the rest of the analyses utilising the two-factor structure. I also considered using the Compassionate Engagement and Action Scales (CAES; Gilbert et al., 2017) to explore compassion for self, compassion for others and compassion from others, considering how each of these is likely to be linked to experience of caregiving. However, I was concerned that this was more burdensome on participants and would increase drop-out. Future research exploring these three flows of compassion in caregivers of those affected by eating disorder is likely to be of great value, particularly in line with the findings that self-compassion did not moderate EOI or CC.

Analyses and Implications for Clinical Practice

When exploring the results of the empirical paper and the themes from the review, I was aware that my interpretation could be impacted by my own difficult experiences of being cared for whilst affected by an eating disorder. I discussed these with my field supervisor to ensure that my interpretations were based upon my analyses, the wider literature and my clinical judgement. This highlighted to me that how service users' perceive EE and accommodating behaviours has not been explored as part of this thesis. The Brief Dyadic Scale of Expressed Emotion (BDSEE; Medina-Pradas et al., 2011a) has been developed to assess EE from the perspective of the person affected by the eating disorder. Results utilising this scale have reported relative congruence between the perception of EE between caregivers and the person affected by the eating disorder; mothers were reported to have significantly higher levels of EOI and were reported to be perceived as being more overprotective compared to fathers (Rhind et al., 2016). Similarly, no differences were perceived or reported by caregivers between maternal and paternal CC (Rhind et al., 2016). People affected by an eating disorder reported CC, followed by EOI to evoke the most stress (Medina-Pradas et al., 2011b). However, only stress due to CC was positively associated with eating disorder symptomatology. This did not differ after adjusting for depression, self-esteem, anxiety, body mass index, or time spent together, highlighting the need to support the emotional climate of the family, particularly focussing on CC.

When writing the clinical implications, I was aware of the emails I had received from participants who engaged in the study, who had requested a copy of the results once these were published. These emails were heartfelt and often demonstrated the pain the person was currently experiencing. I was mindful of how the clinical implications may be interpreted by these caregivers and the wider audience, as I was concerned that by advocating the need for additional support for caregivers, this could be seen to be blaming. The sensitivity and understanding required around promoting caregiver interventions is highlighted in a commentary discussing preventative programmes for eating disorders (Bulik, 2023). The author notes the “outrage” (p. 2) that families have felt at being blamed for their child’s eating disorder and the importance of hearing this pain. However, they also balance this with the need to prevent the development of eating disorders and to intervene in families who are likely to be at risk. My hope for the clinical recommendations made throughout this thesis, is that they can be implemented in an “evidence-based, respectful, and compassionate way” (p. 3), as Bulik (2023) describes.

Language

Through engaging in quantitative research methods and systematically reviewing quantitative studies, I recognise this thesis does not include the voices of caregivers affected by eating disorders. Whilst the items included in the accommodation and enabling scale for eating disorders (AESED; Sepulveda et al., 2009) were reviewed by two “expert caregivers” (both mothers), the involvement of people with lived experience in the co-production of the included studies in the systematic literature review is unclear. This is despite co-production of knowledge being increasingly encouraged (Ferraz, 2018; Lewis & Foye, 2021) and the potential benefits to both the research quality and those who engage in patient and public involvement activities (Richmond et al., 2023). This absence of caregivers’ voices is particularly notable considering the language used around caregivers in this review and throughout the research. The notion that caregivers engage in behaviours which “accommodate … or enable some of the core symptoms” (Sepulveda et al., 2009, p. 2) and that these are “recovery-interfering” (Stillar et al., 2016, p. 173) may be seen as blaming of caregivers. Although the literature states that caregivers engage in these behaviours in an attempt to alleviate family conflict (Sepulveda et al., 2009) and that these responses are “automatic and understandable reactions” (Treasure et al., 2008, p. 337), it would be of interest to explore caregivers’ perceptions of these terms. It may be that they are seen as contributing to the outdated narrative, that caregivers are to blame for the eating disorder (le Grange et al., 2010). This is likely to affect the way in which caregivers respond to treatment and support, as well as who engages with research in this area.

Similarly, in terms of EE, the construct of EOI is associated with an intrusiveness and a suggestion that the caregiver is restricting their loved one's life (Leff & Vaughn, 1984). Historically, it has been proposed as a "destructive force among kin and a failure to preserve culturally appropriate boundaries among self-systems" (Jenkins, 1992, p. 217). Whilst these narratives have been questioned, and instead, EOI has been suggested to be appropriate when supporting an adolescent affected by an eating disorder (Rienecke, 2020) and beneficial to weight restoration (Monteleone et al., 2022), the term EOI still suggests caregiving behaviours that are excessive. This highlights a shift in language is needed away from the outdated term which was developed in relation to supporting an adult affected by a diagnosis of schizophrenia (Leff & Vaughn, 1984). Instead, in some cases EOI may reflect necessary involvement and concern due to the risks posed by eating disorders (Arcelus et al., 2011), and the increased responsibility that may fall on caregivers due to the current delay for treatment. Although EOI may be associated with the perception of stress from the person affected by the eating disorder, this perception is not associated with eating disorder symptomatology (Medina-Pradas et al., 2011b). One hypothesis may be that this stress is associated with the challenge to the eating disorder that the intrusiveness or overprotection can bring. Additionally, it may reflect the individual's knowledge that the eating disorder is difficult for their caregivers, as demonstrated by the caregivers' EOI, and be a response to this. Although individuals underestimate the level of caregiver burden, there are higher levels of agreement around burden for items related to more objective difficulties, such as food disappearing, thus knowledge of this conflict may be associated with stress (Coomber & King, 2013).

Furthermore, more generally the concept of EE as "ordinary" (Brown, 1985, p. 22) does not reflect the changes in society both in relation to understanding of the concept of schizophrenia (Gaebel & Kerst, 2019), as well as the differences in family life compared to the 1980s. Data from the Office for National Statistics suggests that young people are moving out of their parental home later than in previous decades, with 32% of young adults living with their parents in 2017, compared to 25.5% in 1997 (Office for National Statistics, 2019). This may result in parents naturally having more involvement in their childrens' lives, in a way which may have previously been viewed as intrusive. Therefore, whilst the impact of the eating disorder is well documented (Fox & Whittlesea, 2017), the societal context around caregiving appears to differ to when the concept of EE was originally developed. This may explain the high levels of EE reported in relation to eating disorders (Anastasiadou et al., 2014), and suggest a revision of the conceptual terminology is required.

Conclusion

Results from both papers provide potentially important implications for clinical practice. They highlight factors which may leave caregivers more vulnerable to engaging in accommodating and enabling behaviours, and identify factors associated with EE. When offering evidence-based interventions to support caregivers in managing these understandable responses, services should ensure that interactions are compassionate, and caregivers are not left feeling blamed. Further research is needed to ensure the results are generalisable to a wider group of caregivers, considering the relatively homogenous sample these results are drawn from.

References

American Psychiatric Association. (2023). *Practice guideline for the treatment of patients with eating disorders* (4th ed.). American Psychiatric Association Publishing. https://doi.org/10.1176/appi.books.9780890424865

Anastasiadou, D., Medina-Pradas, C., Sepulveda, A. R., & Treasure, J. (2014). A systematic review of family caregiving in eating disorders. *Eating Behaviors*, *15*(3), 464–477. https://doi.org/10.1016/j.eatbeh.2014.06.001

Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry*, *68*(7), 724–731. https://doi.org/10.1001/archgenpsychiatry.2011.74

Atherton, E. (2021). Moralizing hunger: Cultural fatphobia and the moral language of contemporary diet culture. *Feminist Philosophy Quarterly*, *7*(3).

Austin, A., Flynn, M., Richards, K., Hodsoll, J., Duarte, T. A., Robinson, P., Kelly, J., & Schmidt, U. (2020). Duration of untreated eating disorder and relationship to outcomes: A systematic review of the literature. *European Eating Disorders Review*. https://doi.org/10.1002/erv.2745

Ayton, A., Viljoen, D., Ryan, S., Ibrahim, A., & Ford, D. (2022). Risk, demand, capacity and outcomes in adult specialist eating disorder services in South-East of England before and since COVID-19. *BJPsych Bulletin*, *46*(2), 89–95. https://doi.org/10.1192/bjb.2021.73

Barrowclough, C., Johnston, M., & Tarrier, N. (1994). Attributions, expressed emotion, and patient relapse: An attributional model of relatives' response to schizophrenic illness. *Behavior Therapy*, *25*(1), 67–88. https://doi.org/doi.org/10.1016/S0005-7894(05)80146-7

Beat. (2021). *Breaking the Cycle*. https://www.beateatingdisorders.org.uk/about-beat/policy-work/all-party-parliamentary-group-appg-on-eating-disorders/

Brenner, R. E., Heath, P. J., Vogel, D. L., & Credé, M. (2017). Two is more valid than one: Examining the factor structure of the Self-Compassion Scale (SCS). *Journal of Counseling Psychology*, *64*(6), 696. https://doi.org/10.1037/cou0000211

Brown, G. (1985). The discovery of expressed emotion: Induction or deduction. *Expressed Emotion in Families*, 7–25.

Bulik, C. (2023). If we build it, will they come? Commentary on “Preventing eating disorders and disordered eating in high-risk families.” *The International Journal of Eating Disorders*. https://doi.org/10.1002/eat.23914

Cherry, M. G., Taylor, P. J., Brown, S. L., Rigby, J. W., & Sellwood, W. (2017). Guilt, shame and expressed emotion in carers of people with long-term mental health difficulties: A systematic review. *Psychiatry Research*, *249*, 139–151. https://doi.org/10.1016/j.psychres.2016.12.056

Cherry, M. G., Taylor, P. J., Brown, S. L., & Sellwood, W. (2018). Attachment, mentalisation and expressed emotion in carers of people with long-term mental health difficulties. *BMC Psychiatry 18*, 257. https://doi.org/10.1186/s12888-018-1842-4

Coomber, K., & King, R. M. (2013). Perceptions of carer burden: Differences between individuals with an eating disorder and their carer. *Eating Disorders: The Journal of Treatment & Prevention*, *21*(1), 26–36. https://doi.org/10.1080/10640266.2013.741966

Coroiu, A., Kwakkenbos, L., Moran, C., Thombs, B., Albani, C., Bourkas, S., Zenger, M., Brahler, E., & Körner, A. (2018). Structural validation of the Self-Compassion Scale with a German general population sample. *PloS One*, *13*(2), e0190771. https://doi.org/10.1371/journal.pone.0190771

Costa, J., Marôco, J., Pinto-Gouveia, J., Ferreira, C., & Castilho, P. (2016). Validation of the psychometric properties of the Self-Compassion Scale. Testing the factorial validity and factorial invariance of the measure among borderline personality disorder, anxiety disorder, eating disorder and general populations. *Clinical Psychology & Psychotherapy*, *23*(5), 460–468. https://doi.org/10.1002/cpp.1974

Darawsheh, W. (2014). Reflexivity in research: Promoting rigour, reliability and validity in qualitative research. *International Journal of Therapy and Rehabilitation*, *21*(12), 560–568. https://doi.org/10.12968/ijtr.2014.21.12.560

Dixon, S. (2022). *Distribution of Reddit users worldwide as of January 2022, by gender*. Statista. https://www.Statista.Com/Statistics/1255182/Distribution-of-Users-on-Reddit-Worldwide-Gender/

Domínguez-Martínez, T., & Medina-Pradas, C. (2020). Cultural differences in expressed emotion. *Eating Disorders and Expressed Emotion*, 129–155. https://doi.org/doi.org/10.4324/9780429429484-8

Ferrari, M., Ciarrochi, J., Yap, K., Sahdra, B., & Hayes, S. C. (2022). Embracing the complexity of our inner worlds: Understanding the dynamics of self-compassion and self-criticism. *Mindfulness*, 1–10. https://doi.org/10.1007/s12671-022-01897-5

Ferraz, M. (2018). Service user involvement and perspectives. In J. C. Santos & J. R. Cutcliffe (Eds.), *European psychiatric/mental health nursing in the 21st century* (pp. 29–35). Springer.

Fox, J. R. E., & Whittlesea, A. (2017). Accommodation of symptoms in anorexia nervosa: A qualitative study. *Clinical Psychology & Psychotherapy*, *24*(2), 488–500. https://doi.org/10.1002/cpp.2020

Gaebel, W., & Kerst, A. (2019). The debate about renaming schizophrenia: A new name would not resolve the stigma. *Epidemiology and Psychiatric Sciences*, *28*(3), 258–261. https://doi.org/10.1017/S2045796018000513

Gilbert, P., Catarino, F., Duarte, C., Matos, M., Kolts, R., Stubbs, J., Ceresatto, L., Duarte, J., Pinto-Gouveia, J., & Basran, J. (2017). The development of compassionate engagement and action scales for self and others. *Journal of Compassionate Health Care*, *4*(1), 1–24. https://doi.org/10.1186/s40639-017-0033-3

Goddard, E., Macdonald, P., Sepulveda, A., Naumann, U., Landau, S., Schmidt, U., & Treasure, J. (2011). Cognitive interpersonal maintenance model of eating disorders:

Intervention for carers. *The British Journal of Psychiatry*, *199*(3), 225–231. https://doi.org/10.1192/bjp.bp.110.088401

Gopalkrishnan, N. (2018). Cultural diversity and mental health: Considerations for policy and practice. *Frontiers in Public Health*, *6*, 179. https://doi.org/10.3389/fpubh.2018.00179

Gordon, K. H., Brattole, M. M., Wingate, L. R., & Joiner, T. E. Jr. (2006). The impact of client race on clinician detection of eating disorders. *Behavior Therapy*, *37*(4), 319–325. https://doi.org/10.1016/j.beth.2005.12.002

Gregertsen, E. C., Serpell, L., & Mandy, W. (2017). The egosyntonic nature of anorexia: An impediment to recovery in anorexia nervosa treatment. *Frontiers in Psychology*, *8*, 2273. https://doi.org/10.3389/fpsyg.2017.02273

Greiffenhagen, C., Mair, M., & Sharrock, W. (2011). From methodology to methodography: A study of qualitative and quantitative reasoning in practice. *Methodological Innovations Online*, *6*(3), 93–107. https://doi.org/10.4256/mio.2011.009

Hart, L. M., Granillo, M. T., Jorm, A. F., & Paxton, S. J. (2011). Unmet need for treatment in the eating disorders: A systematic review of eating disorder specific treatment seeking among community cases. *Clinical Psychology Review*, *31*(5), 727–735. https://doi.org/10.1016/j.cpr.2011.03.004

Hoste, R. R., Labuschagne, Z., Lock, J., & le Grange, D. (2012). Cultural variability in expressed emotion among families of adolescents with anorexia nervosa. *International Journal of Eating Disorders*, *45*(1), 142–145. https://doi.org/10.1002/eat.20888

Jenkins, J. H. (1992). *Ethnopsychiatry: The cultural construction of professional and folk psychiatries*. State University of New York Press.

Kumlander, S., Lahtinen, O., Turunen, T., & Salmivalli, C. (2018). Two is more valid than one, but is six even better? The factor structure of the Self-Compassion Scale (SCS). *PLoS One*, *13*(12), e0207706. https://doi.org/10.1371/journal.pone.0207706

Leff, J., & Vaughn, C. (1984). *Expressed emotion in families: Its significance for mental illness*. Guilford Press. https://doi.org/10.1176/ps.37.7.741-a

le Grange, D., Lock, J., Loeb, K., & Nicholls, D. (2010). Academy for eating disorders position paper: The role of the family in eating disorders. *International Journal of Eating Disorders*, *43*(1), 1–5. https://doi.org/10.1002/eat.20751

Lewis, H. K., & Foye, U. (2021). From prevention to peer support: A systematic review exploring the involvement of lived-experience in eating disorder interventions. *Mental Health Review Journal*. https://doi.org/10.1108/MHRJ-04-2021-0033

Linardon, J., Messer, M., Rodgers, R. F., & Fuller-Tyszkiewicz, M. (2022). A systematic scoping review of research on COVID-19 impacts on eating disorders: A critical appraisal of the evidence and recommendations for the field. *International Journal of Eating Disorders*, *55*(1), 3–38. https://doi.org/10.1002/eat.23640

López-Gil, J. F., García-Hermoso, A., Smith, L., Firth, J., Trott, M., Mesas, A. E., Jiménez-López, E., Gutiérrez-Espinoza, H., Tárraga-López, P. J., & Victoria-Montesinos, D. (2023). Global proportion of disordered eating in children and adolescents. *JAMA Pediatrics*. https://doi.org/10.1001/jamapediatrics.2022.5848

Lydecker, J. A., Riley, K. E., & Grilo, C. M. (2018). Associations of parents' self, child, and other "fat talk" with child eating behaviors and weight. *International Journal of Eating Disorders*, *51*(6), 527–534. https://doi.org/10.1002/eat.22858

Marcos, Y. Q., Quiles Sebastián, M. J., Aubalat, L. P., Sepúlveda García, A. R., & Treasure, J. (2016). The Spanish validation of the Accommodation and Enabling Scale for Eating Disorders among carers: A pilot study. *European Eating Disorders Review*, *24*(1), 62–68. https://doi.org/10.1002/erv.2378

Medina-Pradas, C., Navarro, J. B., López, S. R., Grau, A., & Obiols, J. E. (2011a). Further development of a scale of perceived expressed emotion and its evaluation in a sample of patients with eating disorders. *Psychiatry Research*, *190*(2–3), 291–296. https://doi.org/10.1016/j.psychres.2011.06.011

Medina-Pradas, C., Navarro, J. B., López, S. R., Grau, A., & Obiols, J. E. (2011b). Dyadic view of expressed emotion, stress, and eating disorder psychopathology. *Appetite*, *57*(3), 743–748. https://doi.org/10.1016/j.appet.2011.08.016

Monteleone, A. M., Cascino, G., Salerno, L., Schmidt, U., Micali, N., Cardi, V., & Treasure, J. (2022). A network analysis in adolescent anorexia nervosa exploring the connection between both patient and carer reactions and outcome. *European Eating Disorders Review*. https://doi.org/10.1002/erv.2933

MQ. (2019). *UK Mental Health Research Funding*. https://www.mqmentalhealth.org/wp-content/uploads/UKMentalHealthResearchFunding2014-2017digital.pdf

Muris, P., & Otgaar, H. (2020). The process of science: A critical evaluation of more than 15 years of research on self-compassion with the Self-Compassion Scale. *Mindfulness*, *11*, 1469–1482. https://doi.org/10.1007/s12671-020-01363-0

Murray, S. B., Nagata, J. M., Griffiths, S., Calzo, J. P., Brown, T. A., Mitchison, D., Blashill, A. J., & Mond, J. M. (2017). The enigma of male eating disorders: A critical review and synthesis. *Clinical Psychology Review*, *57*, 1–11.

Neff, K. D., Tóth-Király, I., Yarnell, L. M., Arimitsu, K., Castilho, P., Ghorbani, N., Guo, H. X., Hirsch, J. K., Hupfeld, J., & Hutz, C. S. (2019). Examining the factor structure of the Self-Compassion Scale in 20 diverse samples: Support for use of a total score and six subscale scores. *Psychological Assessment*, *31*(1), 27. https://doi.org/10.1037/pas0000629

NICE. (2017). *Eating disorders: Recognition and treatment*. NICE Guidelines. https://www.nice.org.uk/guidance/ng69

Noir, L. (2023). *Caregivers expressed emotion: Validating a measure of guilt and shame in a caregiving context [Manuscript in preparation]*. Lancaster University.

Office for National Statistics. (2019). *Milestones: Journeying into adulthood.* https://www.Ons.Gov.Uk/Peoplepopulationandcommunity/Populationandmigration/Populationestimates/Articles/Milestonesjourneyingintoadulthood/2019-02-18.

Oliver, K., Kothari, A., & Mays, N. (2019). The dark side of coproduction: Do the costs outweigh the benefits for health research? *Health Research Policy and Systems*, *17*(1), 1–10. https://doi.org/10.1186/s12961-019-0432-3

Park, Y. S., Konge, L., & Artino, A. R. (2020). The positivism paradigm of research. *Academic Medicine*, *95*(5), 690–694. https://doi.org/10.1097/ACM.0000000000003093

Rhind, C., Salerno, L., Hibbs, R., Micali, N., Schmidt, U., Gowers, S., Macdonald, P., Goddard, E., Todd, G., Tchanturia, K., lo Coco, G., & Treasure, J. (2016). The objective and subjective caregiving burden and caregiving behaviours of parents of adolescents with anorexia nervosa. *European Eating Disorders Review*, *24*(4), 310–319. https://doi.org/10.1002/erv.2442

Richmond, L., Caton, N., Downs, J., Newton, A., Devereux-Fitzgerald, A., & Brooks, H. (2023). Creating positive experiences of involvement in mental health research. *The Lancet Psychiatry*. https://doi.org/10.1016/S2215-0366(22)00430-8

Rienecke, R. D. (2018). Expressed emotion and eating disorders: An updated review. *Current Psychiatry Reviews*, *14*(2), 84–98. https://doi.org/10.2174/1573400514666180808115637

Rienecke, R. D. (2020). Emotional Overinvolvement with adolescents: A problematic construct? *Current Treatment Options in Psychiatry*, *7*(2), 162–185. https://doi.org/10.1007/s40501-020-00205-z

Rienecke, R. D., Sim, L., Lock, J., & le Grange, D. (2016). Patterns of expressed emotion in adolescent eating disorders. *Journal of Child Psychology and Psychiatry*, *57*(12), 1407–1413. https://doi.org/10.1111/jcpp.12594

Royal, S., MacDonald, D. E., & Dionne, M. M. (2013). Development and validation of the Fat Talk Questionnaire. *Body Image*, *10*(1), 62–69. https://doi.org/10.1016/j.bodyim.2012.10.003

Schmidt, U., & Treasure, J. (2006). Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology*, *45*(3), 343–366. https://doi.org/10.1348/014466505x53902

Sepulveda, A. R., Kyriacou, O., & Treasure, J. (2009). Development and validation of the Accommodation and Enabling Scale for Eating Disorders (AESED) for caregivers in eating disorders. *BMC Health Services Research*, *9*. https://doi.org/10.1186/1472-6963-9-171

Stefanini, M. C., Troiani, M. R., Caselli, M., Dirindelli, P., Lucarelli, S., Caini, S., & Martinetti, M. G. (2019). Living with someone with an eating disorder: Factors affecting the caregivers' burden. *Eating and Weight Disorders*, *24*(6), 1209–1214. https://doi.org/10.1007/s40519-018-0480-7

Stillar, A., Strahan, E., Nash, P., Files, N., Scarborough, J., Mayman, S., Henderson, K., Gusella, J., Connors, L., & Orr, E. S. (2016). The influence of carer fear and self-blame when supporting a loved one with an eating disorder. *Eating Disorders*, *24*(2), 173–185. https://doi.org/10.1080/10640266.2015.1133210

Toni, G., Berioli, M. G., Cerquiglini, L., Ceccarini, G., Grohmann, U., Principi, N., & Esposito, S. (2017). Eating disorders and disordered eating symptoms in adolescents with type 1 diabetes. *Nutrients*, *9*(8), 906.

Treasure, J., & Schmidt, U. (2013). The cognitive-interpersonal maintenance model of anorexia nervosa revisited: A summary of the evidence for cognitive, socio-emotional and interpersonal predisposing and perpetuating factors. *Journal of Eating Disorders*, *1*(1), 13. https://doi.org/10.1186/2050-2974-1-13

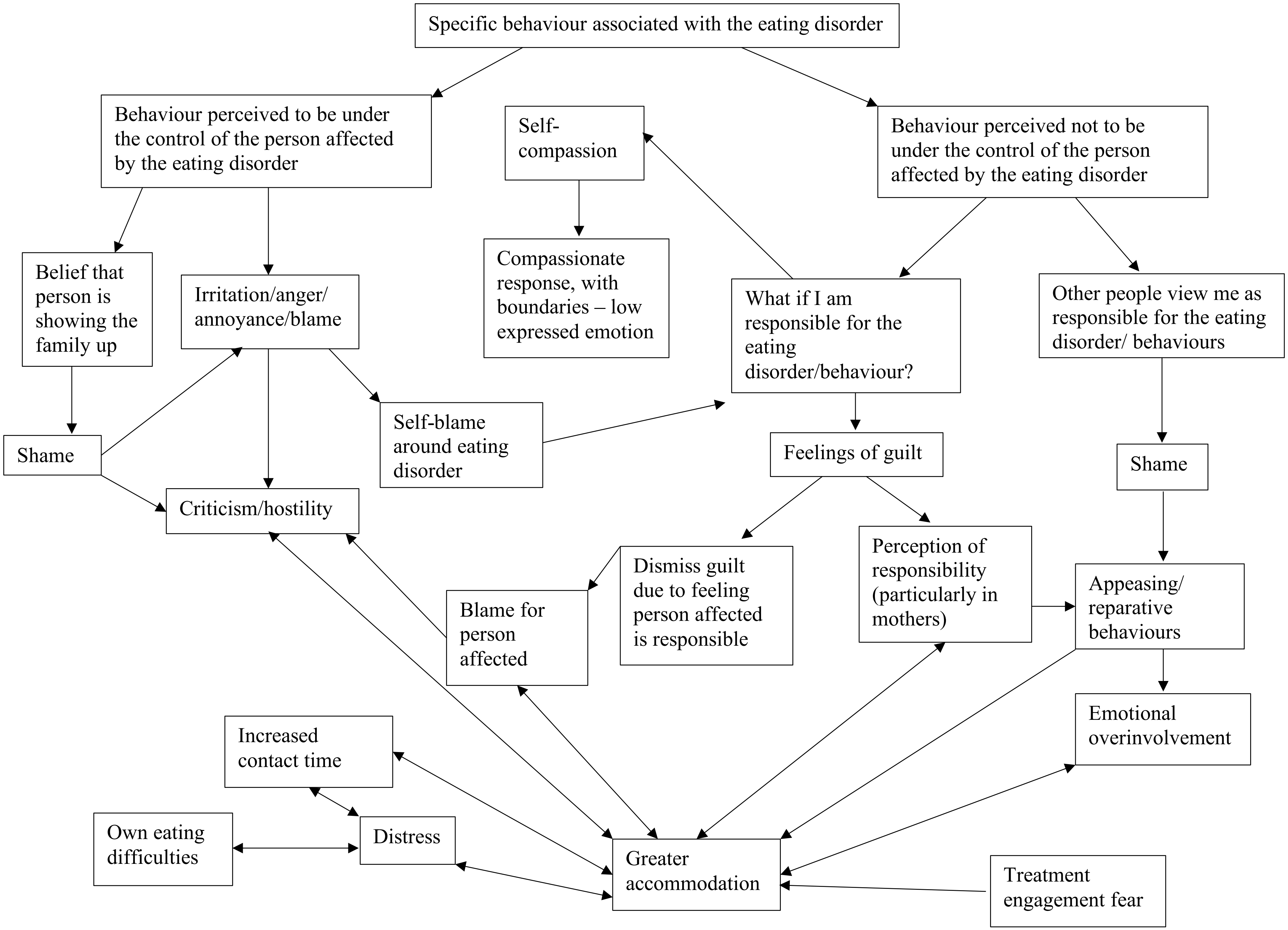
Treasure, J., Sepulveda, A. R., MacDonald, P., Whitaker, W., Lopez, C., Zabala, M., Kyriacou, O., & Todd, G. (2008). Interpersonal maintaining factors in eating disorder: Skill sharing interventions for carers. *International Journal of Child and Adolescent Health*, *1*(4), 331–338. https://doi.org/10.1007/978-3-319-32742-6_9

Wiedemann, G., Rayki, O., Feinstein, E., & Hahlweg, K. (2002). The Family Questionnaire: Development and validation of a new self-report scale for assessing expressed emotion. *Psychiatry Research*, *109*(3), 265–279. https://doi.org/10.1016/S0165-1781(02)00023-9

Winkler, L. A.-D., Frølich, J. S., Gudex, C., Hørder, K., Bilenberg, N., & Støving, R. K. (2017). Patient-and clinician-reported outcome in eating disorders. *Psychiatry Research*, *247*, 230–235. https://doi.org/10.1016/j.psychres.2016.11.047

Figure 1

Hypothetical Formulation Accounting for EE and Accommodation


Specific behaviour associated with the eating disorder
Behaviour perceived to be under the control of the person affected by the eating disorder
Self-compassion
Behaviour perceived not to be under the control of the person affected by the eating disorder
Belief that person is showing the family up
Irritation/anger/annoyance/blame
Compassionate response, with boundaries – low expressed emotion
What if I am responsible for the eating disorder/behaviour?
Other people view me as responsible for the eating disorder/ behaviours
Shame
Self-blame around eating disorder
Feelings of guilt
Shame
Criticism/hostility
Dismiss guilt due to feeling person affected is responsible
Perception of responsibility (particularly in mothers)
Appeasing/ reparative behaviours
Blame for person affected
Emotional overinvolvement
Increased contact time
Own eating difficulties
Distress
Greater accommodation
Treatment engagement fear

Section Four – Ethics Proposal

Word count (excluding references, tables, and appendices): 3,680

Emily Rothwell

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

All correspondence should be sent to:

Emily Rothwell
Doctorate in Clinical Psychology
Lancaster University
Furness College
United Kingdom
LA1 4GY

Email: e.rothwell@lancaster.ac.uk

Ethics Application Form

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research

Title of Project: The role of compassion on expressed emotion in carers of people affected by eating disorders

Name of applicant/researcher: Emily Rothwell

ACP ID number (if applicable)*: NA

Funding source (if applicable): NA

Grant code (if applicable): NA

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM: Trainee Clinical Psychologist

2. Contact information for applicant:
E-mail: e.rothwell@lancaster.ac.uk **Telephone**[redacted]

Address:
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT

3. **Names and appointments of all members of the research team (including degree where applicable)**

Emily Rothwell, Trainee Clinical Psychologist, Lancaster University
Professor Bill Sellwood - Programme Director, Lancaster University
Dr Hannah Wilson – Field Supervisor, Clinical Psychologist, Clinical Psychology Lead and Head of Clinical Governance at Kooth

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant:

Professor Bill Sellwood - Programme Director, Lancaster University
Dr Hannah Wilson – Field Supervisor, Clinical Psychologist, Clinical Psychology Lead and Head of Clinical Governance at Kooth

5. Appointment held by supervisor(s) and institution(s) where based (if applicable): As above

SECTION TWO
Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk
3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' no
4c. If yes, where relevant has permission / agreement been secured from the website moderator? no
4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? no

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? no
6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder
7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?
yes
b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE
Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

Caring for someone affected by an eating disorder (ED) is often extremely challenging. Caregiving can be associated with feelings such as self-blame or blame towards the individual affected. Caregiver responses have been linked to treatment outcomes; people tend to do worse in treatment if they have parents or family members who are highly critical towards them. In other long-term mental health difficulties, feelings of guilt and shame have been found to be associated with these responses. To best support individuals, it is important to learn whether this relationship also occurs in caregivers of those affected by EDs, and to investigate factors which may affect this. This research will study whether guilt, shame and self-compassion are associated with caregivers' responses. Previous research suggests individuals with high self-blame and shame are linked to more unhelpful caregiving responses, and lower levels of self-compassion. This could provide a new focus when supporting carers.

2. Anticipated project dates (month and year only)

Start date: November 2021 End date: March 2023

Data Collection and Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

Participants will be people who identify themselves as a friend, partner or family member of someone affected by an ED, who currently provide unpaid care/support for that individual due to the ED. The person affected by the ED can be any age or gender. There will be no exclusions regarding specific diagnosis of ED, or the relationship type the carer has with the individual with the diagnosed ED. There will be no exclusions regarding time spent caring for the individual affected by the ED.

Participants must be aged 18 years or over (there will be no maximum age). Participants will also need to be able to read and understand English, so to provide informed consent and understand the research questions. This is due to limited funding for research conduct, thus a lack of funding to pay for a transcription service or an individual to transcribe the necessary documentation. Participants will also be required to have access to the internet to complete the questionnaires. This is to increase the efficiency of data collection, compared to mailed paper questionnaires. It also reflects the online nature of working due to the COVID-19 pandemic.

A-priori sample size calculation using G*power found that to detect a medium effect size of 0.15, with a power level of 0.80, a minimum of 85 – 98 people need to be recruited. This varies depending on number of predictors, so 98 people will be aimed for to give a buffer of six predictors. The number of predictors explored will depend on whether there are any significant group differences around caregiver demographics, as these will also be entered into the model.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Participants will be recruited from several sources to gain a wide variety of participants with a range of experiences. An online advert has been created and reviewed by a group of experts by experience (Appendix A). This will be posted on social media platforms such as Twitter, in order to advertise the study and provide the link to the Qualtrics survey. When posting on social media, eating disorder organisations such as Beat (the national eating disorder charity), will be tagged in the advert and asked to promote the study. Beat have agreed to promote the research study on the research section of their website and social media. A specific Twitter account will be created for the study. Posts from this will be shared via the principal researcher's professional Twitter account, to aim to increase responses.

The advert will also be posted on the British Eating Disorder Society (BrEDS) group, since this has some carer members and clinicians who may be able to support recruitment. I will also contact local carer groups via email. One of the carers in the study consultation focus group runs workshops to help support carers, and has agreed to promote the study. Another member of the group has also offered to post the study advert on a Facebook group for carers of those affected by EDs, and this has been agreed. The group has over 2,500 members.

If participants are interested in the study, they will be able to click the link and be taken to the participant information sheet (Appendix B).

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

An online survey has been developed using Qualtrics, an online tool designed for conducting surveys. This will include:
1) Demographics of the caregiver and the person affected by the ED
2) The Family Questionnaire (FQ; Wiedemann et al., 2002)
3) The self-compassion scale (SCS; Neff, 2003)
4) The updated 11-item Caring and Related Emotions (CARE) Questionnaire (Noir, 2021).

The demographic survey can be found in Appendix C, and the updated 11-item CARE Questionnaire in Appendix D. The other surveys are standardised so have not been provided in the Appendices.

Online surveys have been chosen to reduce the cost of printing and posting questionnaires out. Many online carer groups and conferences are currently running online due to COVID-19, so this was also considered when considering the method of data collection and recruitment.

The data will then be exported to SPSS at the time of data analysis. The data will initially be explored using descriptive statistics to look at characteristics of the sample. T-tests will also be completed to determine whether there are significant differences between certain groups, for example, specific carer groups. Correlation analyses will be undertaken to explore the relationship between self-compassion, guilt, shame and expressed emotion (specifically EOI and CC). Assuming the appropriate assumptions are met, multiple linear regressions will be undertaken to explore the relationships between EE (both EOI and CC separately) and the predictor variables (guilt, shame and self-compassion). Since support for the one-factor model of self-compassion using the SCS has been questioned, the two-factor model will instead be utilised during analysis (Brenner et al., 2017).

A secondary research question will be explored if participant numbers, and effect sizes allow - 439 participants would be needed for this to have enough power. This secondary research question would explore whether self-compassion moderates the relationship between guilt, shame and the two components of EE (EOI and CC). A moderation analysis would be utilised to study this.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Participants will not be asked to disclose identifiable information such as their name, date of birth or postcode as part of the Qualtrics survey. The survey data will therefore remain anonymous. Participants will have the opportunity to email the principal researcher to ask for a summary of the results as part of the dissemination process. Unless participants disclose specific data in their email, this will not be able to be matched to the survey results. However, survey data and email addresses will be stored separately from each other, to ensure time stamps do not disclose any identities.

The survey data will first be stored on Qualtrics. The level of data protection held by Qualtrics, meets the approved University requirements. Data will then be exported to SPSS for analysis, and stored on the University's secure OneDrive account. A folder will be created which only the principal researcher and the research supervisor have access to. This will be password protected. Although the principal researcher will mainly be accessing the data away from the University, data will still be accessed via and saved on to the OneDrive account. Any email addresses obtained via email from participants will be transferred and stored on to a separate file and saved in the OneDrive account. Emails will be deleted from the principal researcher's inbox, as soon as the email address is transferred to the OneDrive file. The principal researcher's inbox is password protected, as is their laptop.

The University will have ownership of the data. Once the final copy of the thesis has been completed, the OneDrive account will be securely transferred to the DClinPsy Programme's research coordinator, using OneDrive. The principal researcher will confirm with the research coordinator that data is required to be retained for 10 years. This is in line with the University's data retention policy. Following this, the research coordinator will download the folder and store it securely on the University network for the following 10 years, and will be responsible for deleting this.

The principal researcher and research supervisor have both completed General Data Protection Regulation (GDPR) and Data Protection training. They will work to comply with GDPR and Data Protection Act 2018 in both data collection and data storage.

7. Will audio or video recording take place? ☒ **no** ☐ **audio** ☐ **video**
a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

Data will be collected as part of the Qualtrics survey. This will not be audio or video. No identifiable data will be collected.

b. What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed? N/A

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder
8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

The programme's research coordinator will download the data folder from OneDrive, and this will be stored electronically and securely. PURE is used as Lancaster University's data repository. This will hold data so that it can be managed and accessed where necessary for the next 10 years, in line with the University's retention policy. Any data which may identify a participant will be withheld from being transferred to PURE, however, it is not envisaged that this will occur.

8b. Are there any restrictions on sharing your data?

At this stage, no restrictions for sharing data for open access purposes are envisaged. Even if there was a small sample size, no identifiable data will be collected from the questionnaires so data will remain anonymous.

9. Consent
a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Consent will be obtained electronically via an online consent form. This page will be shared after participants click that they have read the online information sheet and wish to continue with the study. Participants will only be eligible to complete the study, and the research questions will only appear, following online informed consent being given. This will consist of participants ticking a box to state that they agree with the above statements outlining the consent process (Appendix E). They will not provide their name. The principal researcher's name will be provided on the information sheet, if people wish to ask any questions about the study or have any concerns prior to giving consent.

10. What discomfort (including psychological e.g. distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Completing the questionnaires may bring up difficult thoughts and feelings for some participants. The information sheet and debrief sheet (Appendix F) therefore contain contact details for support organisations. An expert by experience focus group have also read through the study's materials and have agreed that they are appropriate.

The information sheet stipulates that participants are able to withdraw from the study at any point during the process of completing the questionnaires, without giving a reason. However, once participants submit their responses, participants will no longer be able to withdraw their data since it will not be identifiable to them, thus cannot be traced. Participants will be reminded of this prior to submitting the questionnaire.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

Due to the online, anonymous and qualitative nature of this study, there are minimal risks to the researcher and research team. The principal researcher's University email address has been included as part of the information sheet, debrief sheet and online advert which may provide a risk of the principal researcher being contacted outside of working hours. This risk will be mitigated through the principal researcher only checking their emails during working hours.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There are not likely to be any direct benefits to participants because of this research. However, participants may find the research interesting. They may also enjoy being involved in research which has the potential to improve future support to both caregivers and people affected by eating disorders.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

No incentives/payments will be offered to individuals. The survey will be completed online, so travel reimbursements will not be necessary.

14. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?
yes
b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

No personal, identifying details will be collected as part of the Qualtrics survey, thus the survey is completed anonymously. The survey will also be completed online, which will aid confidentiality around participation, as the participant will not have to travel to a specific place.

Email addresses will not be collected as part of the survey. Participant email addresses will only be obtained by the principal researcher if the participant emails with questions/concerns, or wishes to be emailed a summary of the findings at the end of the study. There is no way for survey responses and emails to therefore be linked together. Email addresses will be transferred to the securely stored file, as previously described, then deleted straight from the principal researcher's inbox.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

A small group of individuals have formed an expert by experience group. They have provided feedback on the information sheet, the consent form, the online advert, and the demographic questionnaire. They have also been consulted about the use of the standardised questionnaires, although it was stated that the specific questions could not be changed. Instead, any specific insights around the order of the questionnaires and any issues that may come with the use of the standardised questionnaires were gathered. Feedback included adding a question about inpatient treatment in the demographic questionnaire, expanding upon the online advert to help make it more enticing and adding a back button in the survey. The group suggested that the questionnaire would take about 20 minutes to complete.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The research will be written up as part of a thesis for the Doctorate in Clinical Psychology and presented at a thesis presentation day at the University. Results of the research will also be submitted for publication in an academic journal. Results may also be proposed as a poster/workshop to an eating disorder conference, such as Beat's Eating Disorder International Conference. Beat will also be offered a full study report and a summary of the findings, due to their involvement in the recruitment process. A lay summary write up will also be completed and sent to participants who emailed the principal researcher asking for a summary of the findings.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

One ethical consideration across this study is that participants may experience feelings of emotional distress when completing the online survey. The survey asks people to consider their experiences of caregiving and their responses to certain behaviours, which may be difficult to think about. As previously noted, support organisations' contact details have been included to try to manage this potential difficulty. An expert by experience group has also been consulted to foresee potential difficulties.

Another potential ethical consideration may be that participants cannot withdraw their data after the survey has been completed. This has been stipulated in the information sheet, which the individual must read and consent to prior to beginning the survey. Participants can withdraw at any point, prior to submitting the questionnaires too.

References

Brenner, R. E., Heath, P. J., Vogel, D. L., & Credé, M. (2017). Two is more valid than one: Examining the factor structure of the Self-Compassion Scale (SCS). *Journal of Counseling Psychology*, *64*(6), 696. https://doi.org/10.1037/cou0000211

Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and Identity*, *2*(3), 223–250. https://doi.org/10.1080/15298860390209035

Noir, L. (2021). *Caregiver's expressed emotion: Validating a measure of guilt, shame and blame in a care-giving context.* [Unpublished manuscript]. Lancaster University.

Wiedemann, G., Rayki, O., Feinstein, E., & Hahlweg, K. (2002). The Family Questionnaire: Development and validation of a new self-report scale for assessing expressed emotion. *Psychiatry Research*, *109*(3), 265–279. https://doi.org/10.1016/S0165-1781(02)00023-9

SECTION FOUR: signature

Applicant electronic signature: Emily Rothwell Date 1/10/21

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review ☒

Project Supervisor name (if applicable): Bill Sellwood Date application discussed 1/10/21

Submission Guidance

1. Submit your FHMREC application by email to Becky Case (fhmresearchsupport@lancaster.ac.uk) as two separate documents:
   i. **FHMREC application form.**
   Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*
   ii. **Supporting materials.**
   Collate the following materials for your study, if relevant, into a single word document:
      a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
      b. Advertising materials (posters, e-mails)
      c. Letters/emails of invitation to participate
      d. Participant information sheets
      e. Consent forms
      f. Questionnaires, surveys, demographic sheets
      g. Interview schedules, interview question guides, focus group scripts
      h. Debriefing sheets, resource lists

   Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.
2. Submission deadlines:
   i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to Becky Case **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the

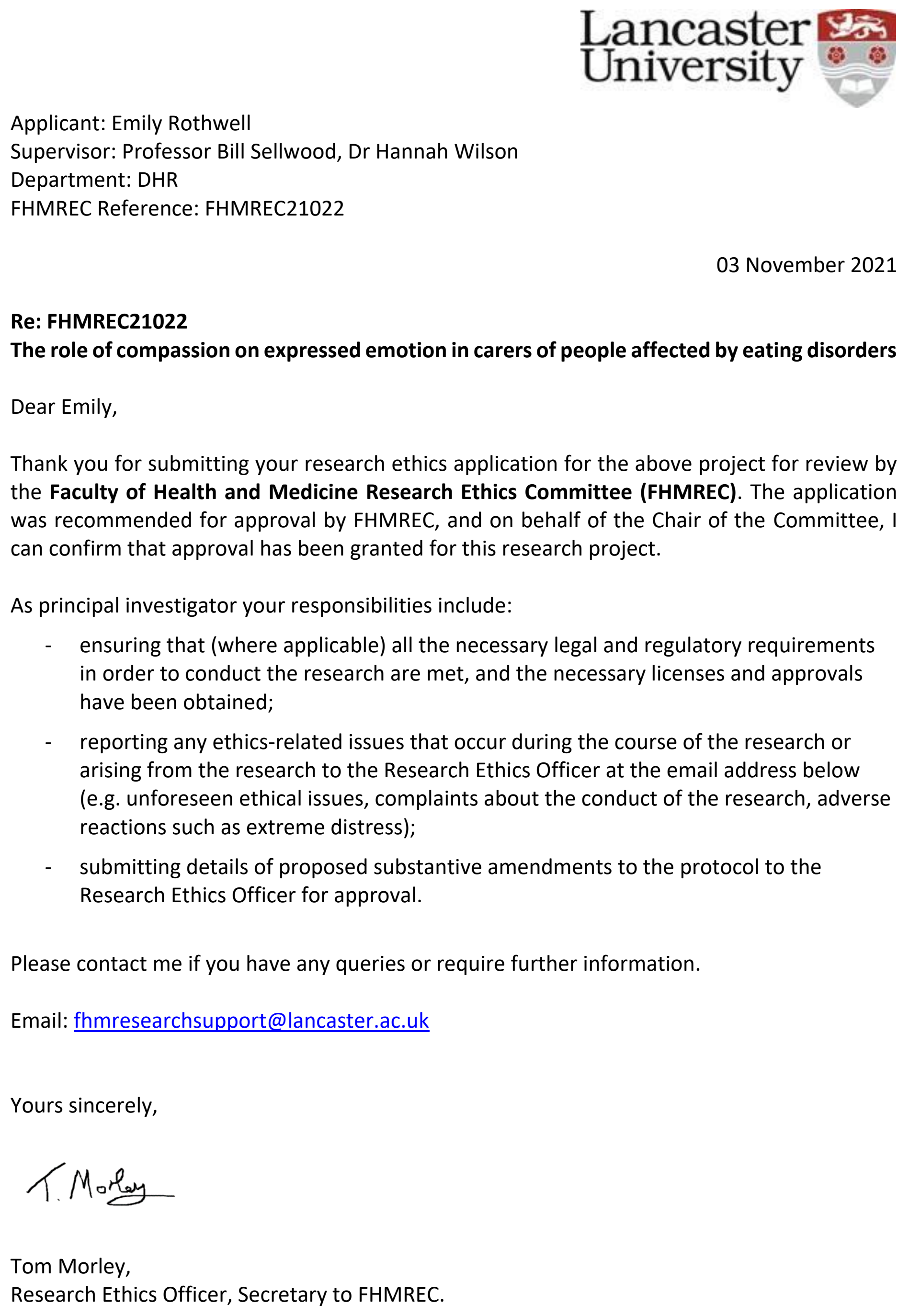
FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.

ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:

   a. existing documents/data only;
   b. the evaluation of an existing project with no direct contact with human participants;
   c. service evaluations.

3. You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application

Ethical Approval Letter



Applicant: Emily Rothwell
Supervisor: Professor Bill Sellwood, Dr Hannah Wilson
Department: DHR
FHMREC Reference: FHMREC21022

03 November 2021

Re: FHMREC21022
The role of compassion on expressed emotion in carers of people affected by eating disorders

Dear Emily,

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

T. Morley

Tom Morley,
Research Ethics Officer, Secretary to FHMREC.

Research Protocol

Introduction

Eating disorders (EDs) are characterised by the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) as involving “a persistent disturbance of eating or eating-related behaviour that results in the altered consumption or absorption of food and that significantly impairs physical health or psychosocial functioning” (American Psychiatric Association, 2013, p. 329). They are estimated to affect 1.25 million people in the UK (Beat, 2017), with their prevalence worldwide high and rising; the weighted means of lifetime ED across 94 studies has been reported as 8.4% for females and 2.2% for males (Galmiche et al., 2019). EDs are associated with significant impairments to physical health (Klump et al., 2009), psychological wellbeing and psychosocial functioning (Bohn et al., 2008; Treasure et al., 2020), and significantly raised mortality rates (Arcelus et al., 2011). They also have a detrimental effect on the wellbeing of the individual’s family (Fox et al., 2017; Zabala et al., 2009).

Although traditionally parents, namely mothers, were viewed negatively in relation to an ED developing (Vander Ven & Vander Ven, 2003), this position has been refuted and it is recommended that family and carers are involved and supported throughout treatment (NICE, 2017). Evidence around the effectiveness of family-based treatment (FBT) for children and young people in relation to the sustainability of treatment gains compared to individual therapy (Couturier et al., 2013), and the rate of early weight restoration compared to enhanced cognitive-behaviour therapy (Le Grange et al., 2020) supports the involvement of the family. However, FBT is not a panacea, and less than half of those who engage in FBT meet the threshold for full remission at the end-of-treatment or at the six- or 12-month follow-ups (Lock et al., 2010) emphasising the need for further understanding of factors which contribute to treatment outcomes.

Expressed emotion (EE) is one aspect of families which influences outcomes across a range of health difficulties (Amaresha & Venkatasubramanian, 2012), including EDs (Duclos et al., 2012). EE comprises a variety of behaviours and attitudes expressed by carers towards the individual they are supporting, which are categorised due to their ability to predict outcomes. There are five components: emotional overinvolvement (EOI), critical comments (CC), hostility, positive remarks (PR) and warmth (Brown & Rutter, 1966; Leff & Vaughn, 1984). Caregivers are classified as ‘high’ EE if they score above a pre-specified cut-off for CC (negative remarks made around specific behaviours the individual engages in), hostility (more generalised criticism of the individual) and EOI (characterised by carer self-blame, overly self-sacrificial behaviours and excessive protectiveness of the individual) (Hooley & Gotlib, 2000). Rather than being pathological or specific to families where mental health difficulties are prevalent, EE behaviours have been cited as “ordinary” (Brown, 1985, p. 22). However, the role that EE can play in treatment outcomes in those where health difficulties are present, means it is important to learn more about what drives EE. Specifically in relation to EDs, high levels of EE, particularly high CC, has been associated with poorer treatment outcomes, increased treatment drop-out (Duclos et al., 2012; Rienecke, 2018), and increased parental anxiety (Rienecke & Richmond, 2017).

Several carer-related factors have been found to affect levels of EE in those caring for someone affected by an ED. For example, several studies have found that mothers of individuals diagnosed with anorexia nervosa tend to have higher EOI scores compared to fathers (Rienecke, 2018). Considerably less literature has explored these factors in relation to carers of people affected by bulimia nervosa or binge eating disorder, despite these having a greater prevalence than anorexia nervosa (Hay et al., 2017). Two key factors which appear to drive EE are shame and guilt, although these have yet to be explored specifically in relation to EDs. A systematic review exploring the levels of EE in carers of long-term mental health difficulties found that EOI is positively associated with guilt and shame, whilst CC/hostility is positively associated with shame only (Cherry et al., 2017). The review suggested that the experiences of guilt associated with EOI, are related to the disorder itself. It also hypothesised that shame drives carers to be defensive, which can lead to both overinvolvement and critical comments. However, due to the cross-sectional nature of the studies, the causality of these associations cannot be drawn.

Self-compassion, defined as "the ability to hold one's feelings of suffering with a sense of warmth, connection, and concern" (Neff & McGehee, 2010, p. 226), is one area that has been explored in relation to this relationship between guilt, shame and EOI. Empson (2017) found that carers of people affected by mental health difficulties who exhibited greater levels of EOI, were more likely to experience increased guilt and shame, and less likely to experience self-compassion. Taken together with Cherry's findings, that EOI is positively associated with guilt and shame, this suggests reducing guilt and shame, and increasing self-compassion, may be important in reducing carers' EOI. However, although self-compassion has been referred to as a "shield" (Sedighimornani et al., 2019, p. 2) against difficult emotions, suggesting it may moderate the relationship between guilt or shame and EOI, this was not supported by Empson (2017). The author notes that this may have been since the study was not sufficiently powered to detect this. This research also only focused on EOI, rather than also considering the potential impact of self-compassion on CC/hostility.

Therefore, this study aims to determine the association between guilt and shame, with CC and EOI in carers of those affected by EDs. It also aims to explore whether self-compassion moderates this relationship, depending on the number of participants recruited. If this effect is confirmed, this has implications for potentially improving outcomes for family-based interventions and for carer wellbeing.

Research Aims

This project aims to investigate whether levels of shame and guilt are associated with emotional and behavioural responses that can come alongside caring for a loved one with a diagnosis of an eating disorder. Following this, it aims to investigate whether self-compassion influences the relationship between shame/guilt and the previously mentioned responses. The study will investigate whether these relationships differ with regards to factors such as diagnostic group, gender of the carer, time spent supporting the loved one, and age of the individual affected by the ED.

Specifically, the following research questions will be explored:

1. Do guilt and shame affect the level of emotional overinvolvement and critical comments caregivers of those affected by eating disorders express?

2. What is the predictive relationship between guilt/shame and self-compassion, on expressed emotion (specifically, the individual components of emotional overinvolvement and critical comments) in caregivers of those affected by eating disorders?

3. A final research question will be explored, if the study is sufficiently powered to allow for a moderation analysis. Does self-compassion moderate the relationship between guilt/shame and expressed emotion (specifically, the components of emotional overinvolvement and critical comments)?

Method

Participants

Participants will be people who identify themselves as a friend, partner or family member who currently provides unpaid care/support for an individual affected by an eating disorder. Participants must be aged 18 years or over, and able to read and understand English, so to provide informed consent and understand the research questions.

There will be no exclusions based on age or gender of either the individual participating in the study, or the individual affected by the eating disorder. There will be no exclusions regarding specific diagnosis of eating disorder, or the relationship type the carer has with the individual with the diagnosed ED. There will be no exclusions regarding time spent caring for the individual affected by the ED.

Inclusion Criteria

- People 18 years and over
- People who identify as a friend, partner or family member who currently provide unpaid care/support for an individual affected by an eating disorder
- People of any gender
- People able to provide informed consent
- People able to access and complete the online survey.

Exclusion Criteria

- People who do not speak English (due to the information sheet, consent sheet and questionnaires being in English).

Planned Sample Size

A-priori sample size calculation using G*power found that to detect a medium effect size of 0.15, with a power level of 0.80, a minimum of 85 – 98 people need to be recruited. This varies depending on number of predictors, so a minimum of 98 people will be aimed for to give a buffer of six predictors. The number of predictors explored will depend on whether there are any significant group differences around caregiver demographics, as these will also be entered into the model.

Recruitment

Participants will be recruited from several sources in the hope to recruit participants with a range of experiences. An online advert has been created and reviewed by a group of experts by experience (Appendix A). This will be posted on social media platforms such as Twitter, in order to advertise the study and provide the link to the Qualtrics survey (https://lancasteruni.eu.qualtrics.com/jfe/form/SV_7Qh7FBBk3mTilbU). When posting on social media, eating disorder organisations such as Beat (the national eating disorder charity), Wednesday's Child (eating disorder support organisation), and SEED (eating disorder support services), will be tagged in the advert and asked to promote the study. A specific Twitter account will be created for the study. Posts from this will be shared via the principal researcher's professional twitter account, to aim to increase responses.

Beat have agreed to promote the research study on the research section of their website. They have also agreed to promote this on social media platforms. Since Beat provides support for both people affected by eating disorders and people caring for those affected, this should allow people with a range of experiences and from a wide geographical area to hear about the study. Beat are also running a virtual conference for carers in November 2021, so there is potential for them to share the study advert at this time. This will be confirmed nearer the time based upon progress with the ethics application.

The advert will also be posted on the British Eating Disorder Society (BrEDS) group, since this has some carer members and clinicians who may be able to support recruitment. The principal researcher will also contact local carer groups via email. One of the carers in the study consultation focus group runs workshops to help support carers, and has agreed to promote the study. Another member of the group has also offered to post the study advert on a Facebook group for carers of those affected by EDs, and this has been agreed. This group has over 2,500 members.

If participants are interested in the study, they will be able to click the link and be taken to the participant information sheet.

Navigating Potential Recruitment Difficulties

The sample size calculation of 98 is an estimation based upon the planned analysis. We will monitor recruitment rates on an ongoing basis to help us track whether it looks like we will meet this. If it looks like we will be unable to meet 98 people, then we will first consider our recruitment strategy. For example, we will look to see if Beat would be able to share our questionnaire again, or we will share this again on the Facebook group of carers previously mentioned. We would also consider other ways of connecting with individuals, such as through contacting support groups for carers. We would also speak to our experts by experience group, to enquire around any ideas they may have around recruitment.

If we do not meet the 98 people that it’s estimated we will need, then we will simplify the relationships that we are exploring as part of the research, using multiple regressions. This will allow relationships to be examined that require less participants in order to be adequately powered to detect statistical significance. For instance, if only three predictors are examined, the estimated sample size to detect statistical significance becomes 77 people. If the study remains underpowered, we will highlight this in the write-up and explore barriers to engagement, and how these could be considered in future research.

Consent

It is likely that participants will initially come across the study online, for example, via social media platforms such as Twitter. The online advert that will be posted can be found in Appendix A. This advert will contain a Qualtrics link which potential participants can then click on.

From here, the first online page that participants will see is the online information sheet (Appendix B). This shares an overview of the study, including the number of questionnaires that will follow and an estimated time the survey will take to complete. The information sheet also states that participants do not have to complete the survey and that they are able to withdraw at any point when completing the survey, without any consequences. It is stated that once participants submit the survey, their data cannot be withdrawn. The contact details of the principal researcher and the research supervisor are also included, and it is noted that any questions or concerns can be raised with them.

If the participant chooses to proceed following the information sheet, the second page will be an online consent form (Appendix E). This consent form will confirm with the participant that they understand what has been stated on the information sheet and wish to continue to participate in the study. Participants will check a box which states that “I consent to the statements above and wish to continue to take part in the study. I understand that I will now proceed to the survey.” Following checking this box, the survey will then appear in Qualtrics, and the individual can continue.

At the end of the survey, participants will then be required to submit their responses. It will again be noted that following this point, participants will not be able to withdraw their data. After pressing submit, a debrief sheet will then follow (Appendix F).

Design

A quantitative, cross-sectional design will be utilised. An online survey will be completed by participants.

Procedure and Materials

Participants will be provided with a Qualtrics link, which will first take them to an information sheet about the study. This contains information about the study, including noting that the individual can withdraw from participating at any point. Following this, participants will be presented with a consent form, which they must complete prior to moving forward to the research questions. The researcher's email address will be provided on the consent form in case the participant would like to raise any questions or concerns before proceeding. Details of several organisations which provide support for carers supporting people affected by eating disorders will also be provided at this point.

If the participant provides consent, they will then proceed to the research questionnaires via a Qualtrics link. Participants will first complete a demographic questionnaire (Appendix C) designed to obtain specific details of the carer's role, and information about the individual with the diagnosed eating disorder. Participants will then proceed to complete the Family Questionnaire (FQ; Wiedemann et al., 2002), a 20-item scale which will be used to measure emotional overinvolvement (EOI) and critical comments (CC). These are two components of expressed emotion (EE) – caregivers' emotional and behavioural responses towards the person affected by the ED. Following this, participants will be presented with the self-compassion scale (SCS), a 26-item scale which measures self-compassion (Neff, 2003). Finally, the updated 11-item Caring and Related Emotions (CARE) Questionnaire (Noir, 2021) will end the questionnaires (Appendix D). Following this, participants will be presented with a debrief sheet which will again provide the researcher's email address and numbers of organisations that provide support for people caring for those affected by an eating disorder. Participants will be invited to contact the researcher if they wish to receive a summary of the findings.

Proposed Analysis

The data will be collected via Qualtrics. This will be exported to SPSS at the time of data analysis. The data will initially be explored using descriptive statistics to look at characteristics of the sample. T-tests will also be completed to determine whether there are significant differences between certain groups, for example, specific carer groups. Correlation analyses will be undertaken to explore the relationship between self-compassion, guilt, shame and expressed emotion (specifically EOI and CC). Assuming the appropriate assumptions are met, multiple linear regressions will be undertaken to explore the relationships between EE (both EOI and CC separately) and the predictor variables (guilt, shame, and self-compassion). Since support for the one-factor model of self-compassion using the SCS has been questioned, the two-factor model will instead be utilised during analysis (Brenner et al., 2017).

A secondary research question will be explored if participant numbers, and effect sizes allow - 439 participants would be needed for this to have enough power. This secondary research question would explore whether self-compassion moderates the relationship between guilt, shame and the two components of EE (EOI and CC). A moderation analysis would be utilised to study this.

Ethical Considerations

Approval from the Faculty of Health and Medicine Research Ethics Committee (FHMREC), Lancaster University, is needed prior to recruitment commencing.

One potential risk to participants is that they may experience feelings of emotional distress when completing the online survey. The survey asks people to consider their experiences of caregiving and their responses to certain behaviours, which may be difficult to think about. As previously noted, support organisations' contact details have been included to try to manage this potential difficulty. An expert by experience group has also been consulted to foresee potential difficulties. There are not likely to be any direct benefits of participating in this research. Participants will not be rewarded for their participation in the study.

Another potential ethical consideration may be that participants cannot withdraw their data after the survey has been completed. This has been stipulated in the information sheet, which the individual must read and consent to prior to beginning the survey. The information sheet also highlights that the research is optional to partake in, and there will be no consequences to the individual if they choose not to complete the survey. Participants can withdraw at any point, prior to submitting the questionnaires too. An online, qualitative survey helps confidentiality to be maintained. The survey will not ask for identifiable information, thus participants will complete the survey anonymously.

Potential Study Amendments

Any necessary amendments to the study protocol will be handled in line with Lancaster University's organisational policies and in consultation with FHM Ethics. The expert by experience focus group will also be consulted on any necessary amendments.

Data Protection

Participants will not be asked to disclose identifiable information such as their name, date of birth or postcode as part of the Qualtrics survey. The survey data will therefore remain anonymous. Participants will have the opportunity to email the principal researcher to ask for a summary of the results, as part of the dissemination process. Unless participants disclose specific data in their email, this will not be able to be matched to the survey results. However, survey data and email addresses will be stored separately from each other, to ensure time stamps do not disclose any identities.

The survey data will first be stored on Qualtrics. The level of data protection held by Qualtrics, meets the approved University requirements. Data will then be exported to SPSS for analysis, and stored on the University's secure OneDrive account. A folder will be created which only the principal researcher and the research supervisor have access to. This will be password protected. Although the principal researcher will mainly be accessing the data away from the University, data will still be accessed via and saved on to the OneDrive account. Any email addresses obtained via email from participants will be transferred and stored on to a separate file and saved in the OneDrive account. Emails will be deleted from the principal researcher's inbox, as soon as the email address is transferred to the OneDrive file. The principal researcher's inbox is password protected, as is their laptop.

The University will have ownership of the data. Once the final copy of the thesis has been completed, the OneDrive account will be securely transferred to the University's research coordinator, using OneDrive. The principal researcher will confirm with the research coordinator that data is required to be retained for 10 years. This is in line with the University's data retention policy. Following this, the research coordinator will download the folder and store it securely on the University network for the following 10 years, and will be responsible for deleting this.

The principal researcher and research supervisor have both completed General Data Protection Regulation (GDPR) and Data Protection training, and will work to comply with GDPR and Data Protection Act 2018 in both data collection and data storage.

Dissemination Policy

The data arising from the study will be owned by Lancaster University. On completion of the study, the principal researcher and research supervisor will have access to the survey data in order for this to be analysed and written up in a full study report. The study protocol will not be written up for publication.

The research will be written up as part of a thesis for the Doctorate in Clinical Psychology, and presented at a thesis presentation day at the University. Results of the research will also be submitted for publication in an academic journal.

Results may also be proposed as a poster/workshop to an eating disorder conference, such as Beat's Eating Disorder International Conference. Due to their involvement in the recruitment process and supporting the expert by experience focus group, Beat will also be offered a full study report and a summary of the findings. A lay summary write up will also be completed and sent to participants who emailed the researcher asking for a summary of the findings.

Data will be deposited in Lancaster University's institutional data repository and made freely available with an appropriate data license. Lancaster University uses Pure as the data repository which will hold, manage, preserve and provide access to datasets produced by Lancaster University research. Within the appropriate license agreement, the research study will also be uploaded to the researcher's Research Gate profile. Here, other researchers can request access to the full paper to aid dissemination.

References

Amaresha, A. C., & Venkatasubramanian, G. (2012). Expressed emotion in schizophrenia: An overview. *Indian Journal of Psychological Medicine*, *34*(1), 12. https://doi.org/10.4103%2F0253-7176.96149

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)*. https://doi.org/10.1176/appi.books.9780890425596

Arcelus, J., Mitchell, A. J., Wales, J., & Nielsen, S. (2011). Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies. *Archives of General Psychiatry*, *68*(7), 724–731. https:// doi:10.1001/archgenpsychiatry.2011.74

Beat. (2017). *Prevalence of eating disorders in the UK*. Beat. https://www.beateatingdisorders.org.uk/how-many-people-eating-disorder-uk

Bohn, K., Doll, H. A., Cooper, Z., O'Connor, M., Palmer, R. L., & Fairburn, C. G. (2008). The measurement of impairment due to eating disorder psychopathology. *Behaviour Research and Therapy*, *46*(10), 1105–1110. https://doi.org/10.1016/j.brat.2008.06.012

Brenner, R. E., Heath, P. J., Vogel, D. L., & Credé, M. (2017). Two is more valid than one: Examining the factor structure of the Self-Compassion Scale (SCS). *Journal of Counseling Psychology*, *64*(6), 696. https://doi.org/10.1037/cou0000211

Brown, G. (1985). The discovery of expressed emotion: induction or deduction. *Expressed Emotion in Families*, 7–25.

Brown, G., & Rutter, M. (1966). The measurement of family activities and relationships: A methodological study. *Human Relations*, *19*(3), 241–263. https://doi.org/10.1177/001872676601900301

Cherry, M. G., Taylor, P. J., Brown, S. L., Rigby, J. W., & Sellwood, W. (2017). Guilt, shame and expressed emotion in carers of people with long-term mental health difficulties: A systematic review. *Psychiatry Research*, *249*, 139–151.

https://doi.org/10.1016/j.psychres.2016.12.056

Couturier, J., Kimber, M., & Szatmari, P. (2013). Efficacy of family-based treatment for adolescents with eating disorders: A systematic review and meta-analysis. *International Journal of Eating Disorders*, *46*(1), 3–11. https://doi.org/10.1002/eat.22042

Duclos, J., Vibert, S., Mattar, L., & Godart, N. (2012). Expressed emotion in families of patients with eating disorders: A review of the literature. *Current Psychiatry Reviews*, *8*(3), 183–202. https://doi.org/10.2174/157340012800792975

Empson, K. (2017). *Family carers and mental health: The role of self-compassion*. [Doctoral dissertation, Lancaster University]. https://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.733506

Fox, J. R. E., Dean, M., & Whittlesea, A. (2017). The experience of caring for or living with an individual with an eating disorder: A meta-synthesis of qualitative studies. *Clinical Psychology & Psychotherapy*, *24*(1), 103–125. https://doi.org/10.1002/cpp.1984

Galmiche, M., Déchelotte, P., Lambert, G., & Tavolacci, M. P. (2019). Prevalence of eating disorders over the 2000–2018 period: A systematic literature review. *The American Journal of Clinical Nutrition*, *109*(5), 1402–1413. https://doi.org/10.1093/ajcn/nqy342

Hay, P., Mitchison, D., Collado, A. E. L., González-Chica, D. A., Stocks, N., & Touyz, S. (2017). Burden and health-related quality of life of eating disorders, including Avoidant/Restrictive Food Intake Disorder (ARFID), in the Australian population. *Journal of Eating Disorders*, *5*(1), 21. https://doi.org/10.1186/s40337-017-0149-z

Hooley, J. M., & Gotlib, I. H. (2000). A diathesis-stress conceptualization of expressed emotion and clinical outcome. *Applied and Preventive Psychology*, *9*(3), 135–151. https://doi.org/10.1016/S0962-1849(05)80001-0

Klump, K. L., Bulik, C. M., Kaye, W. H., Treasure, J., & Tyson, E. (2009). Academy for eating disorders position paper: Eating disorders are serious mental illnesses.

International Journal of Eating Disorders, *42*(2), 97–103.

Leff, J., & Vaughn, C. (1984). *Expressed emotion in families: Its significance for mental illness*. Guilford Press. https://doi.org/10.1176/ps.37.7.741-a

Le Grange, D., Eckhardt, S., Dalle Grave, R., Crosby, R. D., Peterson, C. B., Keery, H., Lesser, J., & Martell, C. (2020). Enhanced cognitive-behavior therapy and family-based treatment for adolescents with an eating disorder: A non-randomized effectiveness trial. *Psychological Medicine*, 1–11. https://doi.org/10.1017/S0033291720004407

Lock, J., Le Grange, D., Agras, W. S., Moye, A., Bryson, S. W., & Jo, B. (2010). Randomized clinical trial comparing family-based treatment with adolescent-focused individual therapy for adolescents with anorexia nervosa. *Archives of General Psychiatry*, *67*(10), 1025–1032. https://doi.org/10.1001/archgenpsychiatry.2010.128

Neff K, McGehee P. Self-compassion and psychological resistance among adolescents and young adults. *Self and Identity.* 2010;9:225–240. https://doi.org/10.1080/15298860902979307

Neff, K. D. (2003). The development and validation of a scale to measure self-compassion. *Self and Identity*, *2*(3), 223–250. https://doi.org/10.1080/15298860390209035

NICE. (2017). *Eating disorders: Recognition and treatment*. NICE Guidelines. https://www.nice.org.uk/guidance/ng69

Noir, L. (2021). *Caregiver's expressed emotion: Validating a measure of guilt, shame and blame in a care-giving context*. [Unpublished manuscript]. Lancaster University.

Rienecke, R. D. (2018). Expressed emotion and eating disorders: An updated review. *Current Psychiatry Reviews*, *14*(2), 84–98. https://doi.org/10.2174/1573400514666180808115637

Rienecke, R. D., & Richmond, R. L. (2017). Psychopathology and expressed emotion in parents of patients with eating disorders: Relation to patient symptom severity. *Eating*

Disorders: The Journal of Treatment & Prevention, *25*(4), 318–329. https://doi.org/10.1080/10640266.2017.1289795

Sedighimornani, N., Rimes, K. A., & Verplanken, B. (2019). Exploring the relationships between mindfulness, self-compassion, and shame. *Sage Open*, *9*(3). https://doi.org/10.1177/2158244019866294

Treasure, J., Duarte, T. A., & Schmidt, U. (2020). Eating disorders. *The Lancet*, *395*(10227), 899–911. https://doi.org/10.1016/S0140-6736(20)30059-3

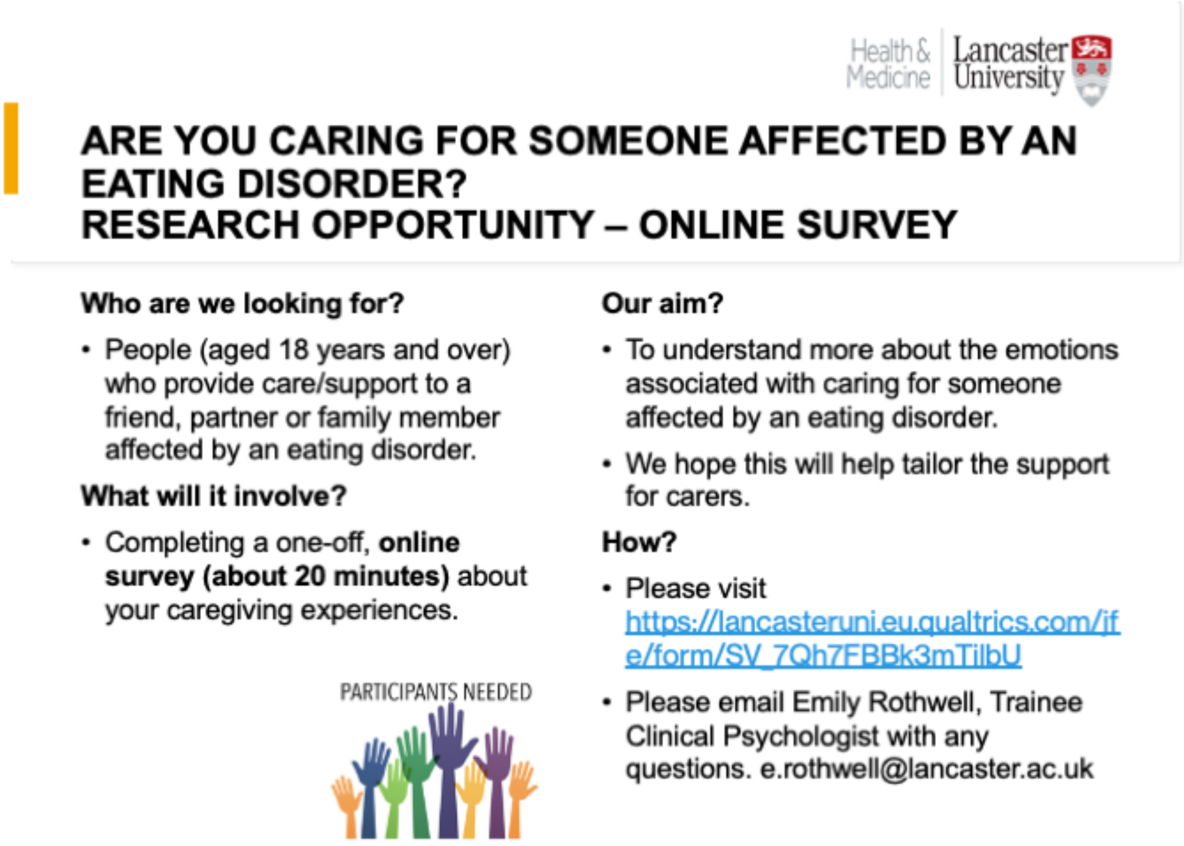
Vander Ven, T., & Vander Ven, M. (2003). Exploring patterns of mother-blaming in anorexia scholarship: A study in the sociology of knowledge. *Human Studies*, *26*(1), 97–119. https://doi.org/10.1023/A:1022527631743

Wiedemann, G., Rayki, O., Feinstein, E., & Hahlweg, K. (2002). The Family Questionnaire: Development and validation of a new self-report scale for assessing expressed emotion. *Psychiatry Research*, *109*(3), 265–279. https://doi.org/10.1016/S0165-1781(02)00023-9

Zabala, M. J., Macdonald, P., Treasure, J., MJ, Z., Macdonald, P., & Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: A systematic review. *European Eating Disorders Review*, *17*(5), 338–349. https://doi.org/10.1002/erv.925

Appendix A

Online Advert



Health & Medicine | Lancaster University

ARE YOU CARING FOR SOMEONE AFFECTED BY AN EATING DISORDER?
RESEARCH OPPORTUNITY – ONLINE SURVEY

Who are we looking for?

- People (aged 18 years and over) who provide care/support to a friend, partner or family member affected by an eating disorder.

What will it involve?

- Completing a one-off, **online survey (about 20 minutes)** about your caregiving experiences.

PARTICIPANTS NEEDED

Our aim?

- To understand more about the emotions associated with caring for someone affected by an eating disorder.
- We hope this will help tailor the support for carers.

How?

- Please visit https://lancasteruni.eu.qualtrics.com/jfe/form/SV_7Qh7FBBk3mTilbU
- Please email Emily Rothwell, Trainee Clinical Psychologist with any questions. e.rothwell@lancaster.ac.uk

Appendix B

Information Sheet

Emotions associated with caring for people affected by eating disorders

Participant Information Sheet

My name is Emily Rothwell, and I am a Clinical Psychology Doctorate student at Lancaster University, United Kingdom. I am conducting this research as part of my thesis. The study aims to explore the emotions related to caring for people affected by eating disorders. The study involves completing an online survey, which is expected to take about 20 minutes to complete. You must be 18 years or older to take part in this study.

You are being invited to take part in this research study as you have identified yourself as a family member, partner or friend currently caring for someone affected by an eating disorder. Please take time to carefully read the following information before deciding whether you wish to take part.

What is the study about?

We know that caring for someone affected by an eating disorder is often very challenging. This study hopes to explore some of the emotions that may be associated with caregiving, as well as relevant reactions. We are aiming to understand whether certain attitudes and emotions have an impact on responses to caregiving. This could aid eating disorder services and support organisations to know how best to help caregivers.

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

If you decide to take part, you will be asked to first read and complete an online consent form. Following this, you will be asked to complete four online questionnaires. One questionnaire will be designed to gather a small amount of background information about yourself and the individual you care for. The following three questionnaires are designed to explore your experiences around caregiving. The questionnaires are expected to take about 20 minutes to complete in total. It is important to complete this in one sitting, to ensure that your data is not lost. You will not be asked to take part in any follow-up studies.

Do I have to take part?

No – it is completely your choice whether you decide to take part. If you do decide to take part, you are able to change your mind at any point when completing the questionnaires. Participation or the decision not to take part, will not impact on any support you receive from organisations such as the NHS or the eating disorder charity Beat. You can withdraw from competing the questionnaires, at any point prior to their submission. Once you have completed the questionnaires, it will not be possible to withdraw consent due to your data being anonymous and pooled with other people's data.

What are the possible benefits from taking part?

You are unlikely to directly benefit from taking part in this study. However, by completing the questionnaires, your answers will help us to improve future support to both caregivers and people affected by eating disorders.

What are the possible risks of taking part?

There are no known risks to taking part in this study, however, the questionnaires may bring up difficult emotions. If you do not wish to continue with the questionnaires, you can withdraw from completing the study without giving a reason. I also encourage you to contact me (Emily, the principal researcher) at any point in the study if you have any questions or concerns. The study will also take about 20 minutes of your time, which may be seen as an inconvenience.

Will my data be identifiable?

No. Your responses to the questionnaire are anonymous, which means that the data cannot be linked to you.

You may wish to email me with any questions/concerns, or to opt in to receive a summary of the findings. This email contact will go through a University email address and will be stored securely. Any email correspondence cannot be linked to your survey findings. All email correspondence will be stored securely until they are no longer needed, and they will then be permanently deleted.

How will my data be stored?

The data collected for this study will be stored securely, on a password protected, secure platform linked to the University. Only myself and my research supervisor will have access to the data. This data will be anonymous. In accordance with University guidelines, data will be stored securely for a period of 10 years. For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

What will happen to the results of the study?

The information that has been shared through the questionnaires will be used for academic purposes only. The results will be summarised and reported in my Doctorate thesis. They may also be submitted for publication in an academic journal and

presented at academic conferences. As previously described, all results will be anonymous, and data pooled across all the responses.

Who has reviewed the project?

The study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee, Lancaster University. Add reference number once obtained.

Where can I obtain further information about the study if I need?

If you have any queries about the study, or are unhappy with anything that happens around your participation in the study, please contact me, the principal researcher:

Emily Rothwell, e.rothwell@lancaster.ac.uk

If you have concerns about this study which you do not wish to discuss with me, my supervisor, Professor Bill Sellwood, b.sellwood@lancaster.ac.uk, can also be contacted about this study.

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

Mrs Yvonne Fox
Associate Director of Research Services
B53, Bowland Main
Lancaster University
LA1 4YT

Sources of support

We recognise that considering your experiences as a carer may raise some difficult thoughts and feelings. The following organisations could provide support around this:

Beat

Website: https://www.beateatingdisorders.org.uk

Telephone: 0808 801 0677 (Free telephone number)

Email: help@beateatingdisorders.org.uk

Samaritans

Website: https://www.samaritans.org

Telephone: 116 123 (Free telephone number)

Email: jo@samaritans.org

Mind

Website: https://www.mind.org.uk

Telephone: 0300 123 3393 (Free telephone number)

Email: info@mind.org.uk

Please note, if you feel in significant distress, then we recommend that you contact your GP or a trusted other for support.

Thank you for taking the time to read this information sheet, and for considering your participation in this study.

Appendix C

Demographic Questionnaire

For ease of completion, we encourage you to complete this survey on a laptop/tablet if possible.

The following questions are to help us understand more about yourself and the person you care for. If you are caring for more than one individual affected by an eating disorder, please answer based on only one of these individuals.

Questions about yourself and your caring role:

1. Do you identify yourself as a friend, partner or family member who currently provides care for an individual affected by an eating disorder?

   If yes, continue.

   If no, end survey.

2. How old are you (years)? This question is optional.

   Open text box

3. What gender do you identify as? This question is optional.
   - Female
   - Male
   - Transgender female
   - Transgender male
   - Non-binary
   - Other

4. What is your ethnic group? This question is optional.

- Asian / Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background

- Black / African / Caribbean / Black British

- African
- Caribbean
- Any other Black / African / Caribbean background

- Mixed / Multiple Ethnic Groups

- White and Black Caribbean
- White and Black African
- White and Asian

Any other Mixed / Multiple ethnic background

- White

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

- Other Ethnic Group

- Arab
- Any other ethnic group

5. Where are you currently based? This question is optional.
   - England
   - Scotland
   - Wales
   - Northern Ireland
   - Outside of the UK: Please enter country here

Currently providing care:

6. How are you related to the person you provide care for?
   - Mother
   - Father
   - Friend
   - Partner
   - Grandparent
   - Child
   - Sibling
   - Other (please enter in text)

7. How long have you been providing care for this person (years)?

   Open text box

8. Do you currently live with the person you provide care for? This question is optional.
   - Yes
   - No

- Sometimes

9. On average, how many hours per week do you spend providing **face to face** care for the person you provide support for (excluding hours asleep)?

   Open text box

10. On average, how many hours per week do you spend providing **virtual** care (e.g. texts, phone calls) for the person you provide support for (excluding hours asleep)?

    Open text box

11. Are you currently caring for another individual with a mental health diagnosis, as well as the individual affected by the ED? This question is optional.
    - Yes
    - No

12a. Have you ever received any support for caring for a loved one affected by an ED?

- Yes
- No
- Unsure

12b. If yes, please choose the type of support you have received.

- NHS support
- Charity support
- Private support
- Other (please enter in text)

Questions about the person you provide care for:

13. How old is the person you provide care for (years)? This question is optional.

    Open text box

14. What gender does the person you provide care for identify as? This question is optional.

    - Female
    - Male
    - Transgender female
    - Transgender male
    - Non-binary
    - Other

15. How long has the person you provide care for experienced/ been diagnosed with an eating disorder (years)? (This question is optional)

    Open text box

16. What type of eating disorder has the person experienced/ been diagnosed with, in the time you have been providing care? Please tick all that apply. This question is optional.

    - Anorexia nervosa
    - Bulimia nervosa
    - Binge eating disorder
    - Avoidant/ restrictive food intake disorder (ARFID)
    - Other specified feeding or eating disorder (OSFED)

- Other (please specify)
- Not known

17. Is your loved one currently receiving treatment for the ED?

- Yes
- No
- Unsure

18. Is your loved one currently receiving inpatient treatment?

- Yes
- No
- Unsure

19. Does the person you provide care for, have another other physical or mental health difficulties? If yes and known, please briefly provide further information. This question is optional.

    Open text box

Appendix D

CARE Scales

Instructions

- Below is a list of situations relatives tell us they have experienced. They may or may not have happened during the time you have cared for your relative.
- For each situation we have listed four possible responses. Please indicate how likely it is you would have this response *if the situation occurred today.*
- You may think or feel multiple responses to each circumstance so please tell us how likely it is that There are no right or wrong answers, we are just looking to understand how relatives in a caring role think and feel about these kind of events.
- All your scores are anonymous.
- Please complete all ratings for the responses a) to d), for all questions.

In the following scenarios, how likely is it you would think or feel the following responses *(if the situation occurred today)…*						
1) Your relative doesn't attend an appointment with mental health services (psychiatrist, psychologist, nurse or other mental health professional)…		Not likely				Very likely
	a) I would worry if this was down to something I did as I haven't supported them as much as I had intended.	1	2	3	4	5
	b) I would think about how my relative should be taking more responsibility for their treatment so that they can be as well as possible.	1	2	3	4	5
	c) I would think about how many people miss appointments, my relative may have a lot to manage at the moment.	1	2	3	4	5
	d) I would worry people think I am not doing a good job as a carer for my relative.	1	2	3	4	5
2) Your relative experiences a period of relapse…		Not likely				Very likely

DRAFT

	a) I would feel like I'm a failure.	1	2	3	4	5
	b) I would think how good weeks and bad weeks are to be expected.	1	2	3	4	5
	c) I would feel bad about the times I might have helped more but didn't and think about ways I could make up for this.	1	2	3	4	5
	d) I would think about how they could have avoided this if they had just learned to look after themselves better.	1	2	3	4	5
3) You have other commitments (such as with work or to other people or hobbies) alongside caring for your relative, and their mental health deteriorates…		Not likely				Very likely
	a) I would think about how I can't always be there to help stop this from happening, and I may not have been able to prevent it anyway.	1	2	3	4	5
	b) I would feel like a bad person.	1	2	3	4	5
	c) I would feel bad that I prioritised other commitments and would try to make amends.	1	2	3	4	5
	d) I would think about how they need to learn to look after themselves better.	1	2	3	4	5
4) You encourage your relative to go for a walk with you but while you're out in public your relative appears distressed (e.g uncooperative, crying, shouting, responding to voices, acting agitated)…		Not likely				Very likely
	a) I would worry about what people think of me.	1	2	3	4	5
	b) I would think they should be able to control their own actions.	1	2	3	4	5
	c) I would think they have a lot going on so it's understandable for them to be acting this way.	1	2	3	4	5
	d) I would feel bad for encouraging them to join me and try to think of ways to be more helpful.	1	2	3	4	5
5) You attend an appointment with your relative's psychiatrist, psychologist, nurse or other professional.		Not likely				Very likely

DRAFT

In the appointment your relative discusses how they have been feeling worse recently…						
	a) I would think about how my relative didn't help themselves as much as they could have.	1	2	3	4	5
	b) I would think about how a lot is going on for my relative, it's reasonable for them to have ups and downs.	1	2	3	4	5
	c) I would feel bad about my role in this and think about what I could do to help them.	1	2	3	4	5
	d) I would feel like all eyes are on me.	1	2	3	4	5
6) Your relative shares their intention to do something to harm themselves or set back their recovery in some way…		Not likely				Very likely
	a) I would wonder if there was something I missed or did wrong and try to make up for it.	1	2	3	4	5
	b) I would feel as if I have failed.	1	2	3	4	5
	c) I would think this can happen when people are really distressed and services/professionals are well placed to help if this happens.	1	2	3	4	5
	d) I would think they should have asked for help earlier if they were becoming this distressed.	1	2	3	4	5
7) Your relative blames you or your family for their mental health difficulties…		Not likely				Very likely
	a) I would think about how they might be right, I could have done things differently and will try and change how I do things in future.	1	2	3	4	5
	b) I would think they should look at their own role in their mental health difficulties.	1	2	3	4	5
	c) I would feel like I'm not good enough and want to end the conversation.	1	2	3	4	5
	d) I would think they are just expressing their frustration at their situation.	1	2	3	4	5

DRAFT

8) Your relative is experiencing a period of relapse at a time when you have not been providing your usual level of support. When talking to your friend, your relative’s mental health difficulties come into the conversation…		Not likely				Very likely
	a) I would raise the things that my relative is not doing to improve their situation.	1	2	3	4	5
	b) I would feel like I’m not good enough and avoid the topic.	1	2	3	4	5
	c) I would go over what I should do differently in order to prevent my relative’s distress.	1	2	3	4	5
	d) I would think how it is good to be able to discuss it because it’s not talked about enough.	1	2	3	4	5
9) During a conversation with your relative they became angry/upset…		Not likely				Very likely
	a) I would think they shouldn’t be so sensitive and have better control over their emotions.	1	2	3	4	5
	b) I would think other families seem to manage without having these problems, why can’t we?	1	2	3	4	5
	c) I would think about how they can quite easily become distressed because there are many things going on for them.	1	2	3	4	5
	d) I would think about where I went wrong and show I am sorry for what I said/did.	1	2	3	4	5
10) You notice that you’ve been less patient with your relative’s mental health difficulties recently…		Not likely				Very likely
	a) I would think it’s reasonable to find it hard, and I need time off from this sometimes.	1	2	3	4	5
	b) I would think if they hadn’t behaved this way then I wouldn’t have become impatient.	1	2	3	4	5
	c) I would feel not good enough so avoid thinking about it or start overthinking it.	1	2	3	4	5
	d) I would feel bad about this and would like to do something to make them feel better about it.	1	2	3	4	5

DRAFT

11) Your relative has been struggling to take care of their own basic needs such as; eating properly or washing themselves or doing their laundry or cleaning their space, and so on…		Not likely				Very likely
	a) I would feel responsible for not supporting their independence more and think about how I could make up for it.	1	2	3	4	5
	b) I would think about how other people will judge me because of this.	1	2	3	4	5
	c) I would think about how their mental health problems can make even quite simple things rather difficult.	1	2	3	4	5
	d) I would think they can do these things for themselves; they are just not doing what they should.	1	2	3	4	5
12) Your relative's symptoms deteriorate and you decide to ring services (e.g. the local mental health team, emergency services). You feel like it is the right thing to phone services but you feel bad because you hadn't directly asked for your relative's permission to make the phone call…		Not likely				Very likely
	a) I would worry if this had damaged the trust in our relationship and think about how to repair this.	1	2	3	4	5
	b) I would think my relative could have prevented this from happening and then I wouldn't have had to call.	1	2	3	4	5
	c) I would feel bad that I couldn't handle this on my own.	1	2	3	4	5
	d) I would think that this can happen when people are unwell and services are better placed to help if this happens.	1	2	3	4	5

Note. Only the validated questions were analysed as part of the results.

DRAFT

Appendix E

Online Consent Form

Emotions associated with caring for people affected by eating disorders

Name of Researcher: Emily Rothwell

Email: e.rothwell@lancaster.ac.uk

Before you consent to participate in this study, we ask that you take time to read the information sheet. If you have any questions before consenting to take part in this study, please email the principal researcher, Emily Rothwell, on e.rothwell@lancaster.ac.uk

By proceeding to the survey, you confirm that:

- You are 18 years or older
- You have read the participant information sheet and understand what is expected of you within this study
- You understand that you can withdraw from completing the questionnaire, at any time prior to submitting your response
- You understand that any responses/information you give will remain anonymous
- You understand that your participation is voluntary
- You consent for the information you provide to be discussed with the research supervisor at Lancaster University
- You consent that the data will be pooled and published
- You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished.

☐ I consent to the statements above and wish to continue to take part in the study. I understand that I will now proceed to the survey.

Appendix F

Debrief Message

Thank you for your participation in this study. We know that many people caring for those affected by eating disorders experience large amounts of distress and difficult emotions. Some carers are also unnecessarily hard on themselves and may feel responsible for the eating disorder. This can understandably impact the way in which they respond to the person they are caring for. We wish to understand more about the emotions associated with caregiving, and the relevant reactions, in order to know how best to support caregivers.

We recognise that considering your experiences as a caregiver may raise difficult thoughts and feelings. Although we have tried to reduce this emotional impact, we encourage you to use the following organisations to seek support if this is needed:

Beat

Website: https://www.beateatingdisorders.org.uk

Telephone: 0808 801 0677 (Free telephone number)

Email: help@beateatingdisorders.org.uk

Samaritans

Website: https://www.samaritans.org

Telephone: 116 123 (Free telephone number)

Email: jo@samaritans.org

Mind

Website: https://www.mind.org.uk

Telephone: 0300 123 3393 (Free telephone number)

Email: info@mind.org.uk

Thank you again for taking part in this study. If you have any questions or concerns or wish to be emailed a summary of our findings, please feel free to contact the principal researcher (contact details below).

Principal Researcher: Emily Rothwell, e.rothwell@lancaster.ac.uk

Research Supervisor: Bill Sellwood, b.sellwood@lancaster.ac.uk