Using the common-sense model to understand parents' illness representations of their child with an eating disorder

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List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
AN	Anorexia Nervosa
APA	American Psychiatric Association
ARFID	Avoidant Restrictive Food Intake Disorder
BED	Binge Eating Disorder
BN	Bulimia Nervosa
CASP	Critical Appraisal Skills Programme
CAMHS	Child and Adolescent Mental Health Services
CBT	Cognitive-Behavioural Therapy
COPE	Coping Orientation to Problems Experiences
CSM	Common-Sense Model or Common-Sense Model of Self-Regulation
DASS	Depression Anxiety Stress Scales
ED	Eating Disorder
EDE	Eating Disorder Examination
EDE-QS	Eating Disorder Examination Questionnaire - Short
FBT	Family-Based Therapy
IPA	Interpretative Phenomenological Analysis
IPQ	Illness Perception Questionnaire
MBCT	Mindfulness-Based Cognitive Therapy
MFT	Maudsley or Multi-Family Therapy
NHS	National Health Service
PICo	Population, Phenomenon of Interest, Context
PIS	Participant Information Sheet
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
OSFED	Other Specified Feeding or Eating Disorders
UK	United Kingdom

Lay Summary

Parents of children with an eating disorder (ED) experience significant distress, which can make it harder for the child to recover. However, we don't fully understand what causes this distress or how it affects parents' ability to cope and manage the child's condition. This research project aims to address this gap by using the "Common-Sense Model" (CSM) to better understand how parents perceive and respond to their child's illness. The project has two objectives: first, to conduct a review of studies on parental illness perceptions when caring for a child with anorexia nervosa, and second, to conduct an empirical study to investigate whether these illness perceptions impact parents' coping strategies and psychological distress.

The systematic review found that parents of children with anorexia nervosa tended to blame themselves for causing the disorder and have threatening cognitive and emotional representations of their child's illness. Specifically, they perceived anorexia nervosa as uncontrollable, incomprehensible, chronic, associated with serious negative consequences and negative emotions. To help reduce parental distress and improve treatment outcomes, this review suggests that clinicians should help these parents by teaching them more about the illness and providing them with individual psychological therapies.

The empirical study found that parents usually blamed external factors (e.g., school, covid-19, social media) or their child for the disorder. They generally perceived their child's ED as a threatening illness with serious consequences, chronicity, severe symptoms, and negative emotions. However, unlike the systematic review, parents had a positive view towards the efficacy of treatment and their own capability to manage and comprehend the illness. Moreover, a threatening emotional illness representation was linked to psychological distress, whereas a positive view of treatment was associated with dysfunctional coping and depression. A better understanding of ED was linked to depression and stress. Targeted psychological therapies that address parents' illness perceptions, particularly their emotional responses, understanding of ED, and perception of the efficacy of treatment, have the potential to reduce psychological distress and improve their child's recovery. However, further research is needed to investigate these findings in more detail.

Thesis Abstract

Background: Previous research has highlighted the significance of parental distress in the context of caring for a child with an eating disorder (ED). Such distress may contribute to accommodating the child's eating behaviours and lead to poorer treatment outcomes. However, several challenges exist in understanding this parental distress. For instance, the factors that contribute to this distress are not fully understood, and the associations have been examined without a theoretical model. As a result, it is challenging to comprehend and interpret the findings and apply them to clinical practice. Therefore, in this doctorate, the theoretical framework of the Common-Sense Model (CSM) will be used to address this gap and clarify the relationship between parental illness representations, coping strategies, and psychological distress. The CSM is recommended for understanding how parents perceive and respond to their child's illness, including psychological distress. Through the CSM, this research project aims to better understand parental illness representations, and how these affect coping strategies and ultimately influence health outcomes.

Objectives: The research project has two main aims: first, to conduct a systematic review of the qualitative literature on parental illness representations when caring for a child with anorexia nervosa, in order to gain insight into their cognitive and emotional profile. Second, to undertake an empirical study that applies the full CSM model to re-examine the profile of parental illness perceptions when caring for a child with ED, and investigate whether these illness perceptions impact their psychological distress and coping strategies.

Methods: The systematic review included 26 relevant studies from the psychINFO, MEDLINE, and EMBASE databases, and used a "best fit" framework analysis to synthesise the qualitative themes. For the empirical study, a cross-sectional design was used to gather data from parents caring for a child with ED. Parental illness representation profiles were examined using descriptive statistics, while a content analysis was used to understand the attributions parents made to their child's ED. Partial correlations were then employed to investigate whether parental illness representations were associated with coping strategies and psychological distress.

Results and discussion: The systematic review found that parents of children with anorexia nervosa tended to blame themselves for causing the disorder and had threatening cognitive and emotional representations of their child's illness according to the CSM. Specifically, they perceived anorexia nervosa as uncontrollable,

incomprehensible, chronic, associated with serious negative consequences and negative emotions. Conversely, the results of the empirical study indicated that parents generally tended to attribute the causes of their child's ED to external factors (e.g., school, covid-19, social media). Additionally, parents generally perceived their child's ED as a threatening illness with serious consequences, chronicity, severe symptoms, and negative emotions, but also had a positive view towards the efficacy of treatment and their own capability to manage and comprehend the illness. A threatening emotional illness representation was linked to psychological distress, whereas a positive view of treatment was associated with dysfunctional coping and depression. A better understanding of ED was linked to depression and stress. Therefore, tailored psychoeducation and evidence-based psychological therapies should be considered for parents of children with ED, given the specific illness representations reported in this study. These therapies should focus on managing the emotional and cognitive aspects of caring for a child with ED, such as addressing parents' perceptions of their child's treatment and understanding of ED. Such interventions may prove beneficial in reducing parental psychological distress and, indirectly, improving their child's recovery. Further research is necessary to explore these findings in greater depth.

Parents' illness representations of their child with anorexia nervosa: A systematic review of qualitative studies using the common-sense model

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Abstract

There is substantial research indicating that parental distress is a key factor in the maintenance of a child's disordered eating behaviours in the context of anorexia nervosa. However, the factors that contribute to this distress have primarily been studied qualitatively and without the use of an appropriate theoretical model. As a result, the current understanding of how parents perceive their child's condition and how this perception contributes to parental distress remains limited. To address this gap, this systematic review synthesises the extant research from qualitative studies reporting on parents' experience of caring for a child with anorexia nervosa in line with the Common-Sense Model (CSM) to understand parental distress through their perceptions of their child's anorexia nervosa. A total of 26 studies published between 1970 to 2022 systematically extracted from psychINFO, MEDLINE, and EMBASE, were eligible for inclusion for this review. Qualitative themes were synthesised using a "best fit" framework analysis. The results indicated that parents generally blamed themselves for causing anorexia nervosa while having a threatening cognitive and emotional representations for their child's illness according to the CSM. They perceived anorexia nervosa as uncontrollable, incomprehensible, chronic, and associated with serious negative consequences and negative emotions. These findings can be used to develop tailored interventions, such as adapting psychoeducation, addressing parental illness representations through individual psychological therapies, and signposting parents to peer support groups to reduce their distress.

Keywords: Parents, Anorexia nervosa, Illness perception, Common-sense model, Children.

1. Introduction

Anorexia nervosa is a life-threatening condition characterised by cognitive disturbances and maladaptive eating behaviours to control weight leading to a low body weight (American Psychiatric Publishing, 2013). Typical onset of anorexia nervosa occurs in adolescence, a stage of life when patients usually live at home with their families (Callio & Gustafsson, 2016). To that end, outcomes from previous studies highlighted that parents of children with anorexia nervosa experienced significant distress which in turn may maintained the condition through inadvertent negative parental responses to their child's disordered behaviour (Goddard et al., 2011; Graap et al., 2008; Sepulveda et al., 2009). This suggests that addressing parental distress in treatments for anorexia nervosa may help mitigate family-related maintaining factors. However, a model of understanding parental distress in the context of their child having anorexia nervosa to guide treatment developments targeting family-related maintaining factors is notably lacking. The Common-Sense Model (CSM) may help to address this gap. The aim of the current review is to synthesise existing qualitative research in line with the CSM framework to identify specific themes of parents' experiences of caring for a child with anorexia nervosa, to develop recommendations for addressing parental distress in treatment.

Family-based therapy (FBT), also known as the Maudsley Approach, is widely recognised as the first line of treatment for anorexia nervosa (Couturier et al., 2010; NICE, 2017). This approach places a strong emphasis on the involvement of parents in the recovery process, as anorexia nervosa is often considered an ego-syntonic disorder (Gregertsen et al., 2017; Loeb & Dimitropoulos, 2023). This means that individuals with anorexia nervosa may view their symptoms as consistent with their self-identity and values, making it challenging for them to engage in therapy effectively. FBT addresses this by actively involving parents in treatment and providing them with comprehensive psychoeducation about the nature of the disorder, as well as the short and long-term physical and psychological risks associated with it (Lock & Le Grange, 2001). As part of the therapy, parents are instructed to take charge of their child's meals initially, ensuring weight restoration, and gradually transitioning responsibility to the child over time (Lock & Le Grange, 2015). FBT also addresses the issue of blame by encouraging parents to externalise anorexia nervosa, helping them separate their child from the illness and cope with any self-blame or guilt they may experience (Lock & Le Grange, 2015). The effectiveness of FBT has been consistently demonstrated in promoting weight restoration and overall improvement in individuals with anorexia nervosa (Couturier et al., 2010; NICE, 2017). By focusing on the family as a central component of treatment, FBT recognises the significant role parents play in their child's recovery. This approach acknowledges that parents have the potential to positively impact their child's treatment outcomes and supports them in taking an active and supportive role throughout the process. Therefore, recognising the importance of parents in the treatment of their child's anorexia nervosa highlights the need to investigate their experiences, perspectives, and the impact of their involvement on the overall treatment outcomes.

Research indicates that parents caring for a young person with anorexia nervosa experienced significant psychological distress which may have deleterious effects on the possible recovery from the condition (Goddard et al., 2011; Graap et al., 2008; Sepulveda et al., 2009; Sepulveda et al., 2010). For instance, studies comparing parents of children with eating disorders (EDs) versus parents of children with other mental health conditions (e.g., schizophrenia, psychosis) specifically showed that carers of individuals with ED experience higher levels of anxiety and depression (Highet et al., 2005; Treasure et al., 2001). Importantly, the state of parents' mental wellbeing may play a unique role in the maintenance of anorexia nervosa among young people (Treasure et al., 2016). For example, anxiety among parents caring for a child with anorexia nervosa (e.g., such as a fear of upsetting them) has been found to be associated with unhelpful parenting behaviours (e.g., skipping or adjusting a meal) that maintained problematic eating behaviour (Goddard et al., 2011; Graap et al., 2008; Sepulveda et al., 2009). Therefore, addressing parental distress may be crucial in treatment, as it can greatly influence outcomes for their child with anorexia nervosa.

Drawing from social cognitive theory, researchers have shown that parents' perceptions of their child's illness shape the way parents cope and manage their distress in the context of caring for a child with physical and/or mental health illness (Hasson-Ohayon et al., 2019; Sonney et al., 2016). While these links between parental perceptions, caregiving ability, and mental health have been studied in other physical and mental health disorders (Kelada et al., 2021; Kuipers et al., 2007; Lo Sterzo & Orgeta, 2017; Scerri et al., 2019; Shanley & Reid, 2015), there is a lack of robust research in the context of parents caring for a child with ED. Many qualitative studies have examined parental experiences, including their perceptions of their child’s illness, and they generally reported a negative parental journey when caring for a child with anorexia nervosa. For example, one previous meta-synthesis highlighted the negative experience parents face while trying to understand and manage anorexia nervosa such as recognising the symptoms of ED, accessing the right services, and managing the symptoms and consequences of ED (Fox et al., 2017). However, the lack of a theoretical model in these qualitative studies makes it difficult to organise, interpret and understand the data, as well as to identify the link between parental perceptions of their child's illness, parental distress, and treatment outcomes. This research design deficiency complicates the analysis and translation of findings into testable hypotheses and clinical practice recommendations.

Adopting the CSM might address this gap by offering a framework for describing how parents create mental interpretations of their child's illness to manage themselves and their child's illness (Hagger et al., 2017; Leventhal et al., 2020). The CSM emphasises the salience of cognitive and emotional elements of illness representations (Banerjee et al., 2022; Hagger & Orbell, 2003). Cognitive illness representations refer to the perceptions of the health threat. It is typically divided into subcategories, namely *identity, coherence, causes, timeline, consequences, and control/cure* (Leventhal et al., 1980; Leventhal et al., 2020; Moss-Morris et al., 2002). *Identity* refers to the label of the disorder and the symptoms associated with it (e.g., physical, emotional symptoms). *Coherence* is the degree of knowledge individuals have, to guide themselves in understanding the disorder (Moss-Morris et al., 2002). *Causes* refer to explanations or attributions for how the disorder developed. *Timeline* refers to representations of how long the disorder will last (e.g., acute, or chronic). *Consequences* refers to representations of the impact that the disorder will have on their life (e.g., mental health, physical health, quality of life). Finally, *control/cure* is how much control individuals believe they have over the disorder and how much they believe that treatment will achieve their goals. Emotional illness representation refers to an individual's emotional awareness and reaction toward the health threat (Hagger & Orbell, 2003; Moss-Morris et al., 2002). A range of emotions, such as anger, fear, optimism, and empowerment, fall under this category (Hagger et al., 2017; Hagger & Orbell, 2003; Moss-Morris et al., 2002). In general, research indicates that viewing an illness as threatening, which is characterised by severe symptoms, chronicity, serious consequences, lack of control, poor understanding, and negative emotions, is linked to poorer health outcomes and psychological distress (Kelada et al., 2021; Kuipers et al., 2007; Lo Sterzo & Orgeta, 2017; Scerri et al., 2019; Shanley & Reid, 2015). The causal attribution has been explained in different ways. Instead of understanding it with a threatening or non-threatening view, the analyses have been adapted to explore internal or external causes, as well as biological, psychological, or social explanations depending on the context (Hagger & Orbell, 2017; Moss-Morris et al., 2002). In the context of caring for a child with ED, research on parental attributions has shown contradictory results. Quantitative studies have reported that parents attributed external factors and their child for causing anorexia nervosa (Whitney et al., 2007), whereas qualitative studies have shown that parents tend to blame themselves (Fox et al., 2017; Whitney et al., 2005).

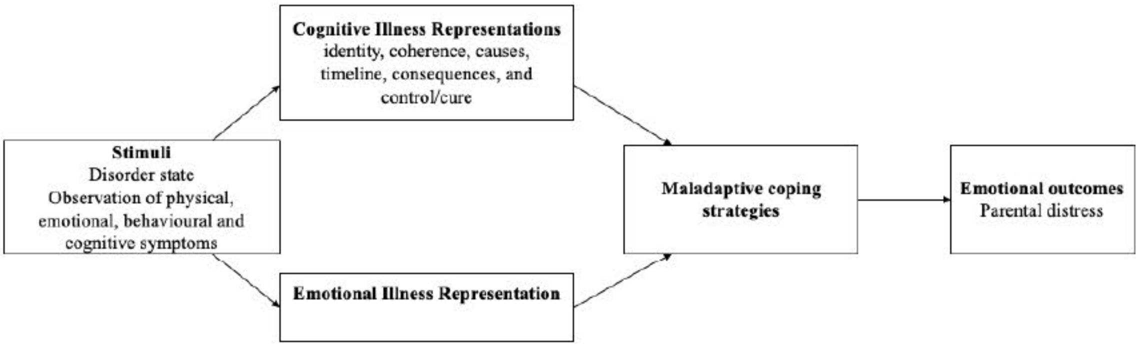
The CSM is widely used in various health contexts including the caregivers of individuals with mental health conditions (Fortune et al., 2005; Quiles & Terol, 2011; Scerri et al., 2019; Wong et al., 2018). It has been successfully applied in both ego-syntonic disorders, such as EDs and psychosis (Fortune et al., 2005; Quiles & Terol, 2011), and ego-dystonic disorders like attention deficit hyperactivity disorder (ADHD) and depression (Scerri et al., 2019; Wong et al., 2018). Consequently, the CSM is suitable for disorders where the risk is high, and patients may find it challenging to engage in recovery when they perceive their disorders as aligning with their self-identity and values. The CSM has already been used in examining caregivers caring for individuals with such disorders (Matthews et al., 2018). The CSM encompasses both threatening and less threatening conditions, aiming to normalise the experience of having threatening perceptions as common and understandable responses to illness (Kaptein et al., 2010; Quiles & Terol, 2011; Wong et al., 2018). Given its comprehensive nature, the CSM is a suitable framework for investigating and gaining insights into the experiences of caregivers of children with anorexia nervosa.

Despite the relevance of this framework to our research question, there is a dearth of research on utilising the CSM in the context of caring for a child with anorexia nervosa. Therefore, the aim of this study is to synthesise the extant research investigating the cognitive and emotional elements of parents' illness representation in the context of caring for a child with an anorexia nervosa, particularly in deriving clinical recommendations for optimising treatment outcomes by attending the potential influence of parental distress in maintaining disordered eating behaviours. The CSM has been utilised successfully to synthesise qualitative data and develop clinical recommendations in situations where qualitative data is predominant (Wong et al., 2018). For instance, a systematic review on parents caring for a child with ADHD utilised the CSM model to guide the analysis of qualitative research and gain insight into the subjective perceptions of parents (Wong et al., 2018). The review produced plausible hypotheses pertaining to specific perceptions, which merit consideration in future studies, and proposed incorporating these intricate illness representations into clinical formulations to optimise interventions (Wong et al., 2018). Another systematic review concerning illness perceptions of peripheral arterial disease employed a "best fit" framework synthesis to facilitate the analysis and synthesis of qualitative data within the CSM framework (Striberger et al., 2021). Based on the outcomes of these reviews, it is timely to conduct similar hypothesis-driven qualitative research using the CSM to comprehend parental perceptions while caring for a child with anorexia nervosa.

In summary, understanding parents' perceptions of their child with anorexia nervosa can be helpful for shaping programmatic developments in addressing parental distress and maximising treatment outcomes. A large body of qualitative research has studied parental experiences of caring for children with anorexia nervosa but without a clear theoretical framework. The aim of the current systematic review was to use the CSM framework to synthesise previous qualitative research and identify common illness representations reported by parents while caring for a child with anorexia nervosa. Based on the CSM (Kelada et al., 2021; Lo Sterzo & Orgeta, 2017), this review hypothesised that parents of children with anorexia nervosa will report threatening cognitive and emotional illness representations of their child's condition. Specifically, parents are expected to perceive their child's anorexia nervosa as having severe symptoms (*identity*), severe consequences, and a chronic timeline. Additionally, it is expected that parents would have a poor understanding (*coherence*) of anorexia nervosa, and poor level of control over managing the situation. Furthermore, parents are expected to associate their child's anorexia nervosa with negative emotional reactions and blame themselves for its cause. A CSM diagram is often used and adapted from its original version to align with a specific research question that is related to the CSM (Diefenbach & Leventhal, 1996; Hagger et al., 2017; Leventhal et al., 1980). To improve the reader's clarification of the research question in this specific context, an adapted diagram is presented below. Previous studies using the CSM model primarily explored the direction from illness representation to coping strategies or health outcomes, such as psychological distress (Knowles et al., 2020; Quiles & Terol, 2011). Accordingly, this study will follow this direction to further investigate the relationship.

Figure 1

Adapted diagram derived from the common-sense model



2. Methods

This systematic review is based on Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for designing search strategy, eligibility criteria, study selection, quality appraisal, data extraction and synthesis of results (Liberati et al., 2009). This review was registered with the international database PROSPERO on March 21st, 2022 (CRD42022313593; see Appendix B).

2.1 Search strategy

Titles and abstracts were queried within electronic databases (psycINFO, MEDLINE, and EMBASE), for the search terms listed in Table 1. The search terms were guided by the Population, Phenomenon of Interest, Context (PICo) framework for qualitative studies (Lockwood et al., 2015). Articles were limited to the time period of 1970 to 2022. This time frame has been selected based on previous studies and because anorexia nervosa was only recognised as a medical disorder in the 1970s (Fox et al., 2017; Keaschuk & Newton, 2009).

Table 1

Ovid database search

Steps	Search terms
1	((illness representation or common sense model or perception or knowledge or belief or attribution or understanding or expect or interpretation or conceptuali* or experience) and (parent or family or guardian or mother or father or maternal or paternal or carer) and (Child* or youth or adolesc* or young adulthood) and (eating disorder or anorexia or eating problems or eating difficulties)).mp. [mp=ti, ab, hw, tc, id, ot, tm, mf, tn, dm, dv, kf, fx, dq, nm, ox, px, rx, ui, sy]
2	("illness representation*" or "common sense model" or perception* or knowledge or belief* or attribut* or understand* or expect or interpretat* or conceptuali* or experienc*).mp. [mp=ti, ab, hw, tc, id, ot, tm, mf, tn, dm, dv, kf, fx, dq, nm, ox, px, rx, ui, sy]
3	(parent* or famil* or guardian* or mother* or father* or maternal or paternal or carer*).mp. [mp=ti, ab, hw, tc, id, ot, tm, mf, tn, dm, dv, kf, fx, dq, nm, ox, px, rx, ui, sy]
4	(Child* or youth or adolesc* or "young adult*" or teen*) mp. [mp=ti, ab, hw, tc, id, ot, tm, mf, tn, dm, dv, kf, fx, dq, nm, ox, px, rx, ui, sy]
5	("eating disorder*" or anorexi* or "eating problem*" or "eating difficult*") mp. [mp=ti, ab, hw, tc, id, ot, tm, mf, tn, dm, dv, kf, fx, dq, nm, ox, px, rx, ui, sy]
6	2 and 3 and 4 and 5
7	limit 6 to yr="1970 -Current"

2.2 Eligibility Criteria

2.2.1 Population

Study participants were parents or primary caregivers living or caring for a child with a confirmed diagnosis of anorexia nervosa. Studies where the majority of the cohort (>50%) had another type of ED, such as bulimia nervosa (BN) were excluded. Parents or caregivers were required to be at least 18 years old. Studies were excluded if most of the sample (>50%) involved clinicians, siblings, or service users.

2.2.2 Phenomenon of Interest

Studies were included if they examined the cognitive or emotional illness representations of parents caring for a child with anorexia nervosa. More specifically, it means that the studies exploring at least one dimension of the illness representations (e.g., *timeline*) were screened.

2.2.3 Context

Studies were included if they were written in English and published in peer-reviewed journals to allow objective comparisons. Studies were excluded if they were quantitative studies, mixed methods, reviews, dissertations, or books.

2.3 Study selection

The search findings from the databases were uploaded to Clarivate Endnote (London, UK), and then analysed using Covidence (Melbourne, Australia), a screening and data extraction tool enabling an efficient structure of the results. The screening process was completed in two steps. First, the lead researcher (DM) and an external reviewer (FK) independently conducted the initial search by screening research titles and abstracts for relevant articles meeting the inclusion criteria. Secondly, selected studies were independently screened by both reviewers for a full text review to verify that only studies meeting the inclusion criteria were included in this review.

2.3 Quality appraisal

The Critical Appraisal Skills Programme (CASP; 2018) was used to assess the quality of the included qualitative studies. The CASP tool has been chosen due to its recommendation and previous use in studies involving the CSM to evaluate qualitative studies (Wong et al., 2018). It has also been used in the field of EDs to assess the quality of their qualitative studies (Sibeoni et al., 2017). This quality assessment tool rates the quality of studies in relation to 10 domains: the aim of the study, the methodology, the design, the recruitment, the data collection, the sample and researcher relationships, ethical issues, data analysis, findings, and the value of the study. Each study was rated on a two-point scale, with a score of "1" indicating that the criterion was completely met, and a score of "0" indicating that the criterion was uncertain, not mentioned, or not met (Kanavaki et al., 2016). Studies with scores ranging from 8 to 10 were classed as ‘high’ quality studies, with a score between 5 and 7 were considered as ‘moderate’ quality, and studies scoring ≤ 4 were considered as ‘low’ quality (Kanavaki et al., 2016). The lead researcher (DM) and a second reviewer (AP) independently assessed the methodological rigour of each study to reduce bias.

2.4 Data extraction

The following information was extracted by the lead researcher (DM) for analysis: authors, years, country, participants, data collection, data analysis, aims and objectives. The lead researcher (DM) independently conducted the data extraction.

2.5 Synthesis of results

A best-fit framework synthesis was used to synthesise findings from qualitative research, drawing upon previous studies that utilised the same approach (Carroll et al., 2013; Striberger et al., 2021). Unlike thematic synthesis, which focuses on identifying common and contrasting themes, or meta-synthesis, which combines concepts from multiple studies, the best-fit framework analysis emphasises the alignment between a theoretical model (the CSM) and the findings of individual studies (Carroll et al., 2013; Sandelowski et al., 1997; Thomas & Harden, 2008). The best-fit framework synthesis methodology is known for its flexibility, as it can be applied within different paradigms and can accommodate both inductive and deductive approaches based on the research question (Carroll et al., 2013). This flexibility is particularly important when studying an understudied topic or when seeking to develop new theories or hypotheses (Carroll et al., 2013). It allows the exploration of existing theories and models while remaining open to emerging themes and patterns that may not have been anticipated. By incorporating a combination of deductive and inductive approaches, this study aims to maximise the strengths of both methods.

Content analysis and coding are integral components of the best-fit synthesis methodology. In this study, a deductive coding analysis was initially conducted based on the pre-established illness representations (e.g., *identity, causes, timeline*) within the CSM. The findings were extracted from the selected studies, and then coded according to the CSM framework (Carroll et al., 2011). This was followed by an inductive conventional content analysis, to include findings that did not fit within the CSM framework and allow new categories (e.g., adding family dynamics to the *consequences* dimension) to be created (Hsieh & Shannon, 2005). The inductive coding process involved: reading the extracted data repeatedly to become familiar with it, highlighting the relevant data addressing the main research question, and developing codes into categories (Hsieh & Shannon, 2005). The lead researcher (DM) conducted the initial coding, which was independently reviewed and validated by an external reviewer (AP; a trainee clinical psychologist, specialised in EDs and qualitative analysis) to ensure the integrity and the quality of the coding system. There was no disagreement in relation to this step.

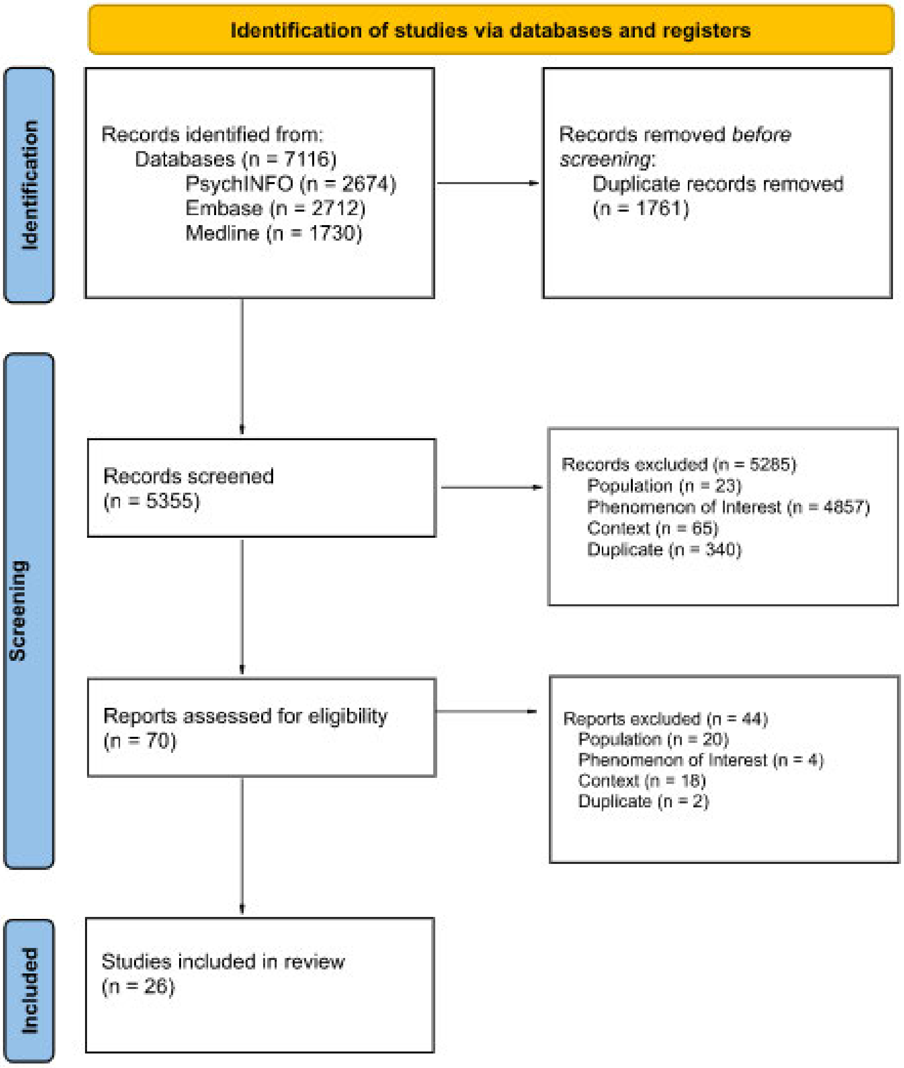
3. Results

3.1 Study selection

Figure 2 is a flow chart of the study selection procedure based on the PRISMA framework. A total of 5,355 articles were found from the initial search of the selected journal databases. After screening titles and abstracts, 70 articles remained for full text screening. Of these, 44 were excluded for not meeting the eligibility criteria, leaving 26 published studies for review. Each step of the full search process was independently screened by the lead researcher (DM) and a second reviewer (FK). The inter-rater reliability was calculated using the Cohen's Kappa (κ) coefficient (McHugh, 2012). The level of consistency between the two reviewers was 99.7% for the title and abstract screening ($\kappa = 0.86$) and 96.7 % for full text review ($\kappa = 0.93$). Inter-reviewer discrepancies were discussed until an agreed resolution was reached.

Figure 2

PRISMA chart



3.2 Quality assessment

Table 2 reports the quality assessment ratings for each of the 26 studies included in the review. Overall, the majority of studies indicated to have strong methodological rigour, with 12 rated (12/26, 46.15%) as high quality and 14 (14/26, 88.5%) as moderate quality. All studies reported clear aims and had appropriate qualitative methodologies. The relevant research design to address the main study purpose was present in 23 studies (23/26, 88.5%). Among the 22 studies (22/26, 84.6%) that reported an appropriate recruitment strategy, the remaining four studies (4/26, 15.4%) provided little to no information on sample selection. The data collection was justified for 20 studies (20/26, 76.9%) while the other six studies (6/26, 23.1%) lacked precision in their methodological approach. The criteria for considering the relationship between the researcher and the sample was only met in five studies (5/26, 19.2%) whereas 14 studies (14/26, 53.8%) did not fully examine the researcher's influence throughout the study process and seven studies (7/26, 26.9%) did not meet the criteria. Furthermore, 11 studies (11/26, 42.3%) mentioned ethical approval, but 15 studies (15/26, 57.7%) did not give sufficient evidence regarding the maintenance of ethical standards. Out of 26 studies, 14 (14/26, 53.8%) had an in-depth description of the analysis process, whilst nine (9/26, 34.6%) had insufficient information on how themes were derived from the data. Three studies (3/26, 11.5%) did not meet the CASP criteria. Most studies (24/26, 92.3%) had explicit findings in relation to the main research question while two were missing discussions regarding the credibility of the findings (2/26, 7.7%). Out of the total 26 studies, 17 studies (17/26, 65.4%) were considered relevant to the contribution of research or clinical practice and nine (9/26, 34.6%) did not identify new areas for future research. All the studies were included regardless of their quality assessment. Cohen's Kappa coefficient was used to assess the inter-rater reliability between two reviewers determining the quality of included studies with a moderate level of agreement of 91.2% ($\kappa = 0.41$) (McHugh, 2012). All studies were deemed to have sufficient quality for inclusion in quality review.

Table 2

Quality assessment of each study

Authors, years	1 Aims	2 Appropriate Qualitative Methodology	3 Design	4 Recruitment	5 Data collection	6 Sample/ researcher relationship	7 Ethical issues	8 Data analysis	9 Findings	10 Value	Total
Baumas et al., (2021)	✓	✓	✓	✓	✓	?	✓	?	?	?	6 Moderate
Bezance & Holliday (2014)	✓	✓	✓	✓	✓	✓	✓	?	?	✓	8 High
Coelho et al., (2021)	✓	✓	✓	✓	✓	?	?	✓	✓	?	7 Moderate
Cottee-Lane et al., (2004)	✓	✓	✓	✓	✓	?	x	✓	✓	?	7 Moderate
Engman-Bredvik et al., (2016)	✓	✓	✓	✓	?	?	?	✓	✓	?	6 Moderate
Fletcher et al., (2021)	✓	✓	✓	✓	✓	?	✓	?	✓	✓	8 High
Honey & Halse, (2005)	✓	✓	✓	?	?	x	x	✓	✓	✓	6 Moderate
Honey & Halse, (2006)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	9 High
Hoskins & Lam, (2001)	✓	✓	✓	✓	✓	?	x	x	✓	✓	7 Moderate

Karlstad et al., (2021)	✓	✓	✓	✓	✓	?	✓	✓	✓	?	8 High
Keitel et al., (2010)	✓	✓	?	✓	?	✓	x	x	✓	?	5 Moderate
Marinaci et al., (2021)	✓	✓	✓	✓	✓	x	?	?	✓	?	6 Moderate
McMahon et al., (2022)	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	9 High
O'Dwyer (2021)	✓	✓	?	✓	?	?	x	x	✓	✓	5 Moderate
Robinson et al., (2020)	✓	✓	✓	?	?	?	x	?	✓	✓	5 Moderate
Sharkey-Orgnero (1999)	✓	✓	?	✓	?	x	x	?	✓	✓	5 Moderate
Svensson et al., (2013)	✓	✓	✓	✓	✓	x	?	✓	✓	?	7 Moderate
Thomson et al., (2014)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10 High
Tierney (2005)	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	9 High
Tuval-Mashiach et al., (2014)	✓	✓	✓	✓	✓	x	?	✓	✓	✓	8 High
Voriadaki et al., (2015)	✓	✓	✓	✓	✓	?	✓	?	✓	?	7 Moderate
Whitney et al., (2012)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	9 High

Whitney et al., (2005)	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	9 High
E. P. Williams et al., (2020)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	8 High
L. T. Williams et al,. (2020)	✓	✓	✓	✓	✓	?	✓	?	✓	✓	8 High
Wufong et al., 2019)	✓	✓	✓	?	✓	?	?	?	✓	✓	6 Moderate

Note. ✓= the criterion was completely met; ? = the criterion was uncertain or not mentioned; x = the criterion was not met

3.3 Characteristics of included studies

A summary of the study characteristics is outlined in Table 3. The 26 studies in this review were published between 1999 and 2022 and were conducted in the United Kingdom (n = 10), Australia (n = 4), Canada (n = 4), Sweden (n = 2), France (n = 1), Italy (n = 1), Israel (n = 1), New Zealand (n = 1), Norway (n = 1), and the United States (n = 1). Most studies included both parents (n = 20) while some studies focused solely on mothers (n = 5) or fathers (n = 1). Fewer studies explored the experience of additional caregivers such as service users (n = 3), siblings (n = 2), and partner (n = 2). Information was provided in 13 studies regarding the age of caregivers, with an average age of 51 years and a range of 44 to 61 years. The severity of anorexia nervosa was specified in 24 studies by including outpatients (n = 12), inpatients (n = 5), both (n = 5) or recovered patients (n = 2). All studies focused on the experience of parents caring for a child with anorexia nervosa. Some of these studies additionally looked at the experiences of parents caring for avoidant/restrictive food intake disorder (ARFID, n = 2), bulimia nervosa (BN, n = 2), binge eating disorder (BED, n = 1), and other specified feeding or eating disorders (OSFED, n = 2). The duration of illness was specified in 21 studies, with an average of four years and ranged from seven weeks to 10 years. In 22 studies, the age of the child was reported, with an average age of 21 years old and a range of 14 to 28 years old.

Lastly, data collection employed by studies included interviews (n = 21), focus group (n = 1), survey (n = 1), clinical notes (n = 1), letters (n = 1), as well as the combinations of rating scales, focus group and daily journals (n = 1). Data was analysed through thematic analysis (n = 6), interpretative phenomenological analysis (IPA) (n = 6), grounded theory (n = 6), narrative analysis (n = 2), interpretive inductive analysis (n = 1), phenomenological analysis (n = 1), contextualised interpretative methodology (n = 1), phenomenological hermeneutical analysis (n = 1), discourse analysis (n = 1), and hermeneutic analysis (n = 1).

Table 3

Characteristics of included studies

Authors, years, country	Participants	Parents characteristics (gender, mean age)	Child characteristics (patient type, diagnosis, mean age, mean illness duration)	Data collection	Data analysis	Aims and objectives
Baumas et al., (2021) France	Parents (n = 6) Children (n = 3)	Mothers (n = 4) Fathers (n = 2) Unknown	Inpatients AN 16 years 3 years	Focus groups	Thematic analysis	To explore the experience of families through MFT program
Bezance & Holliday (2014) United Kingdom	Parents (n = 9)	Mothers (n = 9) 52 years	Inpatients, outpatients AN 15 years 7 weeks	Semi-structured interviews	IPA	To explore mothers' experiences of home treatment for AN
Coelho et al., (2021) Canada	Parents (n = 10)	Mother (n = 6) Fathers (n = 4) 45 years	Inpatients, outpatients AN (n = 8), ARFID (n = 2) 15 years 2 years	In depth semi-structured interviews	Interpretive inductive analysis	To understand parents' experiences over the course of their child's treatment
Cottee-Lane et al., (2004) United Kingdom	Parents (n = 11)	Mothers (n = 7) Father (n = 4) 52 years	Outpatients AN 14 years 2 years	Semi-structured interviews	IPA	To examine the experience of parents who had a child with early onset AN
Engman-Bredvik et al., (2016) Sweden	Parents (n = 12)	Mothers (n = 6) Fathers (n = 6) Unknown	Outpatients AN 14 years 1 years	Structured interviews and questionnaires	Phenomenological analysis	To investigate FBT from a parental perspective.

Fletcher et al., (2021) New Zealand	Parents (n = 8) Partner (n = 1)	Mothers (n = 6) Fathers (n = 2) Partner (n = 1)	Unknown AN (n = 5), BN (n = 2), ARFID (n = 1), BED (n = 1) Unknown Unknown	Semi-structured interviews	Thematic analysis	To investigate perspectives of carers of a family member with a diagnosis of ED
Honey & Halse, (2005) Australia	Parents (n = 22)	Mothers (n = 14) Fathers (n = 8) Unknown	Outpatients AN 17 years 5 years	In-depth interviews	Grounded theory	To examine parents' perceptions and actions in response to AN
Honey & Halse, (2006) Australia	Parents (n = 24)	Mothers (n = 16) Fathers (n = 8) Unknown	Inpatients, outpatients AN 16 years 4 years	In-depth interviews	Grounded theory	To illuminate the coping strategies used by parents of teenage girls who have been diagnosed with AN
Hoskins & Lam, (2001) Canada	Parents (n = 3)	Mothers (n = 3) 50 years	Recovered AN Unknown Unknown	Open-ended interviews	Contextualised interpretative methodology (informed by discursive and constructionist theory).	To examine how daughters' AN influence the mothers' understandings of mothering and self
Karlstad et al., (2021) Norway	Parents (n = 11)	Mothers (n = 7) Fathers (n = 4) 61 years	Inpatients, outpatients AN (n = 6), BN (n = 1) 28 years 10 years	Semi-structured interviews	Grounded theory.	To know how parents of adults with AN experienced their situation in everyday life and to know what strategies they used and what were their experiences of the health services
Keitel et al., (2010) United States	Parents (n = 10)	Mothers (n = 10) Unknown	Inpatients AN Unknown 2 years	In-depth phone interviews	Thematic analysis.	To explore the most significant stressors in dealing with their child's ED disorder
Marinaci et al., (2021) Italy	Parents (n = 4)	Mothers (n = 4) 54 years	Outpatients AN 22 years 1 year	In-depth semi-structured interviews	Narrative analysis	To capture the mothers' experiences of living with a daughter diagnosed with AN

McMahon et al., (2022) United Kingdom	Parents (n = 15)	Fathers (n = 15) Unknown	Outpatients AN 14 years Unknown	Individual interviews	Grounded theory.	To understand the experience of fathers in FBT when caring for their child with AN
O'Dwyer (2021) United Kingdom	Parents (n = 5)	Mothers (n = 5) Fathers (n = 5) Unknown	Inpatients AN 12 years 1 year	Clinical notes from the 36 sessions.	Thematic analysis	To explore patterns of relating that emerge in psychoanalytic parent work with parents of young people hospitalised for ED
Robinson et al., (2020) United Kingdom	Caregivers (n = 616)	Mothers (n = 505) Fathers (n = 40) Others (n = 71) Unknown	Outpatients AN (n = 552), OSFED (n = 337) 21 years Unknown	Survey	Thematic analysis	To explore caregivers' experiences and impact of ED services.
Sharkey-Orgnero (1999) Canada	Parents (n = 28) Siblings (n = 10)	Mothers (n = 10) Fathers (n =8) Siblings (n =10) 52 years	Recovered AN 15 years 9 years	Semi-structured Interviews	Grounded theory	To examine parents' views of their daughters' recovery from AN
Svensson et al., (2013) Sweden	Parents (n = 10)	Mothers (n = 6) Fathers (n = 4) Unknown	Unknown AN (n = 4), OSFED (n = 3) 17 years 3 years	Semi structured interviews	Phenomenological, hermeneutical analysis	To investigate parental experiences of caring for a child with ED
Thomson et al., (2014) United Kingdom	Parents (n = 8)	Mothers (n = 7) Fathers (n = 1) 47 years	Outpatients AN 15 years 1 year	Semi-structured interviews	IPA	To investigate parents' experiences of recognising that their child had ED and deciding to seek help
Tierney (2005) United Kingdom	Parents (n = 14)	Mothers (n = 8) Fathers (n = 6) Unknown	Inpatients, outpatients AN 16 years 4 years	Semi structured interviews	Thematic analysis	To find out parental views in relation to their child treatment
Tuval-Mashiach et al., (2014) Israel	Parents (n = 10)	Mothers (n = 10) 54 years	Outpatients AN Unknown	In-depth interviews	Narrative analysis	To focus on the subjective experience of mothers of daughters with ongoing AN

			6 years			
Voriadaki et al., (2015) United Kingdom	Parents (n = 10) Children (n = 5)	Mothers (n = 6) Fathers (n = 4) Unknown	Outpatients AN 16 years Unknown	Rating scales, daily journals, and two focus groups	IPA	To analyse a familial experience through FBT day by day
Whitney et al., (2012) United Kingdom	Parents (n = 17) Siblings (n = 4) Child (n = 1) Husband (n = 1)	Female (n = 13) Male (n = 10) 47 years	Outpatients AN 25 years 9 years	Interviews	IPA	To examine carers' satisfaction for treatment efficacy and process of changes when caring for AN
Whitney et al., (2005) United Kingdom	Parents (n = 40)	Mothers (n = 20) Fathers (n = 20) 53 years	Inpatients AN 21 years 7 years	Letters	Grounded theory	To gain an understanding of carers illness models and caregiving experiences for AN
E. P. Williams et al., (2020) Canada	Parents (n = 12)	Mothers (n = 10) Fathers (n = 2) 53 years	Outpatients AN 17 years 1 year	Unstructured interviews	Hermeneutic analysis	To examine the experience of parents who discover their child was living with AN
L. T. Williams et al., (2020) Australia	Parents (n = 9)	Mothers (n = 6) Fathers (n = 3) 43 years	Outpatients AN 15 years 2 years	In-depth semi structured interviews	IPA	To examine parents' experiences of FBT for the treatment of adolescents with AN
Wufong et al., (2019) Australia	Parents (n = 13)	Mothers (n = 9) Fathers (n = 4) Unknown	Inpatients AN 19 years 1 year	Semi structured interviews	Discourse analysis	To analyse the parental experiences of AN treatment.

Note. AN = anorexia nervosa; MFT = maudsley or multi-family therapy; IPA = interpretative phenomenological analysis; ARFID = avoidant/restrictive food intake disorder; FBT = family-based treatment; BN = bulimia nervosa; BED = binge eating disorder; ED = eating disorder; OSFED = other specified feeding or eating disorders

3.4 Findings

An overview of the findings can be found in Table 4. All the studies included in this review focused on at least one dimensions of illness representations: *control/cure* (n = 16), *consequences* (n = 14), *emotional illness representation* (n = 14), *coherence* (n = 13), *causes* (n = 11), *identity* (n = 6), and *timeline* (n = 6).

Table 4

Overview of the findings

Authors, years	Identity	Coherence	Causes	Timeline	Consequences	Control/cure	Emotional representation
Baumas et al., (2021)					✓	✓	
Bezance & Holliday (2014)					✓	✓	✓
Coelho et al., (2021)	✓	✓				✓	✓
Cottee-Lane et al., (2004)	✓	✓	✓		✓		✓
Engman-Bredvik et al., (2016)			✓	✓		✓	
Fletcher et al., (2021)					✓	✓	✓
Honey & Halse, (2005)		✓	✓		✓		
Honey & Halse, (2006)			✓			✓	
Hoskins & Lam, (2001)		✓	✓		✓		
Karlstad et al., (2021)		✓		✓			
Keitel et al., (2010)					✓		
Marinaci et al., (2021)		✓	✓		✓		
McMahon et al., (2022)	✓	✓	✓			✓	✓
O'Dwyer (2021)			✓	✓		✓	✓
Robinson et al., (2020)		✓			✓	✓	✓
Sharkey-Orgnero (1999)		✓				✓	
Svensson et al., (2013)			✓		✓		✓
Thomson et al., (2014)	✓	✓		✓			✓
Tierney (2005)		✓			✓	✓	✓
Tuval-Mashiach et al., (2014)			✓		✓	✓	✓
Voriadaki et al., (2015)						✓	
Whitney et al., (2012)						✓	
Whitney et al., (2005)	✓	✓	✓	✓			✓
E. P. Williams et al., (2020)	✓	✓			✓		✓
L. T. Williams et al., (2020)					✓	✓	✓
Wufong et al., (2019)				✓		✓	

3.4.1 Cognitive illness representations

3.4.1.1 Identity (n = 6)

Studies reported that parents observed a range of symptoms associated with anorexia nervosa (Cottee-Lane et al., 2004; Coelho et al., 2021; McMahon et al., 2022; Thomson et al., 2014; Whitney et al., 2005; E. P. Williams et al., 2020). The most common symptoms observed included sudden changes in their child's eating behaviour (e.g., dieting, eating "healthy", becoming vegetarian), physical appearance (e.g., weight loss) and increasing isolation from friends, family, and social activities (Cottee-Lane et al., 2004; Coelho et al., 2021; Thomson et al., 2014; E. P. Williams et al., 2020). Less commonly mentioned symptoms included cognitive changes (e.g., rigidity about food) and emotional changes such as low self-esteem (Cottee-Lane et al., 2004; Thomson et al., 2014; Whitney et al., 2005)

3.4.1.2 Coherence (n = 13)

Findings across studies indicated that parents have a poor understanding of anorexia nervosa (Coelho et al., 2021; Cottee-Lane et al., 2004; Honey & Halse, 2005; Hoskins & Lam, 2001; Karlstad et al., 2021; Marinaci et al., 2021; McMahon et al., 2022; Robinson et al., 2020; Sharkey-Orgnero, 1999; Thomson et al., 2014; Tierney, 2005; Whitney et al., 2005; E. P. Williams et al., 2020). Firstly, parents reported having difficulties recognising the symptoms of anorexia nervosa (Honey & Halse, 2005; McMahon et al., 2022; Sharkey-Orgnero, 1999; Thomson et al., 2014; E. P. Williams et al., 2020). For instance, they initially confused these symptoms with the normal development in adolescence (Honey & Halse, 2005; McMahon et al., 2022; Sharkey-Orgnero, 1999; Thomson et al., 2014). Some parents even viewed weight loss as a positive change (Sharkey-Orgnero, 1999; Thomson et al., 2014). In one example, parents reported that their son's gender contributed to their misunderstanding because they believed that anorexia nervosa was typically a disorder affecting women (Coelho et al., 2021). Furthermore, parents were also found to have a poor understanding of the reasons behind the severity of anorexia nervosa (Whitney et al., 2005). For instance, parents failed to understand why their child would not eat at the risk of their own survival. Finally, parents misunderstood how to manage or influence the course of anorexia nervosa (Coelho et al., 2021; Robinson et al., 2020).

3.4.1.3 Causes (n = 11)

3.4.1.3.1 Child and parent referent attributions (n = 10)

Studies found that parents generally attributed the cause of anorexia nervosa to either themselves or their child (Cottee-Lane et al., 2004; Engman-Bredvik et al., 2016; Honey & Halse, 2005, 2006; Hoskins & Lam, 2001; McMahon et al., 2022; O'Dwyer, 2021; Svensson et al., 2013; Tuval-Mashiach et al., 2014; Whitney et al., 2005). For instance, parents frequently reported feeling responsible for their child illness (Cottee-Lane et al., 2004; Engman-Bredvik et al., 2016; Hoskins & Lam, 2001; McMahon et al., 2022; O'Dwyer, 2021; Svensson et al., 2013; Tuval-Mashiach et al., 2014; Whitney et al., 2005). They thought that their passion for food (e.g., cooking, reading, and writing food books) might have influenced their parenting style and therefore the development of anorexia nervosa (Hoskins & Lam, 2001). Another study suggested that parents believed that their lack of awareness regarding early signs of anorexia nervosa, and therefore poor efforts to prevent it, contributed to the development of anorexia nervosa (Cottee-Lane et al., 2004). Four studies reported instances of parents blaming their child (Honey & Halse, 2005, 2006; O'Dwyer, 2021; Whitney et al., 2005). For instance, parents believed their child had a hereditary illness or had a predisposing vulnerability to anorexia nervosa (Cottee-Lane et al., 2004; Honey & Halse, 2005). Parents also suggested the possibility of anorexia nervosa to be caused by the personality of their child (Cottee-Lane et al., 2004; Honey & Halse, 2005). Finally, parents reported it is their child's fault for choosing not to eat (Cottee-Lane et al., 2004).

3.4.1.3.2 External causes (n = 3)

Existing studies also reported that parents attributed the cause of their child's anorexia nervosa to external factors (Cottee-Lane et al., 2004; Honey & Halse, 2005; Marinaci et al., 2021). Some parents believed that their child's environment or situational factors such as traumatic or stressful experiences could have triggered the development of anorexia nervosa (Cottee-Lane et al., 2004; Honey & Halse, 2005). Parents also reported difficulties in understanding the causes of anorexia nervosa (Honey & Halse, 2005; Marinaci et al., 2021).

3.4.1.4 Timeline (n = 6)

The findings showed that some parents perceived anorexia nervosa as a temporary condition (Engman-Bredvik et al., 2016; Thomson et al., 2014), while other parents viewed anorexia nervosa as a long term one (Engman-Bredvik et al., 2016; Karlstad et al., 2021) or as a chronic disorder (Whitney et al., 2005;

Wufong et al., 2019). A few parents described the symptoms of anorexia nervosa as cyclical where their child's recovery was followed by a lapse or a relapse episode (O'Dwyer, 2021; Wufong et al., 2019). Despite the variation in the perceived timeline of anorexia nervosa, most studies suggested that parents viewed anorexia nervosa as a lifelong condition.

3.4.1.5 Consequences (n = 14)

3.4.1.5.1 Family dynamics (n = 12)

Existing studies speculated that parents felt that their child's illness had profoundly affected their whole family (Baumas et al., 2021; Cottee-Lane et al., 2004; Fletcher et al., 2021; Keitel et al., 2010; Tierney, 2005; Tuval-Mashiach et al., 2014; E. P. Williams et al., 2020; L. T. Williams et al., 2020). These studies indicated that parents saw this multifaceted disorder as a threat to their family dynamics. For instance, parents reported being so consumed by the child's illness that they had neglected other family members (Baumas et al., 2021; Fletcher et al., 2021; Robinson et al., 2020; Svensson et al., 2013; Tuval-Mashiach et al., 2014). Parents also believed that anorexia nervosa had impacted siblings, in a way that they had to adapt their life for their sibling's anorexia nervosa, such as avoiding spending time at home (Svensson et al., 2013; Tuval-Mashiach et al., 2014). Other findings reported that mothers believed that anorexia nervosa had created a created a rupture in their parent-child relationship (Bezance & Holliday, 2014; Hoskins & Lam, 2001; Marinaci et al., 2021; Tuval-Mashiach et al., 2014; E. P. Williams et al., 2020). For instance, they felt that they lost their bond with their child and their trust through the secrecy, manipulation, and deception of their child (Bezance & Holliday, 2014). They also felt that they lost their happy child and seeing their child being distressed impacted on the quality of the relationship (Marinaci et al., 2021). Finally, one study disclosed how anorexia nervosa had contributed to problems in caregivers' romantic relationships, especially when specific caretaking roles were involved such as one parent staying on the ward and the other staying at home (Svensson et al., 2013).

3.4.1.5.2 Work and finance (n = 3)

Findings indicated that most parents needed to take leave or temporarily stopped working to meet the demands of the illness, which impacted not only on their work but on their finances as well (Keitel et al., 2010; Robinson et al., 2020; E. P. Williams et al., 2020). One of these studies was conducted in the US and signalled the financial burden that the treatment and inadequate health insurance cost (Keitel et al., 2010). As a result, parents were in debt and needed to compensate using their savings or ask friends to protect their ill child (Keitel et al., 2010).

3.4.1.5.3 Social life (n = 7)

Studies suggested that parents reduced their social life to protect their child, themselves, and anorexia nervosa (Cottee-Lane et al., 2004; Fletcher et al., 2021; Honey & Halse, 2005; Hoskins & Lam, 2001; Svensson et al., 2013; E. P. Williams et al., 2020; L. T. Williams et al., 2020). To protect their child, some parents complied to challenging behaviours by stopping social activities triggering any distress in their child (Cottee-Lane et al., 2004). These activities tended to involve going for dinners with friends or anything associated with food as food is considered as a component of social behaviour (Cottee-Lane et al., 2004), which contributed to parental isolation. Furthermore, some parents revealed to keep these challenging behaviours confidential to respect the privacy of their child, reducing conversations with others (E. P. Williams et al., 2020). Other parents wanted to spend more time with their ill child to support them during this journey (Hoskins & Lam, 2001; Svensson et al., 2013). To protect themselves, some parents isolated themselves not to be questioned about anorexia nervosa (E. P. Williams et al., 2020). Others avoided people to reduce the risk of being judged by their surroundings (Fletcher et al., 2021; L. T. Williams et al., 2020). Lastly, most parents tended to prioritise the demanding nature of anorexia nervosa, which automatically reduced their time spent with their social environment (E. P. Williams et al., 2020).

3.4.1.6 Control and cure (n = 16)

This domain is often divided by perceptions about how anorexia nervosa can be controlled by treatments and controlled by individuals (Moss-Morris et al., 2002).

3.4.1.6.1 Treatment control (n = 15)

Regarding this dimension, most studies provided a range of definitions for describing the effectiveness of treatment. This included improvement in weight, psychological distress, or family dynamics. Parents generally thought that clinical interventions improved their family dynamics and mental health difficulties (Baumas et al., 2021; Coelho et al., 2021; Engman-Bredvik et al., 2016; Tierney, 2005; Voriadaki et al., 2015; Whitney et al., 2012; Wufong et al., 2019). One study mentioned how parents believed that treatment can cure anorexia nervosa (Fletcher et al., 2021) while most studies revealed that parents doubted the effectiveness of treatment in curing anorexia nervosa (Baumas et al., 2021; Bezance & Holliday, 2014; McMahon et al., 2022; O'Dwyer, 2021; Robinson et al., 2020; Sharkey-Orgnero, 1999; Tierney, 2005; Tuval-Mashiach et al., 2014; Whitney et al., 2012; L. T. Williams et al., 2020; Wufong et al., 2019). A few studies specified how the first line intervention, Family Based Treatment (FBT) or Maudsley Family Therapy (MFT), focused heavily on weight restoration and neglected the psychological side attached to anorexia nervosa impacting on their child's recovery (Robinson et al., 2020; Tierney, 2005; Tuval-Mashiach et al., 2014; L. T. Williams et al., 2020; Wufong et al., 2019). Furthermore, some parents were concerned about the incompetence of clinicians impacting the delivery of the treatment, and therefore, the management and recovery of anorexia nervosa (Sharkey-Orgnero, 1999). Lastly, some studies explained how caregivers believed that treatment was effective in improving the symptoms of anorexia nervosa in the short term but not in the long term by sharing concerns about relapses (O'Dwyer, 2021; Wufong et al., 2019). Therefore, despite the varied perception of the effectiveness of anorexia nervosa, most studies suggested that parents did not expect the treatment to be effective in curing the symptoms of anorexia nervosa.

3.4.1.6.2 Parental control (n = 7)

In general, findings suggested that parents were powerless over the symptoms of anorexia nervosa (Coelho et al., 2021; O'Dwyer, 2021; Robinson et al., 2020; Tierney, 2005). More precisely, they were unsure how to prevent, manage, or control anorexia nervosa (Coelho et al., 2021; O'Dwyer, 2021; Robinson et al., 2020; Tierney, 2005). Furthermore, some studies have shown how treatment influenced parental control (Honey & Halse, 2006; Whitney et al., 2012; L. T. Williams et al., 2020). For instance, some parents felt empowered by the strategies learnt in FBT such as reflective techniques and externalising anorexia nervosa to confront anorexia nervosa (Honey & Halse, 2006; L. T. Williams et al., 2020). However, other parents mentioned how treatments maintained parental sense of powerlessness over anorexia nervosa by the lack of support given in managing meals and challenging behaviours (Whitney et al., 2012).

3.4.2 Emotional illness representation (n = 14)

Selected studies demonstrated that parents experienced a variety of negative emotional reactions when caring for a child with anorexia nervosa, such as fear and anxiety (n = 6), emotional distress (n = 5), shame and guilt (n = 4), loneliness (n = 4), and depression (n = 2) (Bezance & Holliday, 2014; Coelho et al., 2021; Cottee-Lane et al., 2004; Fletcher et al., 2021; McMahon et al., 2022; O'Dwyer, 2021; Robinson et al., 2020;

Svensson et al., 2013; Thomson et al., 2014; Tierney, 2005; Tuval-Mashiach et al., 2014; Whitney et al., 2005; E. P. Williams et al., 2020; L. T. Williams et al., 2020). Some of these emotions have been associated with specific situations or cognitive illness representations. First, most parents reported feeling scared and anxious about various reasons including: the intensity of the symptoms (*identity*), the lack of understanding regarding he nature and the management of anorexia nervosa (*coherence*), the chronicity and relapses (*timeline*), the impact on their child, themselves and their family (*consequences*), and the lack of parental and treatment control over fighting for this condition (*control*) (Cottee-Lane et al., 2004; Fletcher et al., 2021; Svensson et al., 2013; Thomson et al., 2014; E. P. Williams et al., 2020; L. T. Williams et al., 2020). Second, existing studies demonstrated that most parents felt guilty for feeling responsible for their child's mental health difficulties (*causes*) (Svensson et al., 2013; Tuval-Mashiach et al., 2014; E. P. Williams et al., 2020; L. T. Williams et al., 2020). In addition to this, some mothers reported feeling depressed and suicidal for similar reasons. For instance, they disclosed losing their pride in motherhood for failing to be a good parent and meet their child's needs (Robinson et al., 2020; Tuval-Mashiach et al., 2014). They ruminated on their child upbringing and their parenting styles to understand the cause of anorexia nervosa and the disruption in the relationship with their child (Tuval-Mashiach et al., 2014). Third, the literature indicated that parents generally felt lonely and abandoned by their partner, their child and clinical staff (Bezance & Holliday, 2014; McMahon et al., 2022; Robinson et al., 2020; Tuval-Mashiach et al., 2014). Tuval-Mashiach et al., (2014) suggested that most mothers particularly felt lonely because they could not count on their partners. Some believed that their partners could not manage their emotions, so it was easier to exclude them to protect themselves from becoming the carer of multiple family members, while some reported a lack of involvement from their partner (Tuval-Mashiach et al., 2014). Interestingly, even when fathers were involved in the care of their child, mothers continued feeling lonely (McMahon et al., 2022; Tuval-Mashiach et al., 2014). Moreover, most parents felt lonely for the loss of their bond with their child, which has been bruised through the secrecy, manipulation, and deception that anorexia nervosa had caused (Bezance & Holliday, 2014). Furthermore, most parents felt abandoned by clinical staff when they had to exclude them from treatment for confidential or clinical reasons (McMahon et al., 2022; Robinson et al., 2020; Tuval-Mashiach et al., 2014). Lastly, Whitney et al., (2005) indicated that mothers are more likely to react in an emotional way whereas fathers tend to be more cognitive and avoidant.

4. Discussion

The aim of this systematic review was to use the framework of the CSM to synthesise the qualitative literature on parents' cognitive and emotional illness representations when caring for a child with anorexia nervosa. As anticipated, the results were consistent with a threatening pattern of parents’ cognitive illness representations, characterised by a poor understanding of anorexia nervosa, viewing it as chronic, uncontrollable, severe, and associated with serious consequences. In terms of the causal perceptions of their child's illness, parents mostly blamed themselves for the development and maintenance of their child's condition. Additionally, parents reported experiencing threatening emotional representations of anorexia nervosa, including fear, anxiety, emotional distress, shame, guilt, loneliness, and depression.

The themes that emerged from parents' cognitive illness representations while caring for a child with anorexia nervosa align with both the literature on EDs and the CSM for other physical or mental health disorders (Fox et al., 2017; Kelada et al., 2021; Kuipers et al., 2007; Lo Sterzo & Orgeta, 2017; Scerri et al., 2019; Shanley & Reid, 2015). These findings suggest that parents may share a common pattern of cognitive illness representations when caring for a child with a complex disorder. This has important implications for the development of effective interventions to address parental distress and improve treatment outcomes. By understanding the common patterns of cognitive illness representations shared by parents, healthcare providers can develop tailored interventions that address parents' cognitions and improve their ability to support their child's recovery. Additionally, the tendency for parents to attribute self-blame to their causal perception of their child’s anorexia is consistent with the dominant qualitative literature, where mothers often feel responsible for their child’s wellbeing (Caplan, 1990; Hoskins & Lam, 2001). Addressing parental self-blame may be an important component of interventions to reduce psychological distress. However, this result was not found in the limited quantitative studies, where parents appeared to attribute the causes of anorexia to external factors such as stressful events in their child's life (Whitney et al., 2007). This inconsistency could be due to the methodology used, where parents may only report internal causes to their child's condition when interviewed qualitatively.

The themes discovered in the emotional illness representation were consistent with the qualitative literature, with parents reporting feeling emotionally distressed and burdened when caring for a child with ED (Fox et al., 2017). This reinforces the struggles that parents face and emphasises the importance of offering appropriate mental health support to them during this time.

4.1 Theoretical implications

The review has revealed that parents tend to hold a consistent perception of their child's anorexia nervosa as threatening. Previous studies using the CSM have shown that when parents perceive a child's illness as threatening, they tend to cope poorly and experience distress, ultimately impacting their ability to care for their child effectively and leading to poor treatment outcomes (Kelada et al., 2021; Kuipers et al., 2007; Lo Sterzo & Orgeta, 2017; Scerri et al., 2019; Shanley & Reid, 2015; Whitney et al., 2007). Therefore, it is important to further investigate whether the hypothesis and findings from previous research remain true in the context of caring for a child with anorexia nervosa. To achieve this, future research should use validated measures of illness representation and examine the impact of these representations on parents' coping strategies, psychological distress and health outcomes.

The study highlights the challenging thoughts and emotional processes that parents go through when dealing with their child's anorexia nervosa. As parental mental health is crucial to their child's recovery and family factors can maintain the condition, this research emphasises the importance of considering parents in both research and clinical practice related to anorexia nervosa.

4.2 Clinical implications

Clinicians need to be aware of these illness representations and incorporate them into their practice. Although parents play a crucial role in supporting their child with weight restoration through FBT (L. T. Williams et al., 2020; Wufong et al., 2019), there is currently no dedicated space within this treatment for parents to address their emotional distress in the context of caring for their child with anorexia nervosa. These results highlight the need for parents to have a space to cope with their range of negative emotions. Effective psychological therapy for this specific population is limited, but previous studies on other physical and mental health disorders have recommended Cognitive Behavioural Therapy (CBT) or Mindfulness-Based Cognitive Therapy (MBCT) to address threatening illness representations (Dalili & Bayazi, 2019; Lemos et al., 2020). These therapies focus on cognitive processes and help individuals develop more positive and accurate perceptions of illnesses (Dalili & Bayazi, 2019; Lemos et al., 2020). Future research could explore the potential of these therapies to shift parents' threatening perceptions to a less threatening one.

Furthermore, parents appear to have misconceptions about certain aspects of anorexia nervosa, including symptom recognition, understanding of consequences, causes, and management. Therefore, psychoeducation should target these specific areas to potentially shift their threatening perception of anorexia towards a more realistic one. If monitored and studied in the future, the impact of adapted psychoeducation on parental wellbeing could be evaluated.

Lastly, caregivers of children with anorexia nervosa, particularly mothers, reported feeling a strong sense of loneliness. Parental peer support has been found to alleviate this feeling (Binford Hopf et al., 2013; Grennan et al., 2022). Therefore, healthcare professionals should consider recommending or directing caregivers towards peer support resources in addition to treatment.

It is important to acknowledge that previous research has indicated a strong link between parental distress and the adoption of maladaptive coping strategies, ultimately impacting their child's recovery (Goddard et al., 2011; Graap et al., 2008; Sepulveda et al., 2009; Sepulveda et al., 2010). The purpose of this study is to investigate these parental cognitions within the context of their emotional distress. Therefore, it can be inferred that by reducing these perceptions and alleviating parental distress, the child's chances of recovery are likely to improve. However, it is essential to reevaluate this assumption and ensure that reducing threatening illness perceptions leads to enhanced coping strategies and better child recovery outcomes. The goal is not to eliminate the perceived threat entirely, as it is important for parents to maintain an awareness of the risks associated with anorexia nervosa. Instead, the aim is to achieve a realistic illness representation where parents are aware of the disorder's risks without feeling overwhelmed or compromised in their ability to manage their emotions and support their child's recovery.

4.3 Limitations and strengths

This is the first systematic review using the CSM studying parents' illness representations of their child with anorexia nervosa. However, the findings need to be interpreted carefully considering the number of limitations this review entails. First, the review only focused on peer-reviewed studies, which may have excluded relevant information from grey literature and introduced potential publication bias. Second, relying purely on the qualitative studies can be problematic as most studies have a small sample size making it difficult to generalise the final outcomes. Moreover, qualitative study designs may not enable further exploration of the interactions between the various dimensions of the CSM and their impact on health outcomes. This is unfortunate because it does not fully represent the capabilities of the CSM framework and limits the understanding of illness representation. Third, some studies overemphasise on certain dimensions (e.g., *control/cure, consequences, and emotional representation*), which may bias the outcomes. Fourth, there was a lack of diversity in the selected results (e.g., lack of fathers' engagements and exclusion of non-western countries) neglecting cultural and gender differences, which can impact on global perspectives of illness beliefs.

Despite these limitations, the findings presented in this review are robust for several reasons. Firstly, the inclusion of peer-reviewed empirical studies ensured that only studies with a rigorous research process and high-quality data were selected, allowing for objective and meaningful comparisons. This was reflected in the assessment of each study's quality using the CASP tool, where most studies were rated as "moderate to high" quality by the reviewers. Secondly, a moderate to high inter-rater validity was found by two independent reviewers, further reinforcing the quality of the included studies. Finally, using the "best-fit" approach allowed the exploration of the relevant data to address the main research question without being limited to the CSM framework.

5. Conclusion

This review synthesised previous qualitative research examining illness representations among parents caring for a child with anorexia nervosa within the framework of the CSM. The results suggested that parents held threatening cognitive and emotional illness representations, viewing their child's anorexia nervosa as uncontrollable, incomprehensible, chronic, and associated with negative consequences and emotions. These specific illness representations can inform the development of tailored psychoeducation, and promote the use of evidence-based psychological therapies such as CBT and MBCT for parents. Peer group support can also be helpful to address the isolation associated with these representations. By using validated measures, further studies could explore the relationship between threatening illness representations and health outcomes, including psychological distress, in more detail.

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Using the common-sense model to understand parents' illness representations of their child with an eating disorder: An empirical study

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Abstract

Previous research has suggested that the emotional burden experienced by parents caring for a child with an eating disorder (ED) is associated with poorer treatment outcomes (Goddard et al., 2011; Graap et al., 2008; Sepulveda et al., 2009). However, the specific factors contributing to this emotional burden have not been well understood or studied in a theoretical framework. As a result, previous research offers limited interpretation and meaningful suggestions for clinical practice. To address this gap, this cross-sectional study applies the common-sense model (CSM) to examine parents' unique illness perceptions, causal attributions, and how these illness perceptions impact their coping strategies, and psychological distress. The study used descriptive statistics to examine the profile of parents caring for a child with ED, a content analysis to capture their causal attributions of their child's ED, and partial correlations to investigate the relationship between illness representations, coping styles, and psychological distress. These statistical analyses demonstrated that parents tended to perceive their child's ED as a threatening illness with serious consequences, chronicity, severe symptoms, and negative emotions. On the one hand, parents also had a positive view towards the efficacy of treatment and their own capability to manage and comprehend the illness. Parents tended to attribute external factors to understand the causes of their child's ED. Furthermore, negative emotional illness representation of their child's ED was linked to psychological distress. On the other hand, a positive view of treatment was associated with dysfunctional coping and depression, while a better understanding of ED was linked to depression and stress. These findings suggest the need for tailored psychological therapies that address parents' illness perceptions with a particular emphasis on their emotional response, treatment effectiveness perception, and comprehension of ED to mitigate psychological distress among parents of children with ED.

Keywords: Illness perception, common-sense model, parents, coping, eating disorder, mental health

1. Introduction

Previous research has shown the utility of the Common-Sense Model (CSM, also known as the self-regulation model) for understanding how caregivers make sense of their child's illness, and how these mental representations influence parents' coping strategies, and treatment outcomes (Hagger et al., 2017; Leventhal et al., 2020). However, research has been slow to apply the CSM to parents of children with an eating disorder (ED). EDs are one of the most complex mental health conditions involving maladaptive eating behaviours, thoughts, and emotions (American Psychiatric Publishing, 2013; Yaffa et al., 2021). The onset of EDs often occurs in early adolescence, a moment in time where caregivers may play an important role in their children's life (Callio & Gustafsson, 2016; Micali et al., 2014). Previous research has established that a link exists between parental mental health and health outcomes, and that poor parental mental health may exacerbate disordered eating in their child (Goddard et al., 2011; Graap et al., 2008; Sepulveda et al., 2009). The objective of this study is to fill gaps in the knowledge of applying the CSM to examine the illness perceptions and causal attributions of parents caring for a child with ED.

Research indicates that parents struggle emotionally when supporting a child with ED (Fox et al., 2017). Parents experience a range of negative emotions such as stress, fear, depression, loneliness, helplessness, and guilt when supporting their child through their illness, and when realising the significant impact the illness has on their whole life (Cottee-Lane et al., 2004; Fletcher et al., 2021; Svensson et al., 2013; Thomson et al., 2014; Tuval-Mashiach et al., 2014; Whitney et al., 2005; E. P. Williams et al., 2020; L. T. Williams et al., 2020). Parents also face practical challenges in navigating the healthcare system, such as long waiting lists and accessing appropriate services (Coelho et al., 2021; Robinson et al., 2020). Parental mental health has been shown to suffer when caring for a child with ED, more so than when caring for a child with other mental health conditions such as schizophrenia (Highet et al., 2005). This reinforces the importance of focusing on parental mental health in the context of ED to capture their unique experience.

Research has demonstrated a link between parental distress and treatment outcomes of children with EDs. For instance, one study found that parental trauma was associated with a delay for adolescents with anorexia nervosa reaching a healthy weight range (Timko et al., 2022). Another study found that parental anxiety was linked to the maintenance of ED by accommodating unhelpful behaviours such as skipping a meal (Goddard et al., 2011; Graap et al., 2008; Sepulveda et al., 2009). These findings suggest that poor parental mental health may lead to worse treatment outcomes. Despite the relevance of parental distress to their child's recovery, the factors contributing to this distress remain unknown. It is imperative to utilise a theoretical model to comprehensively understand the relationship between the factors leading to parental distress, the distress itself, and the subsequent treatment outcomes that are indirectly impacted by it.

The CSM is a theoretical framework that suggests the way individuals understand and make sense of their health condition, or their child's illness can impact their coping mechanisms, emotions, and behaviours, ultimately affecting their health outcomes, such as recovery (Hagger et al., 2017; Leventhal et al., 2020). When referring to "making sense of their illness," the CSM is referring to the cognitive and emotional representations that individuals have about their child's condition (Hagger et al., 2017; Leventhal et al., 2020). The CSM proposes that these cognitive and emotional representations of illness are formed by both internal factors, such as personal knowledge and beliefs, and external factors, such as knowledge and communication received from healthcare providers and family members (Hagger & Orbell, 2003, 2022).The cognitive component represents how individuals perceive a health threat, by analysing the *identity* (e.g., symptoms), *coherence* (e.g., understanding)*, causes* (e.g., biological, psychological), *timeline* (e.g., acute, chronic), *consequences* (e.g., work, family), *personal control* (e.g., the level of control parents believe have over the illness) *and treatment or cure control* (e.g., the perception of the treatment's effectiveness in curing the illness) (Leventhal et al., 1980; Leventhal et al., 2020; Moss-Morris et al., 2002). The emotional component refers to individuals' insight and emotional responses when confronted with this health threat (Hagger & Orbell, 2003; Moss-Morris et al., 2002). This can include a range of feelings such as anger, fear, optimism, and empowerment (Hagger et al., 2017; Hagger & Orbell, 2003; Moss-Morris et al., 2002). Previous studies on the CSM proposed that individuals with a threatening view of an illness are less likely to cope and more likely to experience poorer health outcomes (Kelada et al., 2021; Kuipers et al., 2007; Lo Sterzo & Orgeta, 2017; Scerri et al., 2019; Shanley & Reid, 2015). The CSM defines a threatening view of illness as one with severe symptoms, a poor understanding of the disease, chronicity, serious consequences and a lack of control over managing the illness (Hagger et al., 2017; Moss-Morris et al., 2002). Moreover, a threatening view of illness is also associated with negative emotions such as depression and anxiety (Hagger et al., 2017; Moss-Morris et al., 2002). Rather than adopting a dichotomy of threatening versus non-threatening, causal attribution has been conceptualised and investigated in various ways, including internal versus external causes, as well as biological, psychological, or social explanations depending on the specific context (Hagger & Orbell, 2017; Moss-Morris et al., 2002). Although parental illness representations are likely to be useful knowledge to understand parental psychological distress, and to facilitate successful interventions, there is a lack of research looking at the role of parents' perceptions of caring for a child with ED on illness management.

Previous research on parental illness perceptions when caring for a child with ED has primarily utilised qualitative designs and found consistent patterns of threatening illness perceptions, with parents often feeling responsible for their child's ED (Cottee-Lane et al., 2004; Engman-Bredvik et al., 2016; Hoskins & Lam, 2001; McMahon et al., 2022; O'Dwyer, 2021; Svensson et al., 2013; Tuval-Mashiach et al., 2014; Whitney et al., 2005). However, these studies have lacked a theoretical framework, making it challenging to interpret and apply the findings in a clinical setting (Fox et al., 2017). Although limited quantitative studies have demonstrated that a threatening illness representation is associated with poorer outcomes in the context of anorexia nervosa (Matthews et al., 2018; Sim & Matthews, 2013; Whitney et al., 2007), these studies have mainly focused on cognitive illness representations and have neglected the role of emotional illness representation and coping strategies, which are crucial in understanding health outcomes such as parental psychological distress (Hagger et al., 2017; Hagger & Orbell, 2003; Moss-Morris et al., 2002). Moreover, some quantitative studies have suggested that parents attribute ED to their child's social circumstances or personality, contributing to their distress (Whitney et al., 2007). Nevertheless, no study has examined the entire CSM framework, which includes both emotional and cognitive illness perceptions, parental attributions of their child’s illness, coping strategies, and health outcomes, such as parental psychological distress, in the context of caring for a child with ED. This study aims to address this gap.

In summary, applying the CSM framework in the context of parents providing care for a child with ED may provide an important path of investigation to gain understanding into the extent to which parental illness perceptions contribute to parental distress. This is particularly relevant given that previous studies have highlighted that poor mental health outcomes in parents have been associated with poorer treatment outcomes for their children, including recovery. Moreover, the qualitative literature has highlighted that parents experience emotional difficulties when caring for a child with ED, reinforcing the significance of this line of research. While limited quantitative studies in the context of caring for a child with ED have suggested a possible link between illness perception and parental distress, no investigations have comprehensively examined the complete CSM to clarify how parental illness perceptions, at both cognitive and emotional levels, influence their coping strategies and subsequent distress. Without using a full, clear and validated theoretical framework, clinical recommendations cannot be meaningfully provided.

1.1 Aims and research questions

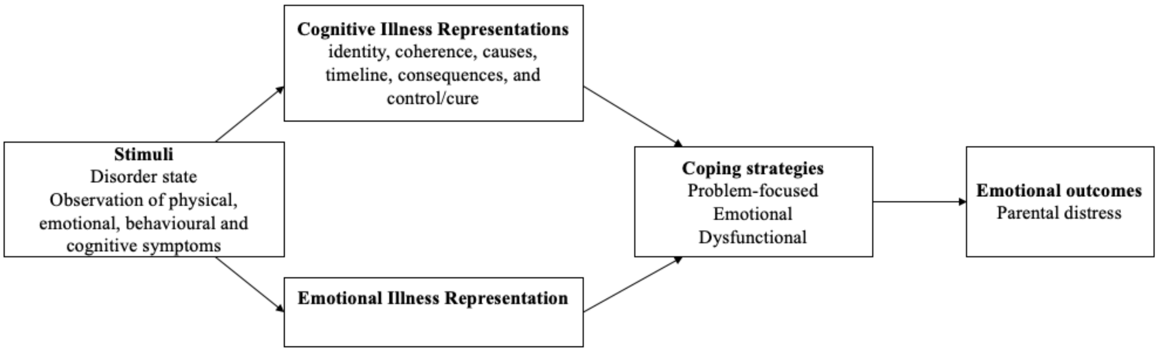
The first aim is to examine the causal attributions of parents caring for a child with ED. The second and final aim is to investigate whether parents' illness representations are associated with how parents cope with having a child with ED and their mental health. The purpose of this study is to provide insight and help improve clinical interventions for families dealing with a child with ED. The following research questions will be analysed:

1) Parents will have threatening cognitive and emotional illness representations
2) Parents will blame themselves for their child's ED.
3) A higher level of threatening cognitive and emotional illness representations in parents will be positively associated with a dysfunctional coping style and psychological distress.

The CSM diagram is often used to provide clarity on the CSM process, and it is commonly adapted to align with specific research related to the CSM (Diefenbach & Leventhal, 1996; Hagger et al., 2017; Leventhal et al., 1980). Previous research using the CSM model predominantly examined the path from illness representation to coping strategies or health outcomes, such as psychological distress (Knowles et al., 2020; Quiles & Terol, 2011). Consequently, this present study will align with this direction to conduct further exploration of the relationship. Figure 1 illustrates a revised version of the CSM's diagram, aimed at enhancing the understanding of the second research question.

Figure 1

Revised diagram based on the common-sense model



2. Methods

2.1 Study design

The current study entails a cross-sectional research design. A questionnaire battery was developed to record demographic information on parents and their children (Appendix H). Standardised questionnaires were used to assess illness perceptions, coping strategies, and psychological distress in parents with, and without, a child with ED (Appendices I, J, K, L). The software Qualtrics XM was used to create, share, and collect the responses from the survey. Ethics approval was obtained from an NHS Research Ethics Committee (REC; 21/YH/0287) and the University of Edinburgh's School of Health and Social Sciences ethics committee. Furthermore, this study was reviewed by The Clinical Studies Oversight Group (COG) within the Grampian NHS health board and approved by the Grampian NHS Research and Development (R&D). These approvals were required to recruit and access the data of the clinical and control samples (Appendices C, D, E).

2.2 Participants and Recruitment

This study recruited participants consisting of parents who had a child aged 12-18 years with ED and were recruited from the Child and Adolescent Mental Health Service (CAMHS) unit of National Health Service (NHS) Grampian in Aberdeen. The lead researcher (DM) presented the study to clinicians, who were asked to identify parents who meet the inclusion criteria. Clinicians were provided with the Participant Information Sheet (PIS) to facilitate their understanding and support appropriate recruitment (see appendix F). Clinicians who identified parents potentially eligible for the study provided parents with the PIS. Clinicians were informed that if participants had further questions, these questions could be directed to the lead researcher. Contact details of the lead researcher were provided in the PIS. Potential participants found a link to a survey on the PIS to take part in the study. The link contained a digital copy of the PIS, demographic questionnaires and four standardised questionnaires addressing the research questions. Written instructions as to how to fill in the questionnaires were clarified above each questionnaire. Participation was entirely voluntary, as stated in the PIS, and it was explicitly stated that participation, or lack thereof, will not impact on clinical care. The survey was completed online by the participant to ensure anonymity. Participants were asked to complete the questionnaires thinking about the beginning of their treatment to improve the accuracy of the data. It is noteworthy that all participants in the study had been offered family-based treatment (FBT) as part of their treatment plan. A total of 157 eligible parents who have attended the clinic between 2018 until 2023 were contacted. Of these, 109 parents expressed interest and completed the questionnaires required for participation. Subsequently, 14 participants were excluded from the study due to incomplete questionnaire responses. Consequently, the final clinical sample group consisted of 95 participants.

Table 1 presents an overview of the demographic characteristics of the clinical (n = 95) sample. The majority of participants were white mothers (66.3%) aged between 45 to 54 years (57.9%). More than half of the parents were married (73.7%), university educated (50.5%) and working full time (58.9%). Most parents did not have any pre-existing mental health diagnoses (92.6%). In terms of gender and age, most parents were caring for a daughter (88.4%) falling within the age range of 14 to 15 years old (49.5%). Whilst the inclusion criteria for the clinical sample was to support a child with any type of ED, most children in the clinical group had a diagnosis of anorexia nervosa (83.2%) and were outpatients.

Table 1

Sample characteristics

	Parents			Child	
	Count	N %		Count	N %
Age			Age		
25-34	4	4.2%	12-13	33	34.7%
35-44	23	24.2%	14-15	47	49.5%
45-54	55	57.9%	16-17	10	10.5%
55-64	13	13.7%	18	5	5.3%
Gender			Gender		
Male	32	33.7%	Male	11	11.6%
Female	63	66.3%	Female	84	88.4%
Ethnicity			ED		
White	92	96.8%	AN	79	83.2%
Asian	0	0%	BN	2	2.1%
Black	0	0%	OSFED	6	6.3%
Arab	2	2.1%	Mixed	5	5.3%
Other	1	1.1%	Other	3	3.2%
Education			N/A	0	0%
Secondary	14	14.7%	EQE-QS	**N**	**Mean (SD)**

Professional	31	32.6%
University	48	50.5%
Other	2	2.1%
Marital status		
Married	70	73.7%
Single with partner	14	14.7%
Single without partner	6	6.3%
Divorced	4	4.2%
Other	1	1.1%
Employment		
Student	1	1.1%
Carer	3	3.2%
Part-time	25	26.3%
Full-time	56	58.9%
Unemployed	5	5.3%
Other	5	5.3%
Mental health		
Yes	7	7.4%
No	88	92.6%

95	23.65 (9.24)

Note. ED = eating disorder; AN = anorexia nervosa; BN = bulimia nervosa; BED = binge eating disorder; OSFED = other specified feeding or eating disorders; EDE-QS = eating disorder examination questionnaire - short

2.3 Power calculation

The G*Power was the software tool used to determine the appropriate sample size for the different statistical tests (Erdfelder et al., 1996; Faul et al., 2007). For the partial correlation analysis, the exact bivariate model normal model with an effect size of 0.3, a significance level at 0.05 and a power of 0.80 was used. The G*power software tool suggested a sample size of at least 84 participants for the clinical sample to detect moderate correlations between the predictor and outcome variables.

2.4 Measures

Validated and reliable measures in shorter formats were selected to reduce participant burden and improve the likelihood of questionnaire completion.

2.4.1 *Demographic information*

The questionnaire battery included items to gather demographic information about parents (e.g., age, gender, ethnicity, educational level, marital status, employment status, mental health diagnosis) and about their child (e.g., age, gender, type of ED; see Appendix H).

2.4.2 Brief illness Perceptions Questionnaire (Brief IPQ)

The Brief IPQ is a brief version of the original Revised Illness Perception Questionnaire (IPQ-R), which is based on the CSM and assesses individuals' cognitive and emotional illness representations about an illness (Appendix I; Broadbent et al., 2006; Moss-Morris et al., 2002). It includes nine questions assessing each dimension of illness representation (Broadbent et al., 2006). The cognitive illness representations are measured by seven questions reflecting the dimensions of c*onsequences, timeline, personal control, treatment control, identity, and coherence*. The emotional illness representation is based on two questions, which consisted of individuals' *concerns*, which related the worries regarding the illness and emotional illness representation. Each question was rated on a 0-10 scale. A higher score on the dimension of *consequences, timeline, identity, concern and emotional* and a lower (or reverse) score on the domains of *personal control, treatment control and illness coherence* indicate a threatening perception of the illness (Kelada et al., 2021; Lo Sterzo & Orgeta, 2017; Norfazilah et al., 2013). The total score can vary between 0 and 80 where a higher score represents a more threatening perception of the illness (Cheng et al., 2020). The causal representation is an open question asking participants to rank the three most important causes of their child's disorder. Response to this question can be analysed into categories such as internal (e.g., self-blame) and external causes (e.g., blaming social circumstances) (Broadbent et al., 2006, Nelson et al., 2009). Based on previous studies, the brief IPQ has been adapted for caregivers and eating disorders by addressing each question to caregivers and by replacing the word "illness" with "ED" (Lo Sterzo & Orgeta, 2017, Matthews et al., 2018). Previous research has established the brief IPQ to be valid and reliable ($\alpha = 0.85$) (Karatas et al., 2017). However, the current dataset in this study demonstrates only moderate consistency reliability for internal validity ($\alpha = 0.60$).

2.4.3 Brief Coping Orientation to Problems Experienced (Brief COPE)

The Brief COPE is a shorter version of the COPE inventory, designed to measure coping styles (Appendix J; Carver, 1997). It includes 28 questions (or 14 two-item subscale) assessing three categories of coping styles: problem-focused (active planning, planning, use of instrumental support), emotional (use of emotional support, positive reframing, acceptance, religion, humour) and dysfunctional (venting, denial, substance use, behavioural disengagement, self-distraction, self-blame) (Coolidgeet al., 2000; Cooper et al., 2008). Each question is rated on a Likert scale ranging from 1 (“I have not been doing this at all”) to 4 (“I have been doing this a lot”). A higher score in each subscale reflects a higher use of the coping styles studied (Snell et al., 2011). Although previous studies have established the Brief COPE as a valid and reliable instrument (Cronbach's alpha values ranging from 0.50 to 0.90) (Coomber & King, 2013), the current study demonstrated even higher internal validity. Specifically, the whole questionnaire demonstrated high internal consistency ($\alpha = 0.92$), as did the problem-focused coping ($\alpha = 0.93$), emotional coping ($\alpha = 0.81$), and dysfunctional coping ($\alpha = 0.76$) categories.

2.4.4 Depression, Anxiety and Stress Scale (DASS)

The DASS-21 is a measure of psychological distress, commonly used in medical and psychological research (Appendix K; Anthony et al., 1998; Lovibond & Lovibond, 1995). It is a brief modified version from the original DASS-42 questionnaire (Lovibond & Lovibond, 1995). The DASS-21 is based on 21 questions measuring the severity and frequency of depression, anxiety, and stress (Anthony et al., 1998). Each item is scored on a Likert scale from 0 (“Did not apply to me at all”) to 3 (“Applied to me very much, or most of the time”) (Norton, 2017). A higher score reflects a higher level of psychological distress (Fox et al., 2018). Monteleone et al., (2023) reported high reliability of the DASS-21 with Cronbach's alpha values of 0.90 and 0.83 for the depression and anxiety subscales, respectively. In this study, the internal validity was also high, with an overall Cronbach's alpha of 0.95, and similar values for the subscales of depression ($\alpha = 0.89$), anxiety ($\alpha = 0.81$), and stress ($\alpha = 0.91$).

2.4.5 Eating Disorder Examination Questionnaire - Short (EDE-QS)

The EDE-QS is a 12-item self-report questionnaire adapted from the original EDE-Q for measuring the severity of eating disorder (ED) symptoms over the past week (Appendix L; Fairburn et al., 1993; Gideon et al., 2016). Each item is based on a scale from 0 (0 days) to 3 (6-7 days) reflecting the frequency and the severity of the cognitive and behavioural eating symptoms (Steinberg et al., 2023). The total score can vary from 0 to 36 where higher scores indicate a more severe presentation of disordered eating pathology (Steinberg et al., 2023). The EDE-QS has been adapted to caregivers by replacing the word “you” to “your child” (Lydecker & Grilo, 2017). The EDE-Q was established as a valid and reliable tool with a high internal validity ($\alpha = 0.91$) (Gideon et al., 2016). In this study, the internal validity was similarly high ($\alpha = 0.95$).

2.5 Data analysis

Data were analysed with IBM SPSS (version 27). To address the first research question, descriptive statistics including mean scores and standard deviation were utilised to examine parental cognitive and emotional representations. In keeping with previous research, the score in the *coherence, personal* and *treatment control* subscales of the illness representations were reversed to ease the calculation of illness perception (Norfazilah et al., 2013; Schwartz et al., 2020). Therefore, a higher score of the overall subscales reflects a more threatening view of the illness (Norfazilah et al., 2013; Schwartz et al., 2020).

To investigate the second research question, an initial deductive approach was employed by utilising themes from the systematic review associated with this doctoral thesis (Marchetti & Sawrikar, 2023). A content analysis was conducted using the Hsieh & Shannon (2005) framework, where the data was repeatedly reviewed to become familiar with it, coded, and categorised according to research questions. Based on the systematic review, three categories were identified to explain parental causal attributions for their child's eating disorder: parent referent attributions (e.g., self-blame), child referent attributions (e.g., blaming the child's personality or genes), and external causes (e.g., stressful events). Within each category, an inductive approach was used to identify further categories that were not predetermined within the dataset in the systematic review (e.g., adding social media to external causes) (Harwood & Garry, 2003; Hsieh & Shannon, 2005). The coding process was undertaken independently by two coders (annotated as DM & AP). To ensure the validity and reliability of the analysis, the Cohen's kappa coefficient was calculated. Any discrepancies or disagreements between the coders were resolved through discussion.

To address the last research question, in the clinical sample, a partial correlation procedure was computed to examine the unique relationship between (i) the different dimensions of parental cognitive and emotional illness perceptions and the dimensions of coping strategies (problem-focused, emotional, dysfunctional), and (ii) the different dimensions of parental cognitive and emotional illness perceptions and parental psychological distress measured in relation to depression, anxiety and stress. In each partial correlation analysis, covariates such as parental and child demographic information, as well as the other subscales of illness perceptions, were included to account for potential confounding variables. The inclusion of demographic information as covariates is based on research indicating that parental demographics can influence their perceptions and responses to their child's illness. For example, a study by Whitney et al. (2005) found that mothers are more prone to emotional reactions, while fathers tend to exhibit more cognitive responses and avoidance tendencies when caring for a child with ED. Similarly, child demographics may also influence parental responses. Karlstad et al. (2021) found that parents may experience greater distress when caring for an older child or when dealing with a chronic presentation of the ED. Including the subscales of illness perceptions is aligned with previous research in the context of the CSM (Mereuta & Craciun, 2009). By incorporating all of these covariates, potential confounding variables can be effectively controlled for. As a result, each partial correlation represents the unique association between different dimensions of parental cognitive and emotional illness perceptions and outcomes related to coping and psychological distress.

3. Results

3.1 Descriptive statistics

Table 2 indicated that parents caring for a child with ED demonstrated higher mean scores, indicating a more threatening perception of their child's ED across multiple subscales. Specifically, higher mean scores were observed in the consequences (M = 9.76, SD = 1.62), concern (M = 8.95, SD = 1.84), emotional illness representation (M = 8.86, SD = 1.35), identity (M = 8.13, SD = 1.90), personal control (M = 7.31, SD = 2.41) and timeline subscales (M = 6.83, SD = 2.55). Conversely, the subscales of treatment (M = 2.99, SD = 2.52) and coherence (M = 4.44, SD = 3.03) reflected a relatively less threatening or more positive perception among the parents. Therefore, these findings partially support the research hypothesis, as not all subscales were found to be threatening, with the exceptions of the treatment and coherence subscales.

Table 2

Descriptive statistics - IBQ

IPQ subscales	Mean	*SD*
Personal control	7.31	2.41
Treatment control	2.99	2.52
Coherence	4.44	3.03
Consequences	9.76	1.62

Timeline	6.83	2.55
Identity	8.13	1.90
Concern	8.95	1.84
Emotional illness representation	8.86	1.35

Note. IPQ = illness perception questionnaire

3.2 Causal attributions

Table 3 presents the most frequent perceived causal factors attributed by parents caring for a child with ED. The majority of parents (67%) perceived the causes of their child's ED to be external factors such as school-related factors (n = 31, 14.90%), being the most common, followed by the impact of covid-19 (n = 30, 14.42%), social media (n = 22, 10.58%), life situations (n = 21, 10.10%), family issues (n = 21, 10.10%), unknown causes (n = 11, 5.29%) and parental divorce (n = 3, 1.44%). On the other hand, 33% attributed ED to their child's mental health difficulties (n = 53, 25.48%), as well as their child's genetic predispositions (n = 16, 7.69%). There were no reported factors related to parental attributions. The inter-rater reliability was determined using the Cohen's Kappa (κ) coefficient (McHugh, 2012). The two reviewers (DM and AP) demonstrated perfect agreement (100%) in assigning themes to the pre-established categories (κ = 1). For a detailed calculation, please see Appendix N.

Table 3

Frequency (%) of causal attributions made by clinical sample

External causes		N	%
	School	31	14.90%
	Covid-19	30	14.42%
	Social media	22	10.58%
	Life situations	21	10.10%
	Family problems	21	10.10%
	Unknown	11	5.29%
	Parental divorce	3	1.44%
Child referent attributions		N	%
	My child's mental health	53	25.48%
	My child's genes	16	7.69%

3.3 Partial correlation between illness representations, coping strategies, and psychological distress

To assess the robustness of the partial correlation analysis, Shapiro-Wilk tests were employed, revealing that the continuous data derived from the illness perception questionnaire among the clinical sample, consisting of eight sub-variables, were non-normally distributed ($p = <0.05$). However, the central limit theorem indicates that the partial correlation analysis is tolerant of normality assumption violations (Kwak & Kim, 2017). This theorem postulates that if a sufficiently large sample is drawn from a population, the sample means will be normally distributed, regardless of the population distribution. Consequently, the partial correlation analysis can be implemented even if the normality assumption is not satisfied.

The results for the partial correlation analysis demonstrated a positive correlation between a threatening emotional illness representation and psychological distress (Table 4). Specifically, moderate correlations were found with depression ($r = 0.368$, $p < 0.001$), and anxiety ($r = 0.387$, $p < 0.001$), while a strong correlation was found with stress ($r = 0.517$, $p < 0.001$). However, when controlling for covariates, these correlations became weaker. Only a positive moderate correlation with anxiety ($r_{\text{child, parent demographics, IPQ}} = 0.360$, $p < 0.001$) and stress ($r_{\text{child, parent demographics, IPQ}} = 0.436$, $p < 0.001$) remained, while a weak correlation was found for depression ($r_{\text{child, parent demographics, IPQ}} = 0.281$, $p < 0.05$). On the other hand, no significant relationship was observed between emotional illness representation and coping style. These results show that the emotional illness representation is partially in line with the second hypothesis as it is linked to psychological distress, but not coping style.

In contrast to the main hypothesis, the analysis did not reveal any positive correlation between a threatening cognitive illness perception and coping styles or psychological distress. However, there was a moderate correlation observed between a more positive perception of *treatment* and dysfunctional coping ($r = 0.348$, $p = 0.001$) and depression ($r = 0.311$, $p < 0.05$). It is important to note that when controlling for covariates, this relationship weakened. Additionally, there was a moderate correlation found between a positive perception of *coherence* and depression ($r = 0.336$, $p = 0.001$) and stress ($r = 0.313$, $p < 0.05$). Another interesting finding was related to the *personal control* subscale. While no significant correlations were found, a moderate negative relationship was observed between a positive view of personal control and dysfunctional coping, when controlling for the covariates. This indicates that perceiving a higher sense of *personal control* is associated with a decrease in maladaptive coping strategies. It is noteworthy that the remaining variables either had no or small correlation with each other. Therefore, the results contradict the second hypothesis by revealing a relationship between a positive perception of *treatment* and *coherence* with psychological distress and dysfunctional coping.

Table 4

Zero order correlations analysis between IPQ, coping styles and psychological distress.

Zero order correlations	Emotional coping	Problem solving coping	Dysfunctional coping	Depression	Anxiety	Stress
Personal control	-0.167	-0.072	-0.153	0.033	-0.028	-0.017
Treatment control	-0.077	0.057	0.348**	0.311**	0.152	0.299*
Coherence	0.031	-0.087	0.227*	0.336**	0.264**	0.313**
Consequences	0.086	-0.008	0.037	0.193	0.147	0.249*
Timeline	-0.070	0.041	0.152	0.235*	0.093	0.259*
Identity	-0.079	-0.109	-0.275**	0.080	0.034	0.058
Concern	0.064	0.120	-0.013	0.228*	0.159	0.283*
Emotional illness representation	0.111	0.176	0.084	0.368**	0.387**	0.517**

Table 5

Partial order correlations analysis between IPQ, coping styles and psychological distress.

Partial order correlations	Emotional coping	Problem solving coping	Dysfunctional coping	Depression	Anxiety	Stress
Personal control	-0.261*	-0.121	-0.310*	-0.195	-0.158	-0.280*
Treatment control	-0.080	0.052	0.277*	0.223*	0.082	0.290*
Coherence	0.011	-0.105	0.222	0.323*	0.183	0.316*
Consequences	0.218*	0.056	0.094	0.023	0.020	-0.037
Timeline	-0.254*	-0.137	-0.001	0.164	-0.022	0.206
Identity	-0.278*	-0.220*	-0.238*	0.011	-0.095	-0.131
Concern	0.198	0.209	0.094	0.055	0.029	0.102

Emotional illness representation	0.124	0.121	0.194	0.281*	0.360**	0.436**

Note. ED = eating disorder; IPQ = illness perception questionnaire
*p value <0.05
** p value <0.01

4. Discussion

This study used the CSM model to explore parental distress in the context of caring for a child with ED, which has not been done in previous research. Prior research has consistently reported emotional burden in parents, which can adversely affect their child's treatment outcomes, including recovery (Goddard et al., 2011; Graap et al., 2008; Sepulveda et al., 2009). However, previous studies have lacked a robust theoretical model, which limits the strengths of their findings. Thus, this study seeks to comprehend the mechanism underlying parental distress by first investigating parental illness perceptions in this specific population, examining their causal attributions, and finally applying the full CSM model to explore the impact of illness representations on coping strategies and psychological distress.

The results of the study are partially consistent with the first hypothesis that parents caring for a child with ED would have cognitive and emotional threatening illness perceptions. More specifically, parents had higher mean scores in c*onsequences, concern, emotional, identity, personal control and timeline* subscales, indicating a more threatening view. This finding is consistent with the first hypothesis and previous literature that has shown parents caring for a child with ED have more threatening illness perceptions, even when compared to those caring for children with other physical or mental health conditions (Highet et al., 2005). Interestingly, mean scores were significantly lower in *treatment control, and coherence* subscales, indicating less threatening views. These results contradict the first hypothesis and are inconsistent with previous literature (Matthews et al., 2018; Sim & Matthews, 2013; Whitney et al., 2007). However, these inconsistencies may be interpreted in the context that all families had already started their treatment and might have received psychoeducation about ED. Moreover, illness representations may change over the course of the illness (Christensen et al., 2015; Fischer et al., 2013). Thus, the perceptions of ED among the participants may have already shifted due to treatment.

Previous research has produced conflicting results regarding parental attributions for their child's ED, with a large body of qualitative evidence suggesting self-blame (Cottee-Lane et al., 2004; Engman-Bredvik et al., 2016; Hoskins & Lam, 2001; McMahon et al., 2022; O'Dwyer, 2021; Svensson et al., 2013; Tuval-Mashiach et al., 2014; Whitney et al., 2005), while limited quantitative research suggests blame on the child or external factors (Whitney et al., 2007). Contrary to the second hypothesis and the qualitative evidence, the current findings suggest that parents generally attribute the cause of their child's ED to external factors or their child rather than themselves. It is worth noting that the patterns of parental explanations reported across different studies vary, which may be attributed to differences in methodology and context. For instance, when qualitative interviews were used, a pattern of parental self-blame was apparent, while when questionnaires with open questions were used, parents seemed to be reporting more external causes to their child's conditions. Moreover, these differences can be explained by the possibility that attributions can shift over time, such as when starting treatment (Christensen et al., 2015; Fischer et al., 2013). Furthermore, previous research on parents of children with attention deficit hyperactivity disorder (ADHD) has also demonstrated a tendency to attribute the causes of their child's illness to external factors (Johnston & Mash, 2001). This pattern aligns with the predictions of attribution theory, which proposes that people often attribute negative events to external factors to protect their self-esteem and sense of control, providing temporary relief (Sawrikar & Dadds, 2018). Nevertheless, externalising blame may lead to feelings of powerlessness (Sawrikar & Dadds, 2018), which corresponds to the distressing emotional representation reported by the parents in this study.

The partial correlation analysis found that parents' threatening emotional illness perception of their child's ED was linked to psychological distress, but not a dysfunctional coping style. However, the threatening cognitive illness perceptions were not associated with a dysfunctional coping style or psychological distress. Unexpectedly, the results revealed that when parents perceived treatment as effective and understood the complexity of ED, they were more likely to experience psychological distress. Additionally, perceiving the treatment as effective was linked to a dysfunctional coping style. The findings that parents hold a threatening emotional representation of their child's ED and the correlation found between a threatening emotional perception, and psychological distress has been demonstrated in previous research (Matthews et al., 2018; Sim & Matthews, 2013; Whitney et al., 2007). These results highlight the persistent emotional suffering experienced by parents in the context of their child's ED. Furthermore, the assumption that a relationship exists between threatening cognitive illness representations and poorer health outcomes such as unhelpful coping styles and psychological distress was not met in this current study. Importantly, the results show that a less threatening or a more positive view of treatment was linked to a dysfunctional coping style, and depression whilst a better understanding of ED was associated with depression and stress. Even though the majority of research on the CSM has demonstrated that a highly threatening view of illness predicts poorer outcomes, some studies have found that a positive view of illness may also lead to poorer outcomes. According to de Ridder et al., (2000), maintaining a realistic perception of illness is important, as overly positive, or threatening perceptions may be associated with poorer treatment outcomes, such as avoidance. For instance, a study on smoking found that a misplaced optimism might be associated with an underestimation of risk maintaining the symptoms of the disorder (Dillard et al., 2006). This might explain why a positive view of *treatment* and *coherence* is correlated to psychological distress and dysfunctional coping style. Consistent with previous research, the findings suggest that there is minimal correlation between the illness dimensions and coping strategies (Gould et al., 2010; Quiles & Terol, 2011). This accentuates the meaningful relationship between illness perception and psychological distress, rather than coping style.

3.1 Theoretical and clinical implications

This is the first study to apply the CSM to parents caring for a child with ED, finding a link between positive cognitive illness perceptions and dysfunctional coping style and psychological distress, as well as a link between negative emotional representation and parental psychological distress. These findings demonstrated that the CSM can be applied to this specific population, providing insight into how parents perceive and cope with their child's ED, and could inform future research and interventions aimed at improving parental coping and psychological wellbeing.

It is recommended that future research in this field should aim to investigate the generalisability of the findings by examining longitudinal changes in illness perceptions over time and across different settings. It is important to highlight that the participants in this study had already started FBT which involves active parental involvement in the treatment process and comprehensive psychoeducation regarding the nature of the disorder, as well as its short and long-term physical and psychological consequences (Lock & Le Grange, 2001). Initially, parents take responsibility for their child's meals to ensure weight restoration, gradually transitioning this responsibility to the child over time (Lock & Le Grange, 2015). FBT also addresses the issue of blame by encouraging parents to externalise anorexia nervosa, assisting them in differentiating their child from the illness and managing any self-blame or guilt they might experience (Lock & Le Grange, 2015). Therefore, the absence of threatening views regarding their child's ED in this study may be attributed to the commencement of FBT. It would be interesting for future studies to examine whether illness perceptions change with FBT and assess their perceptions before and after treatment. Additionally, it is essential to replicate this study, as it is the first to demonstrate a relationship between positive illness representations and dysfunctional coping style and psychological distress. In addition, exploring the role of parental attributions could be beneficial for future research, as there appears to be an inconsistency between the qualitative and quantitative literature regarding this topic. Investigating the impact of parental attributions on treatment outcomes and how they change with treatment could also provide valuable insights. Furthermore, it is recommended that future research examine relevant health outcomes such as attendance and recovery to better understand the link between illness representations and health outcomes, as this study and previous research have shown that this link is not necessarily with coping strategies (Gould et al., 2010; Quiles & Terol, 2011).

Despite the potential role of FBT in shifting some threatening perceptions, there are still issues regarding emotional illness perceptions, positive perceptions of treatment (*treatment control*), and understanding of ED (*coherence*), which are associated with parental psychological distress. Therefore, FBT alone may not be sufficient to alleviate psychological distress and dysfunctional coping strategies. Previous research on physical health disorders suggests that incorporating Cognitive-Behavioral Therapy (CBT) or Mindfulness-Based Cognitive Therapy (MBCT) may be effective in modifying illness perceptions and reducing psychological distress (Dalili et al., 2019; Lemos et al., 2020). While FBT and psychoeducation about ED are currently utilised in the treatment of children with ED, there is a need for dedicated spaces for parents to explore their thoughts, emotions, and behaviours (L. T. Williams et al., 2020; Wufong et al., 2019). Clinicians should provide a reflective space for parents to assess, monitor, and modify their illness representations, particularly targeting emotional illness perceptions, confidence in the effectiveness of treatment (*treatment control*), and understanding of ED (*coherence*), through clinical interventions. However, it is crucial to validate these psychological approaches before implementing personalised parental interventions to address cognitive and emotional illness representations, ensuring that they effectively reduce parental distress and maladaptive coping strategies while also considering the potential impact on their child's recovery.

3.2 Limitations and strengths

While this study provides valuable insights into the illness representations, coping strategies, and psychological distress of parents supporting a child with ED, there are several limitations that should be acknowledged. First, the cross-sectional nature of the study means that longitudinal and causal relationships cannot be established. Second, the lack of diversity in the sample, consisting mainly of white, educated mothers caring for outpatient children with anorexia nervosa, limits the generalizability of the findings to other populations. Third, the use of recall cues may have influenced the accuracy of the responses, as all participants were instructed to complete the questionnaire while recalling the beginning of their child's treatment. Fourth, the unequal sample size between the control and clinical groups may have biased the results of the first hypothesis, as the clinical group may have had a more significant impact on the overall findings. Fifth, the voluntary participation of individuals may have introduced social desirability bias, limiting the extent to which participants were honest in their responses. Overall, these limitations suggest the need for further research to confirm and expand upon these findings in more diverse populations and using more robust study designs.

Despite the limitations of this study, there are several strengths that should be highlighted. Firstly, this study is novel as it is the first study that aims to investigate the relationships between illness perception, coping styles, and psychological distress in parents of children with EDs. Additionally, this is the first study to include a control group, which helps to identify the unique needs of parents caring for children with EDs. Importantly, the study was appropriately powered ensuring that the conclusions drawn from it are well-founded.

Furthermore, this study used recommended and standardised questionnaires to measure illness perception, coping styles, and psychological distress, which increase the validity of the reliability of these current results. Moreover, all parents were asked to complete the questionnaires recalling the beginning of their child's treatment, which helps with objective comparisons. Identifying and addressing these perceptions could help to improve the wellbeing of parents and, in turn, the recovery of their children. Overall, this study adds valuable insights into the experiences of parents of children with EDs and provides a foundation for future research in this area.

5. Conclusion

This study seeks to comprehend the mechanism underlying parental distress when caring for a child with ED, by investigating parental illness perceptions, causal attributions, and applying the full CSM model to explore the impact of illness representations on coping strategies and psychological distress. Our findings demonstrated that parents tended to perceive their child’s ED as threatening, with serious consequences, chronicity (*timeline*), severe symptoms (*identity*), and negative emotions (*emotional representation*). However, they also had a positive view of their ability to manage and understand the illness, as well as the efficacy of treatment. As for the causal attribution, parents tended to attribute external factors to understand the causes of their child's ED. Moreover, a threatening emotional illness representation of their child’s ED was associated with psychological distress but not coping strategies. However, a positive view of treatment was linked to dysfunctional coping and depression, while a more positive view of their understanding of ED was linked with depression and stress. Importantly, these results indicated the importance of addressing parents' illness perceptions in clinical interventions and incorporating personalised psychological therapy to help them cope with their negative emotions. Clinicians should focus on addressing their perceptions of treatment and understanding of ED to mitigate psychological distress and unhelpful coping strategies. Further research is needed to determine whether personalised psychological therapy can shift these illness perception views and improve wellbeing for parents of children with EDs.

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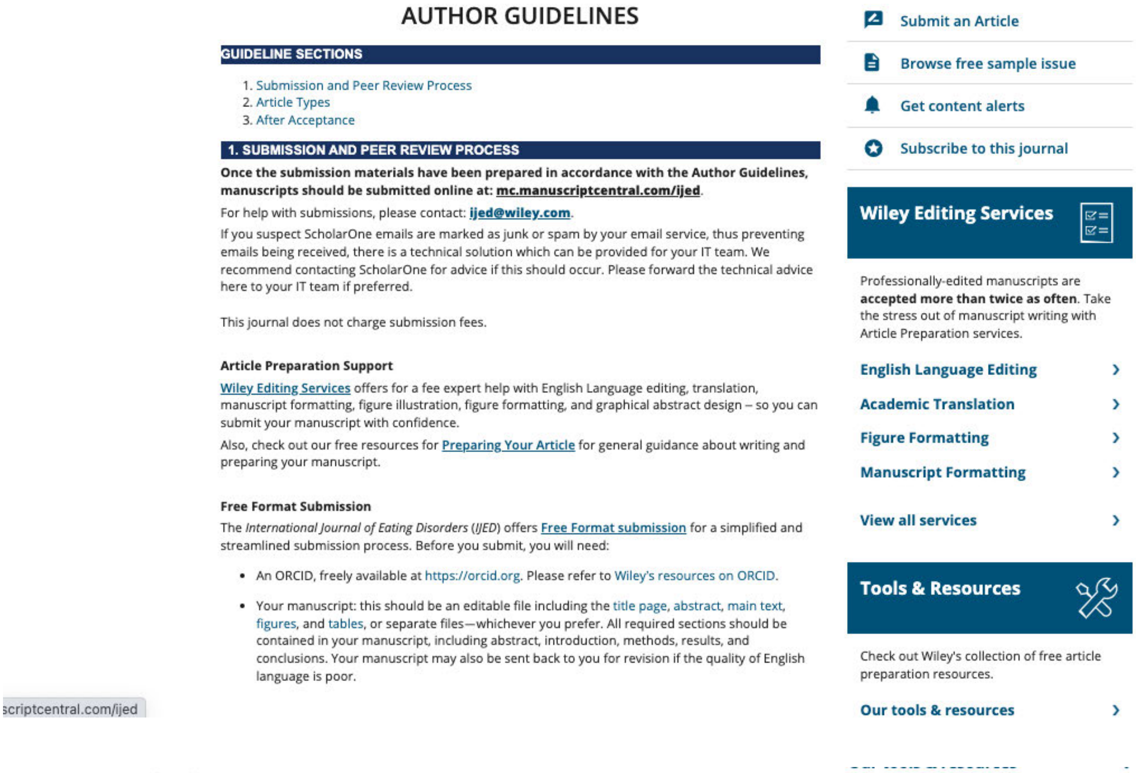
Appendices

Appendix A. Author guidelines for submission to the International Journal of Eating Disorders (relevant sections)



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GUIDELINE SECTIONS

1. Submission and Peer Review Process
2. Article Types
3. After Acceptance

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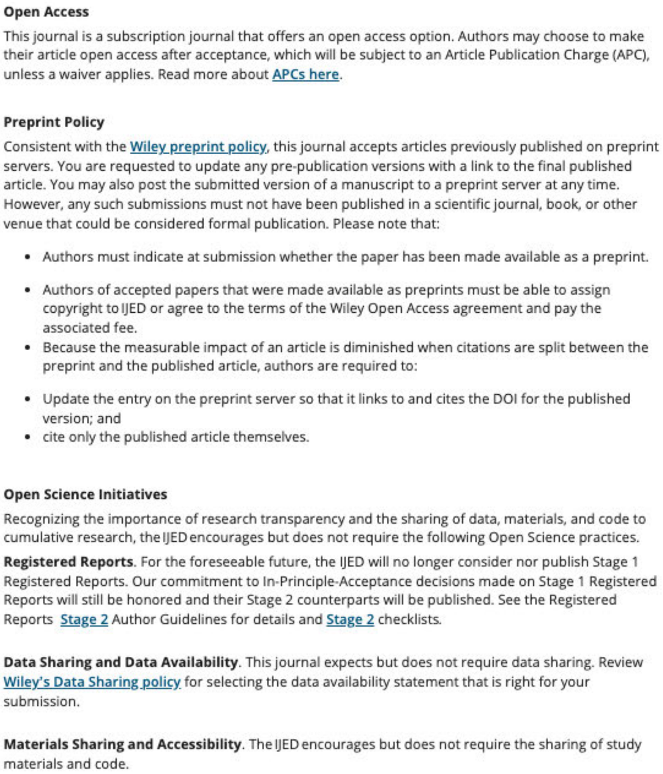

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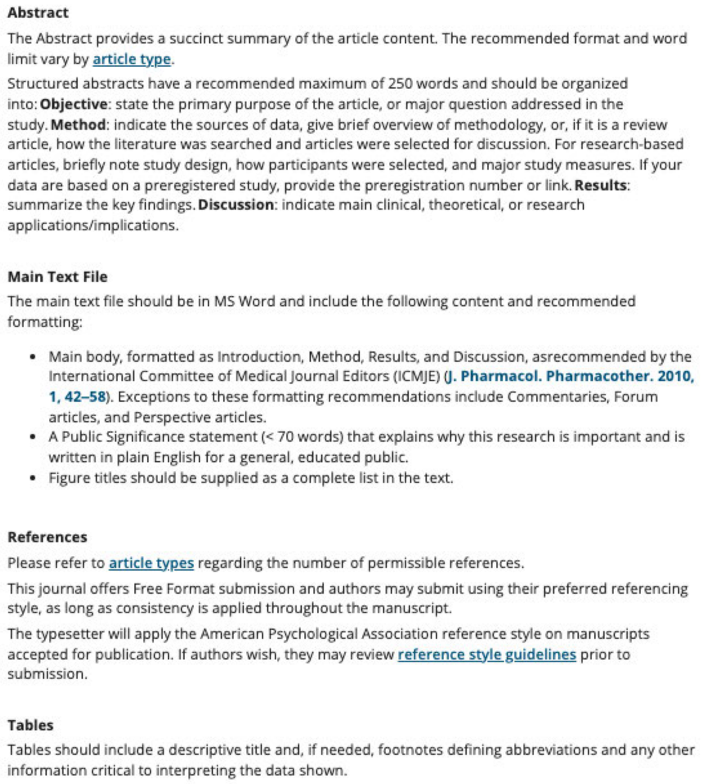

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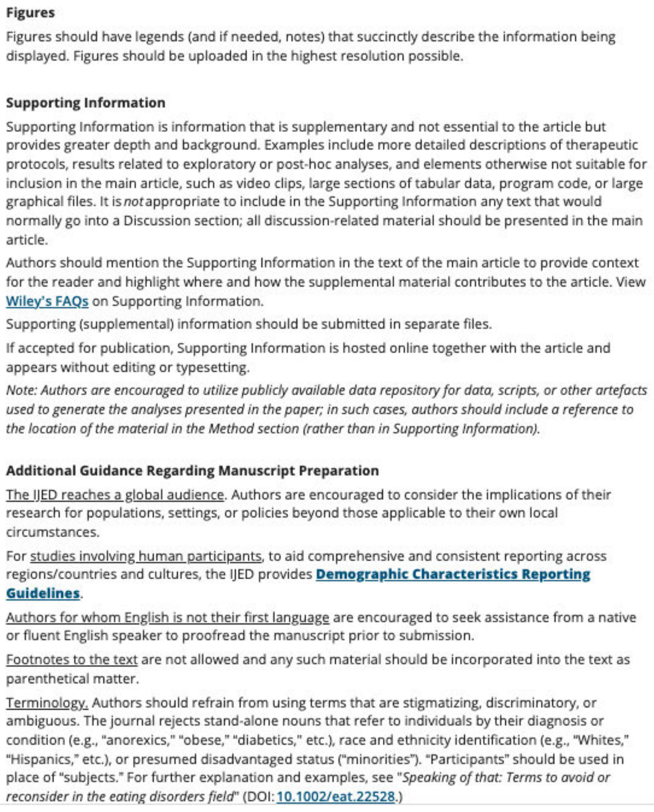

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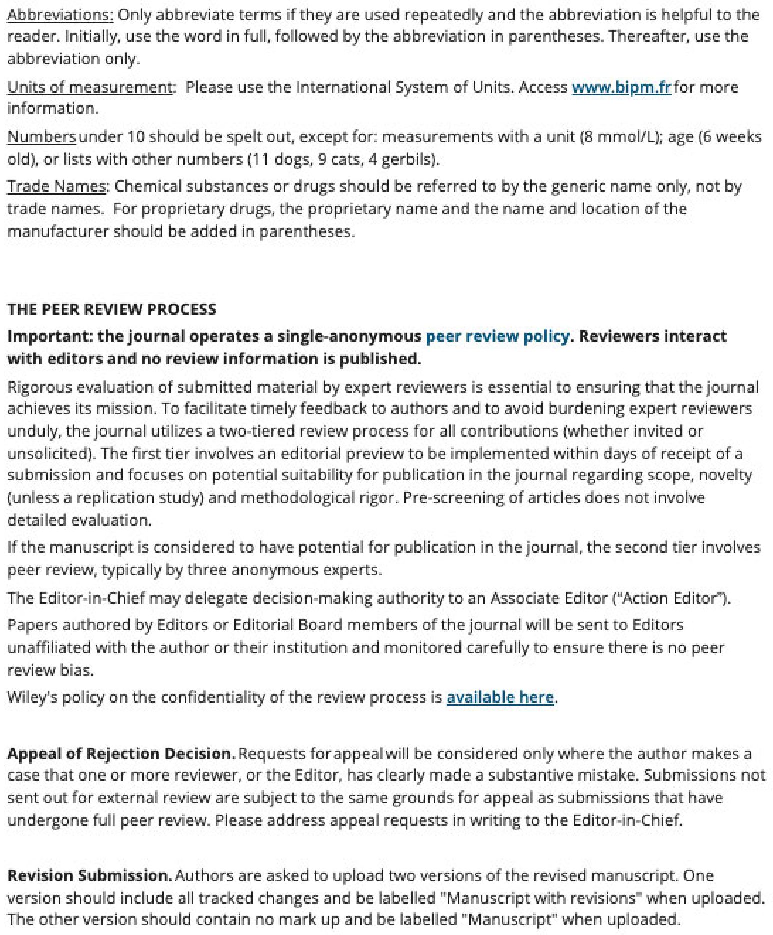

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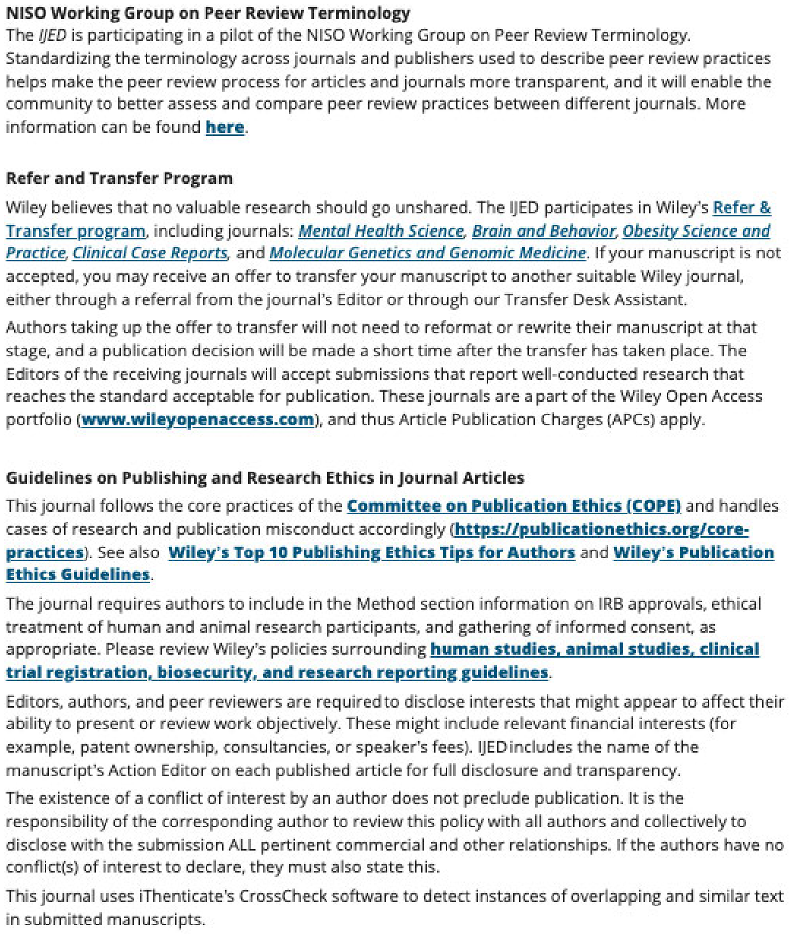

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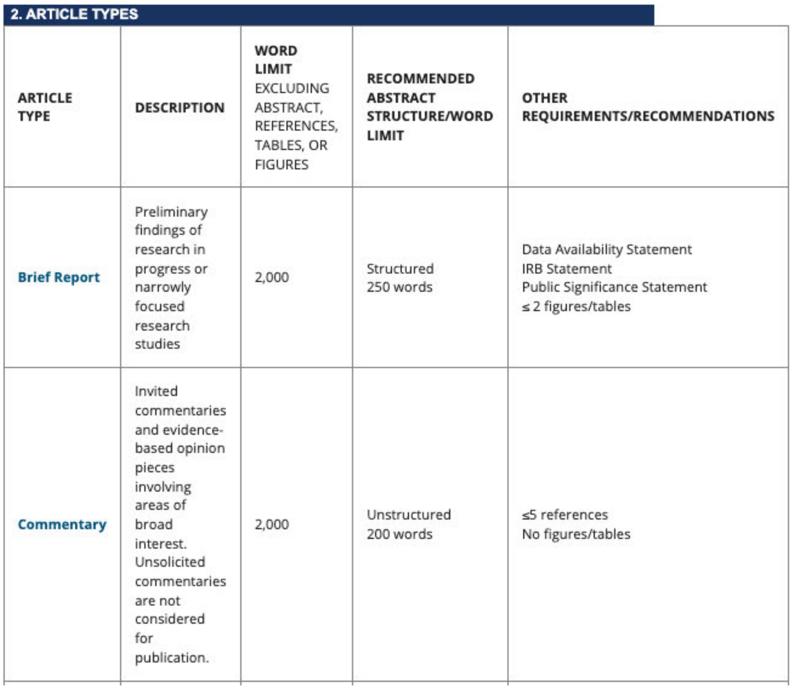

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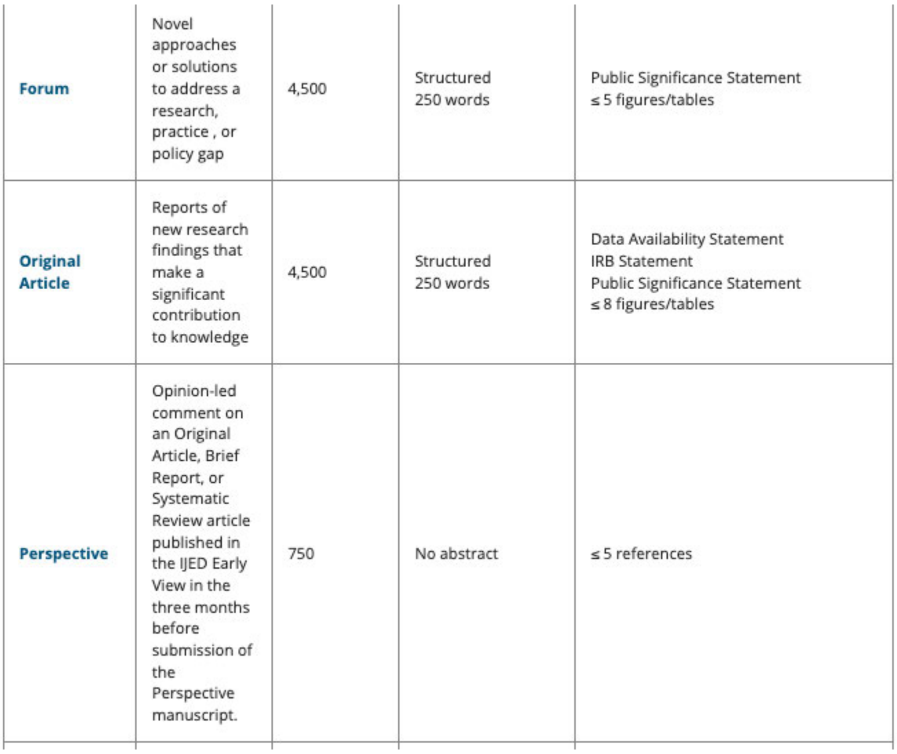

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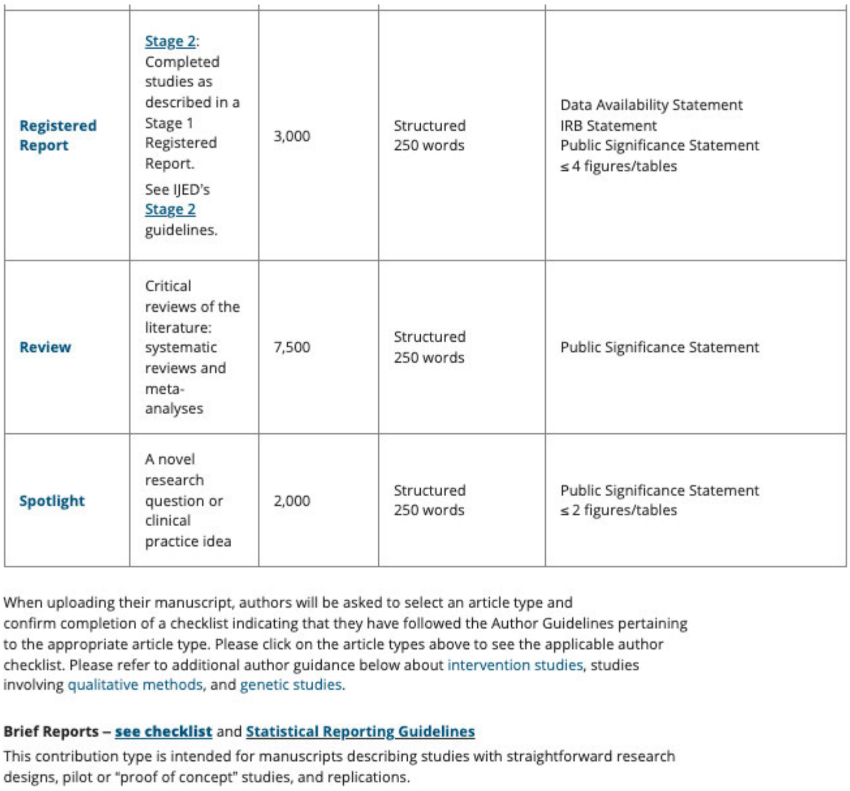

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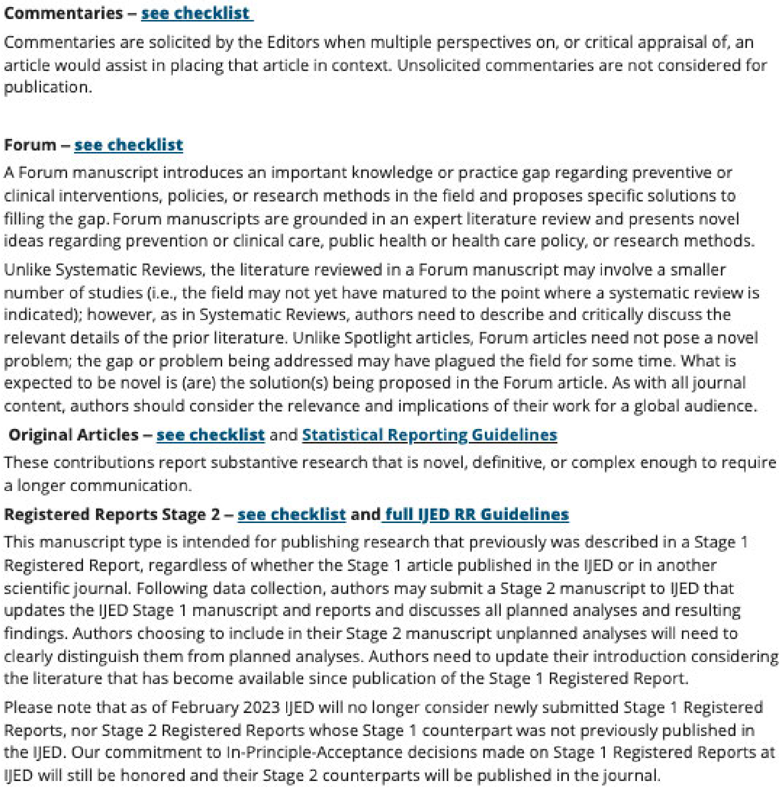

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Forum – see checklist

A Forum manuscript introduces an important knowledge or practice gap regarding preventive or clinical interventions, policies, or research methods in the field and proposes specific solutions to filling the gap. Forum manuscripts are grounded in an expert literature review and presents novel ideas regarding prevention or clinical care, public health or health care policy, or research methods.

Unlike Systematic Reviews, the literature reviewed in a Forum manuscript may involve a smaller number of studies (i.e., the field may not yet have matured to the point where a systematic review is indicated); however, as in Systematic Reviews, authors need to describe and critically discuss the relevant details of the prior literature. Unlike Spotlight articles, Forum articles need not pose a novel problem; the gap or problem being addressed may have plagued the field for some time. What is expected to be novel is (are) the solution(s) being proposed in the Forum article. As with all journal content, authors should consider the relevance and implications of their work for a global audience.

Original Articles – see checklist and **Statistical Reporting Guidelines**

These contributions report substantive research that is novel, definitive, or complex enough to require a longer communication.

Registered Reports Stage 2 – see checklist and full IJED RR Guidelines

This manuscript type is intended for publishing research that previously was described in a Stage 1 Registered Report, regardless of whether the Stage 1 article published in the IJED or in another scientific journal. Following data collection, authors may submit a Stage 2 manuscript to IJED that updates the IJED Stage 1 manuscript and reports and discusses all planned analyses and resulting findings. Authors choosing to include in their Stage 2 manuscript unplanned analyses will need to clearly distinguish them from planned analyses. Authors need to update their introduction considering the literature that has become available since publication of the Stage 1 Registered Report.

Please note that as of February 2023 IJED will no longer consider newly submitted Stage 1 Registered Reports, nor Stage 2 Registered Reports whose Stage 1 counterpart was not previously published in the IJED. Our commitment to In-Principle-Acceptance decisions made on Stage 1 Registered Reports at IJED will still be honored and their Stage 2 counterparts will be published in the journal.

Reviews and Meta-Analyses – see checklist

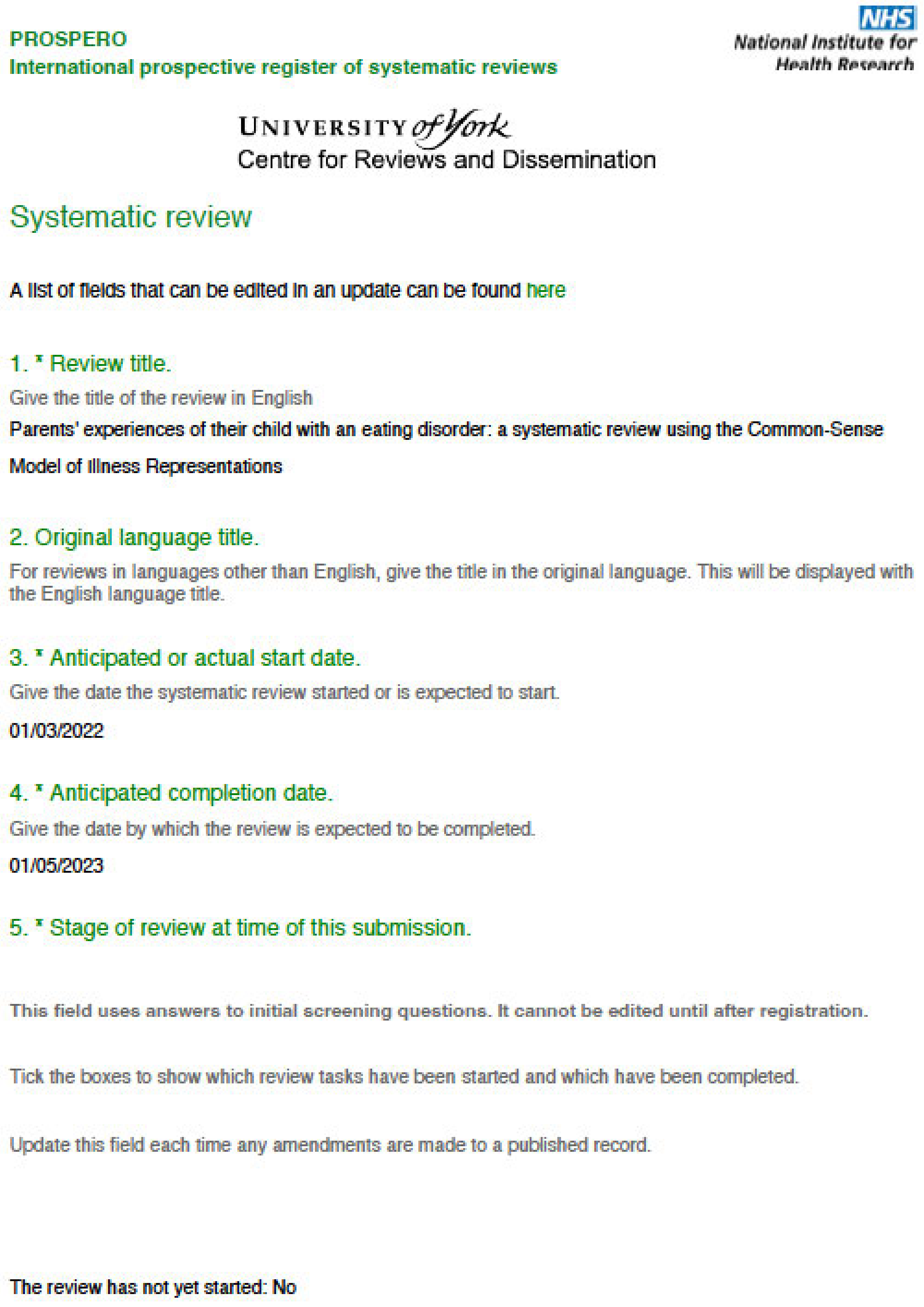
These articles critically review the status of a given research area and propose new directions for research and/or practice. Both systematic and meta-analytic review papers are welcomed if they review a literature that is advanced and/or developed to the point of warranting a review and synthesis of existing studies. Reviews of topics with a limited number of studies are unlikely to be deemed as substantive enough for an IJED Review paper. The journal does not accept papers that merely describe or compile a list of previous studies without a critical synthesis of the literature that moves the field the forward.

All Review articles must follow the PRISMA Guidelines, summarized in Page et al. (2021) article entitled *"The PRISMA 2020 statement: an updated guideline for reporting systematic reviews"* (J. Clin. Epidemiol.). See translations of PRISMA documents. Authors who choose this contribution type must include the 2020 PRISMA Flow Diagram and complete the IJED Review Checklist upon submission of the manuscript. This example is for informational purposes only. During the submission process, authors will be prompted to confirm they have followed the Review checklist in the submission form. The rationale for any unchecked items on the Review Checklist must be explicitly described in the accompanying Cover Letter.

In addition to the required PRISMA review paper components, all Review articles must also include a full description of the age, gender, race, ethnicity, and socioeconomic status of participants in the reviewed studies. This information will most often take the form of separate entries in tables describing the studies included in the review. If a paper included in the review does not report these demographic variables, then "NR" (Not Reported) should be indicated in the appropriate table cells. Review papers must also explicitly discuss (in the text) the diversity of the samples and the ways in which this diversity (or lack thereof) may impact the generalizability and representativeness of the study results and conclusions.

In the interest of representing the global literature, authors are strongly encouraged to include non-English language articles where practically possible. Minimally, authors are expected to initially search the literature without filtering out non-English language articles. In their PRISMA flow diagram, authors should report the number of articles they excluded based on language. References of articles excluded due to language barriers should be saved in a supplemental file, along with English-language abstracts if available. The supplemental file containing these references and abstracts must be uploaded when submitting the review article. While not required, to the extent possible, we encourage authors to pursue opportunities for accessing non-English language papers such as inviting collaborators with the requisite language skills; employing translation software; or seeking expert assistance in translating articles.

Appendix B. PROSPERO protocol, CRD42022313593



PROSPERO
International prospective register of systematic reviews

NHS
National Institute for Health Research

UNIVERSITY of York
Centre for Reviews and Dissemination

Systematic review

A list of fields that can be edited in an update can be found here

1. * Review title.

Give the title of the review in English

Parents' experiences of their child with an eating disorder: a systematic review using the Common-Sense Model of Illness Representations

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3. * Anticipated or actual start date.

Give the date the systematic review started or is expected to start.

01/03/2022

4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

01/05/2023

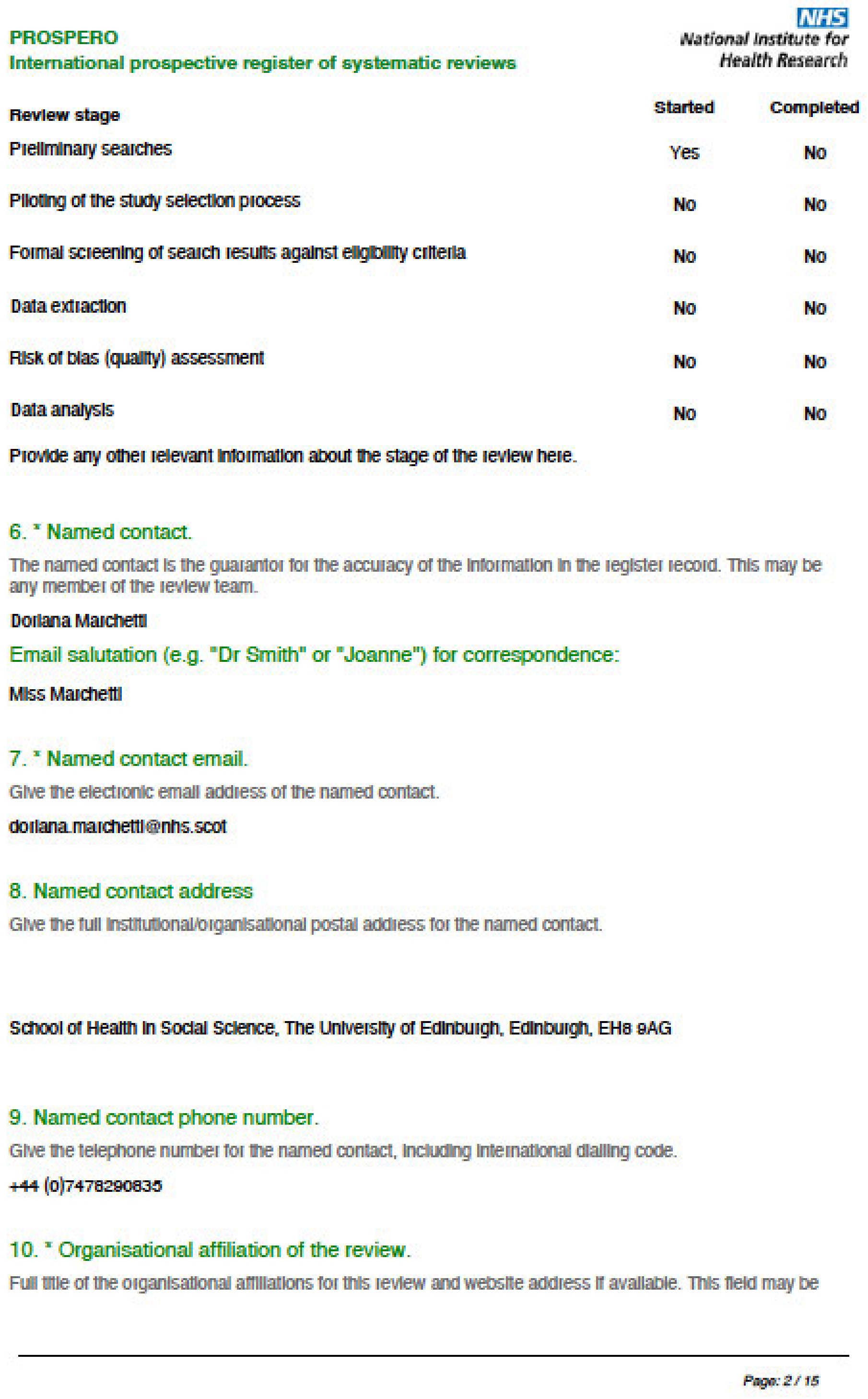
5. * Stage of review at time of this submission.

This field uses answers to initial screening questions. It cannot be edited until after registration.

Tick the boxes to show which review tasks have been started and which have been completed.

Update this field each time any amendments are made to a published record.

The review has not yet started: No



Review stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

Provide any other relevant information about the stage of the review here.

6. * Named contact.

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Doriana Marchetti

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Miss Marchetti

7. * Named contact email.

Give the electronic email address of the named contact.

doriana.marchetti@nhs.scot

8. Named contact address

Give the full institutional/organisational postal address for the named contact.

School of Health in Social Science, The University of Edinburgh, Edinburgh, EH8 9AG

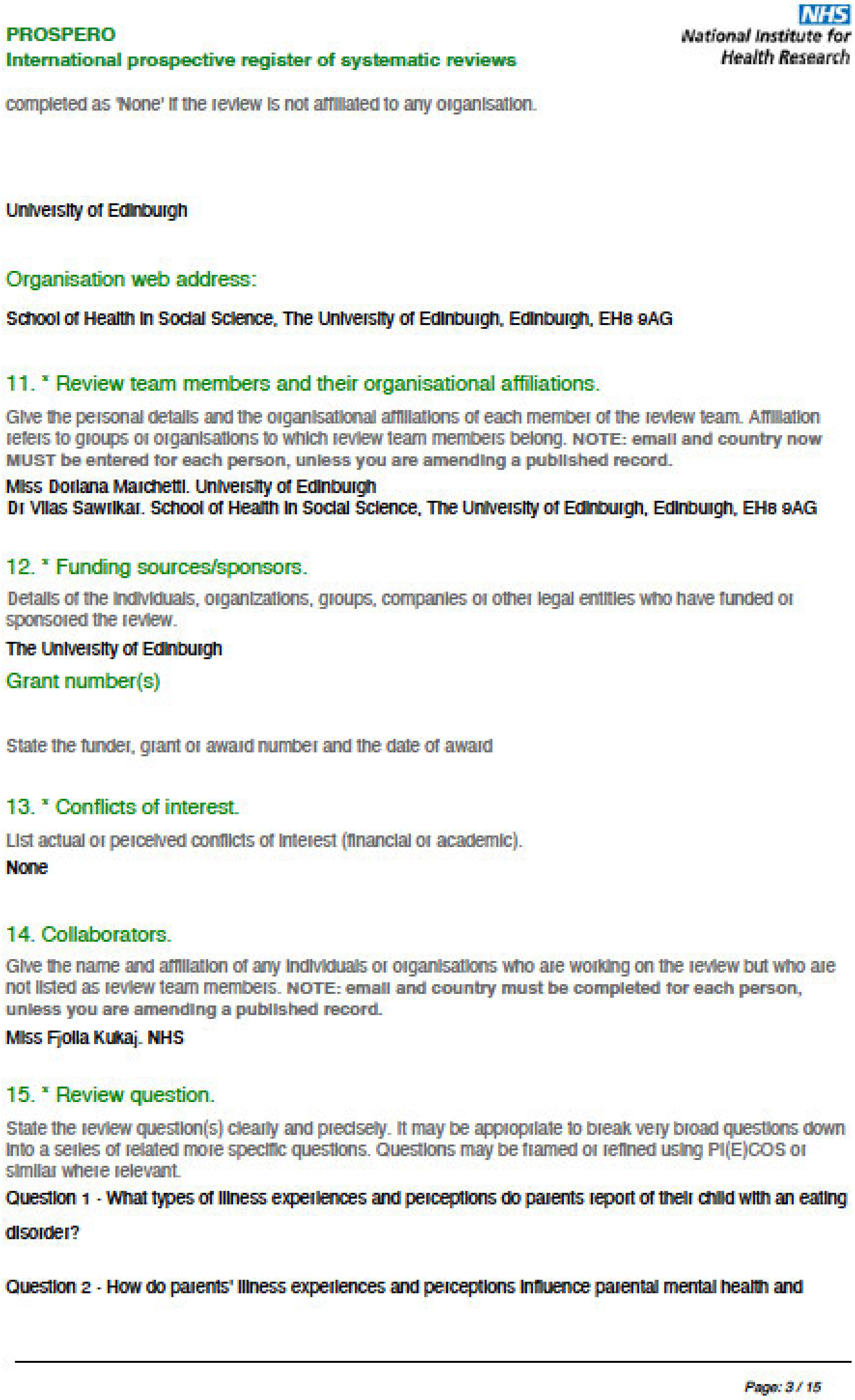
9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

+44 (0)7478290835

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be



completed as 'None' if the review is not affiliated to any organisation.

University of Edinburgh

Organisation web address:

School of Health in Social Science, The University of Edinburgh, Edinburgh, EH8 9AG

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong. **NOTE: email and country now MUST be entered for each person, unless you are amending a published record.**

Miss Doriana Marchetti. University of Edinburgh
Dr Vilas Sawrikar. School of Health in Social Science, The University of Edinburgh, Edinburgh, EH8 9AG

12. * Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

The University of Edinburgh

Grant number(s)

State the funder, grant or award number and the date of award

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. **NOTE: email and country must be completed for each person, unless you are amending a published record.**

Miss Fjolla Kukaj. NHS

15. * Review question.

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

Question 1 - What types of illness experiences and perceptions do parents report of their child with an eating disorder?

Question 2 - How do parents' illness experiences and perceptions influence parental mental health and coping ability in the context of their child's eating disorder?

16. * Searches.

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

A literature search using PsycINFO, MEDLINE and EMBASE) will be conducted.

Search terms:

illness representation OR common sense model OR view' OR perce' OR knowledge OR belie' OR attribut' OR understand' OR expect' OR interpret' OR conce' OR experienc'

AND

parent' OR famil' OR car' OR gardian' OR mother' OR father' OR maternal OR paternal

AND

eating disorder' OR bulim' OR anorex' OR bing' OR eat'

Parents or guardians of children with an eating disorder (e.g., AN, BN or EDs not otherwise specified) as a primary diagnosis

Studies with a focus on perceptions of ED among parents or guardian caring for a child with ED

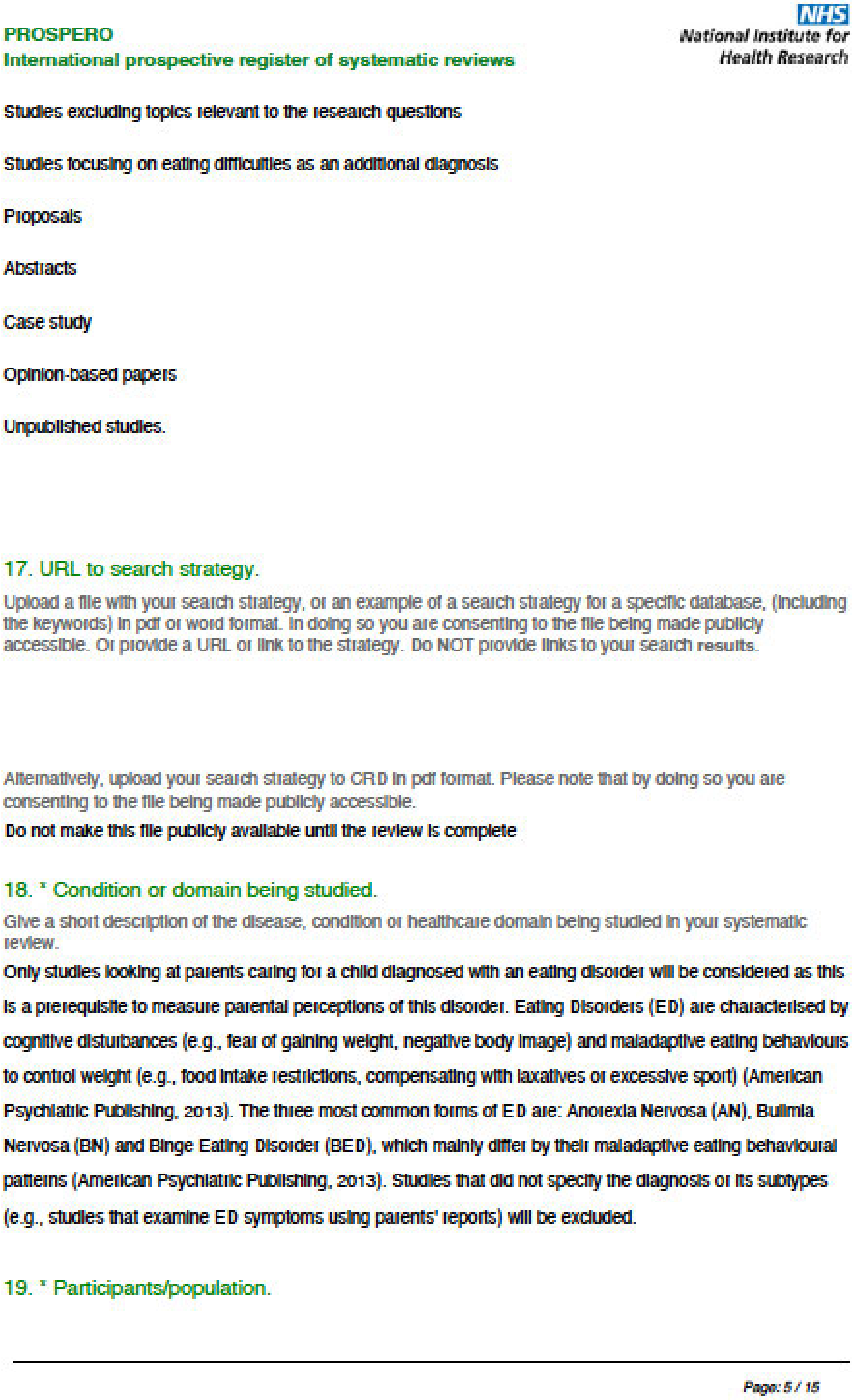
Studies examining at least one dimension of the illness representation

Studies written in English

Studies published from 1970

Studies employing a qualitative (e.g., interview) or quantitative (e.g experimental or observational) or mixed designs methodology.

Exclusion criteria -



Studies excluding topics relevant to the research questions

Studies focusing on eating difficulties as an additional diagnosis

Proposals

Abstracts

Case study

Opinion-based papers

Unpublished studies.

17. URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible. Or provide a URL or link to the strategy. Do NOT provide links to your search results.

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

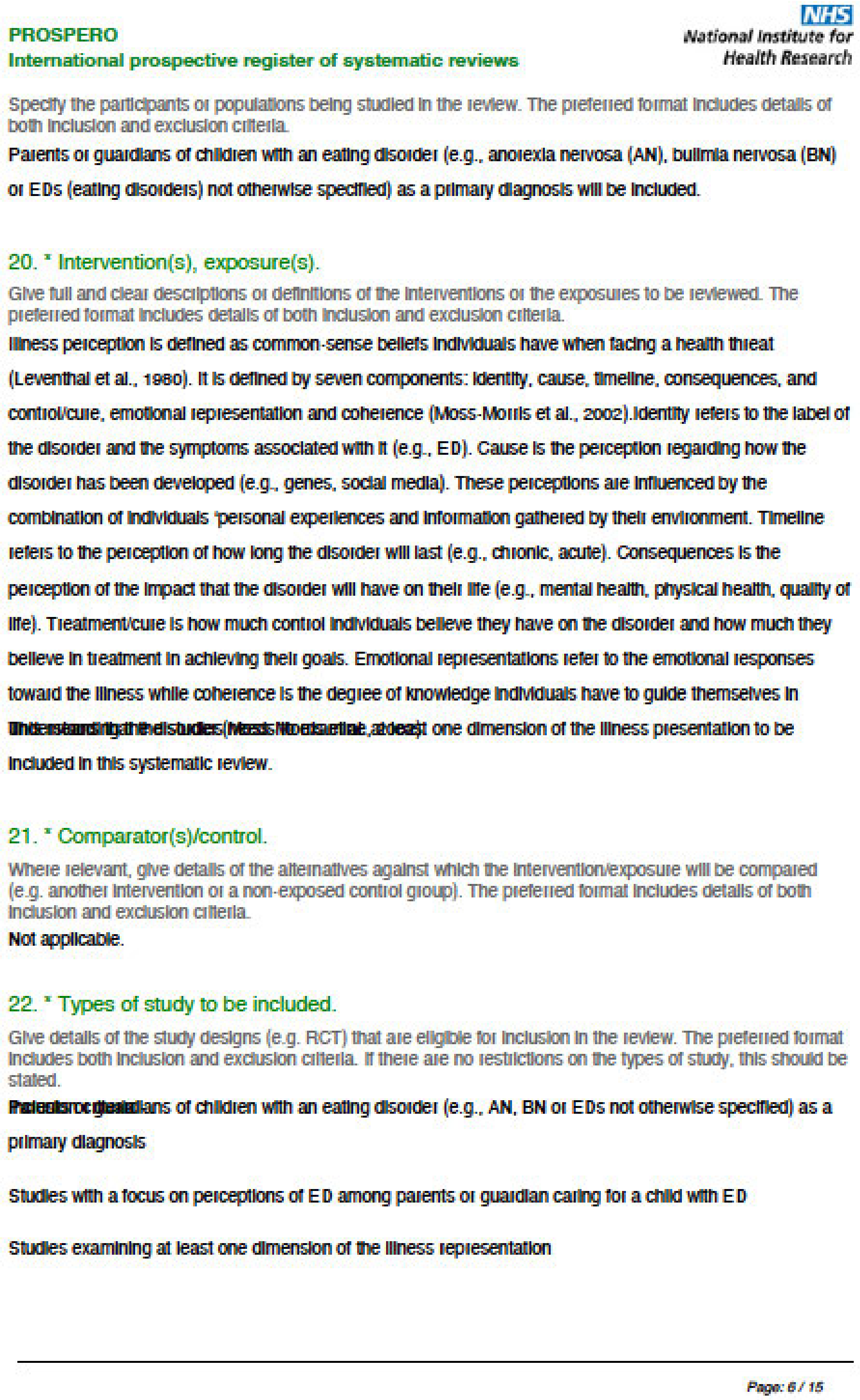
Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

Only studies looking at parents caring for a child diagnosed with an eating disorder will be considered as this is a prerequisite to measure parental perceptions of this disorder. Eating Disorders (ED) are characterised by cognitive disturbances (e.g., fear of gaining weight, negative body image) and maladaptive eating behaviours to control weight (e.g., food intake restrictions, compensating with laxatives or excessive sport) (American Psychiatric Publishing, 2013). The three most common forms of ED are: Anorexia Nervosa (AN), Bulimia Nervosa (BN) and Binge Eating Disorder (BED), which mainly differ by their maladaptive eating behavioural patterns (American Psychiatric Publishing, 2013). Studies that did not specify the diagnosis or its subtypes (e.g., studies that examine ED symptoms using parents' reports) will be excluded.

19. * Participants/population.



Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and exclusion criteria.

Parents or guardians of children with an eating disorder (e.g., anorexia nervosa (AN), bulimia nervosa (BN) or EDs (eating disorders) not otherwise specified) as a primary diagnosis will be included.

20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format includes details of both inclusion and exclusion criteria.

Illness perception is defined as common-sense beliefs individuals have when facing a health threat (Leventhal et al., 1980). It is defined by seven components: identity, cause, timeline, consequences, and control/cure, emotional representation and coherence (Moss-Morris et al., 2002).Identity refers to the label of the disorder and the symptoms associated with it (e.g., ED). Cause is the perception regarding how the disorder has been developed (e.g., genes, social media). These perceptions are influenced by the combination of individuals 'personal experiences and information gathered by their environment. Timeline refers to the perception of how long the disorder will last (e.g., chronic, acute). Consequences is the perception of the impact that the disorder will have on their life (e.g., mental health, physical health, quality of life). Treatment/cure is how much control individuals believe they have on the disorder and how much they believe in treatment in achieving their goals. Emotional representations refer to the emotional responses toward the illness while coherence is the degree of knowledge individuals have to guide themselves in understanding the disorder (Moss-Morris et al., 2002). In the studies, at least one dimension of the illness presentation to be included in this systematic review.

21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Not applicable.

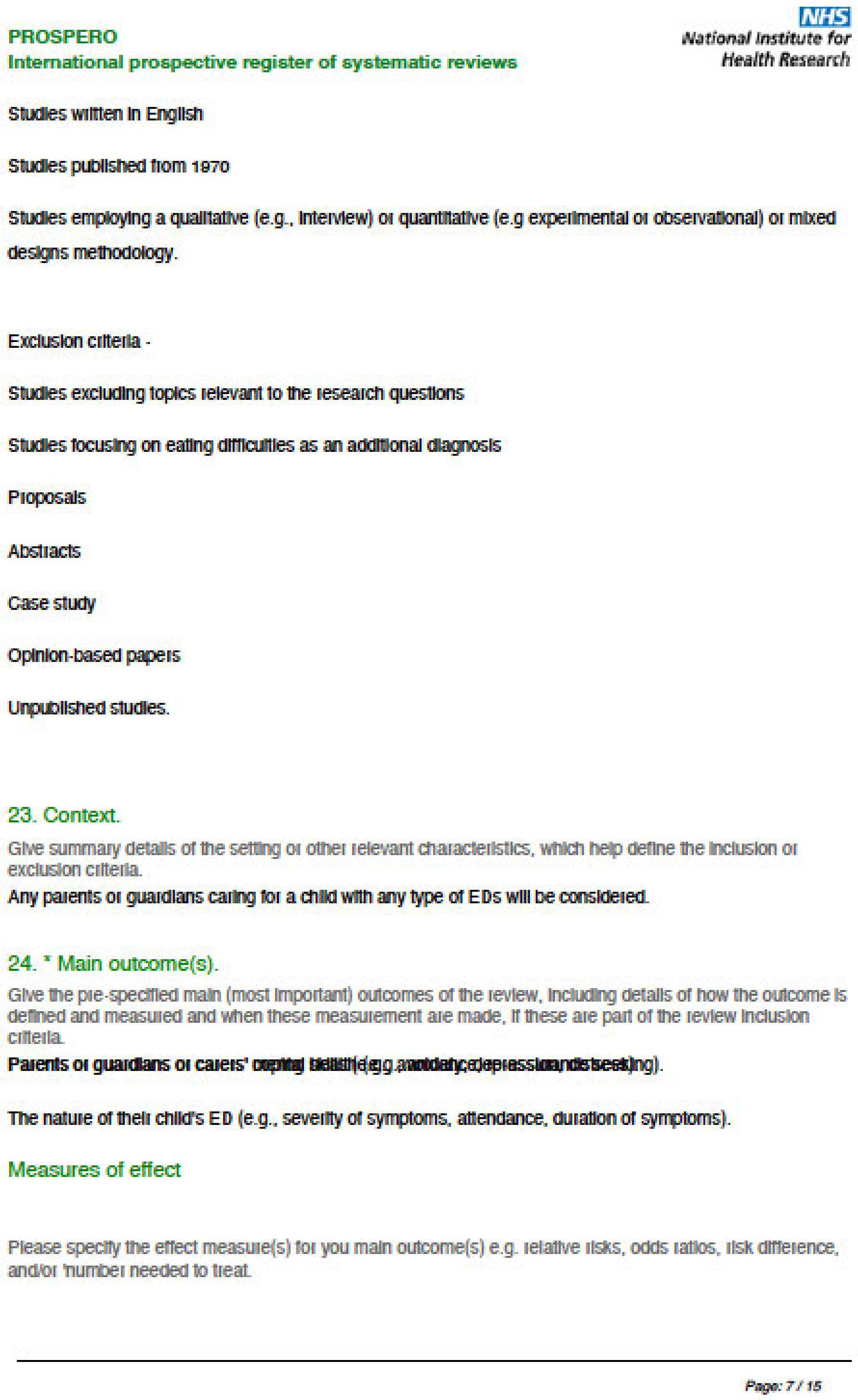
22. * Types of study to be included.

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

Parents or guardians of children with an eating disorder (e.g., AN, BN or EDs not otherwise specified) as a primary diagnosis

Studies with a focus on perceptions of ED among parents or guardian caring for a child with ED

Studies examining at least one dimension of the illness representation



Studies written in English

Studies published from 1970

Studies employing a qualitative (e.g., interview) or quantitative (e.g experimental or observational) or mixed designs methodology.

Exclusion criteria -

Studies excluding topics relevant to the research questions

Studies focusing on eating difficulties as an additional diagnosis

Proposals

Abstracts

Case study

Opinion-based papers

Unpublished studies.

23. Context.

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

Any parents or guardians caring for a child with any type of EDs will be considered.

24. * Main outcome(s).

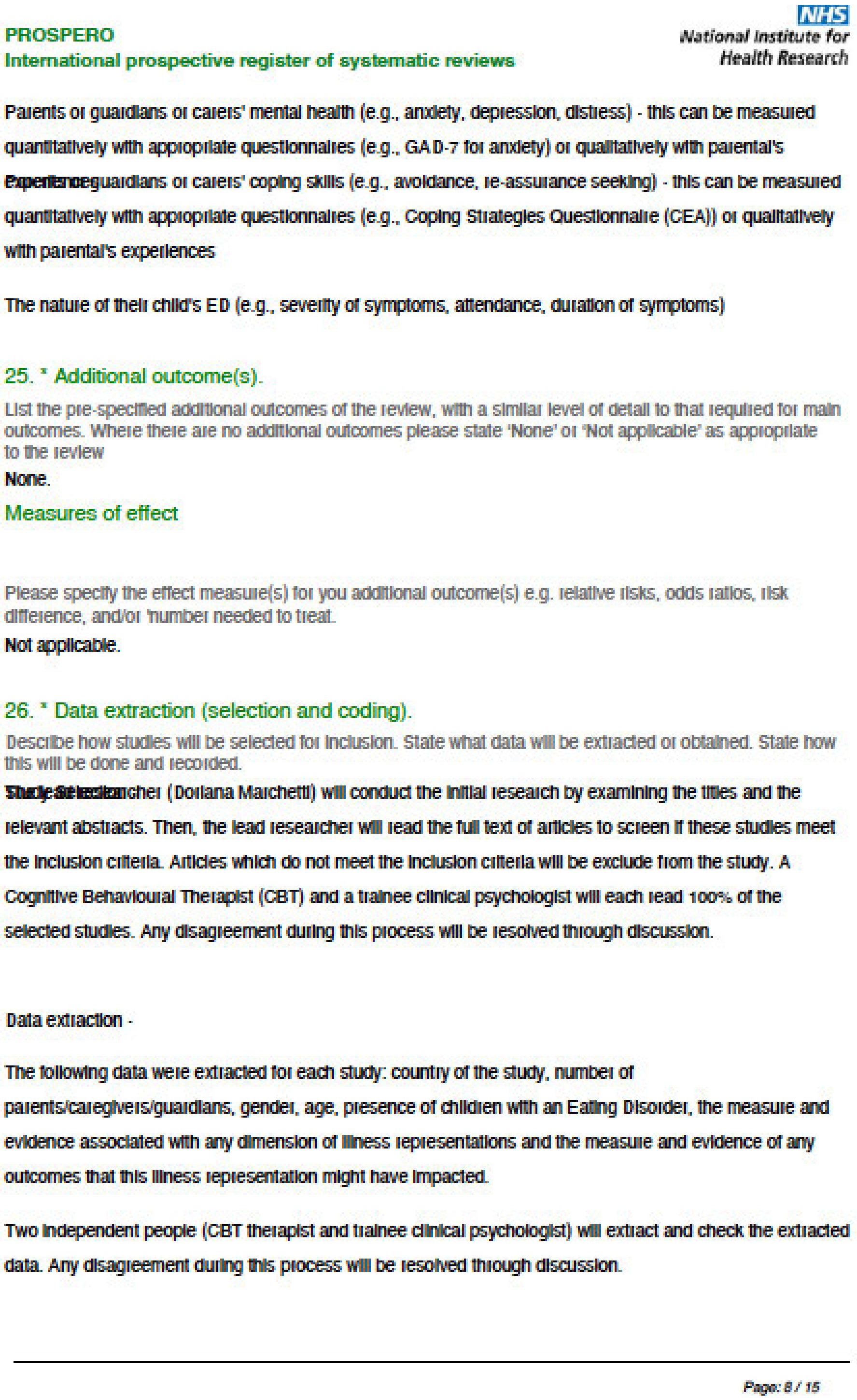
Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

Parents or guardians or carers' [illegible] (e.g., [illegible]ng).

The nature of their child's ED (e.g., severity of symptoms, attendance, duration of symptoms).

Measures of effect

Please specify the effect measure(s) for you main outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.



Parents or guardians or carers' mental health (e.g., anxiety, depression, distress) - this can be measured quantitatively with appropriate questionnaires (e.g., GAD-7 for anxiety) or qualitatively with parental's Experience

Parents or guardians or carers' coping skills (e.g., avoidance, re-assurance seeking) - this can be measured quantitatively with appropriate questionnaires (e.g., Coping Strategies Questionnaire (CEA)) or qualitatively with parental's experiences

The nature of their child's ED (e.g., severity of symptoms, attendance, duration of symptoms)

25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

None.

Measures of effect

Please specify the effect measure(s) for you additional outcome(s) e.g. relative risks, odds ratios, risk difference, and/or 'number needed to treat.

Not applicable.

26. * Data extraction (selection and coding).

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done and recorded.

Study Selection

The lead researcher (Doriana Marchetti) will conduct the initial research by examining the titles and the relevant abstracts. Then, the lead researcher will read the full text of articles to screen if these studies meet the inclusion criteria. Articles which do not meet the inclusion criteria will be exclude from the study. A Cognitive Behavioural Therapist (CBT) and a trainee clinical psychologist will each read 100% of the selected studies. Any disagreement during this process will be resolved through discussion.

Data extraction -

The following data were extracted for each study: country of the study, number of parents/caregivers/guardians, gender, age, presence of children with an Eating Disorder, the measure and evidence associated with any dimension of illness representations and the measure and evidence of any outcomes that this illness representation might have impacted.

Two independent people (CBT therapist and trainee clinical psychologist) will extract and check the extracted data. Any disagreement during this process will be resolved through discussion.

27. * Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

Risk of bias of included studies will be assessed using an adapted version of the Critical Appraisal Skills Programme (CASP). All studies will be rated using this tool and assigned a quality classification mark. Studies will be re-rated by two independent researchers utilising the same checklist. The agreement between the ratings will suggest an adequate inter-rater reliability.

28. * Strategy for data synthesis.

Describe the methods you plan to use to synthesise data. This **must not be generic text** but should be **specific to your review** and describe how the proposed approach will be applied to your data. If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

[illegible]ensions, which are identity, cause, timeline, consequences, and control/cure, emotional representation and coherence.

If the majority of studies are qualitative, a meta-synthesis will be used, which will be in line with the guidelines developed by Noblit and Hare (1988) and expounded by Walsh and Downe (2005).

If both qualitative and quantitative studies are considered, the Joanna Briggs Institute Critical Appraisal will be used. Due to lack of comparators and research this area, a meta-analysis will not be considered.

29. * Analysis of subgroups or subsets.

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in each group or covariate investigated. State the planned analytic approach.

Data will be synthesised using the Common Sense Model of illness representations' dimensions, which are identity, cause, timeline, consequences, and control/cure, emotional representation and coherence.

30. * Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
Yes

Individual patient data (IPD) meta-analysis

No

Intervention
No

Living systematic review
No

Meta-analysis
No

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system

No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
Yes

Complementary therapies
No

COVID-19
No

Crime and justice
No

Dental
No

Digestive system
No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development

No

Mental health and behavioural conditions
Yes

Musculoskeletal
No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
No

Rehabilitation
No

Respiratory disorders
No

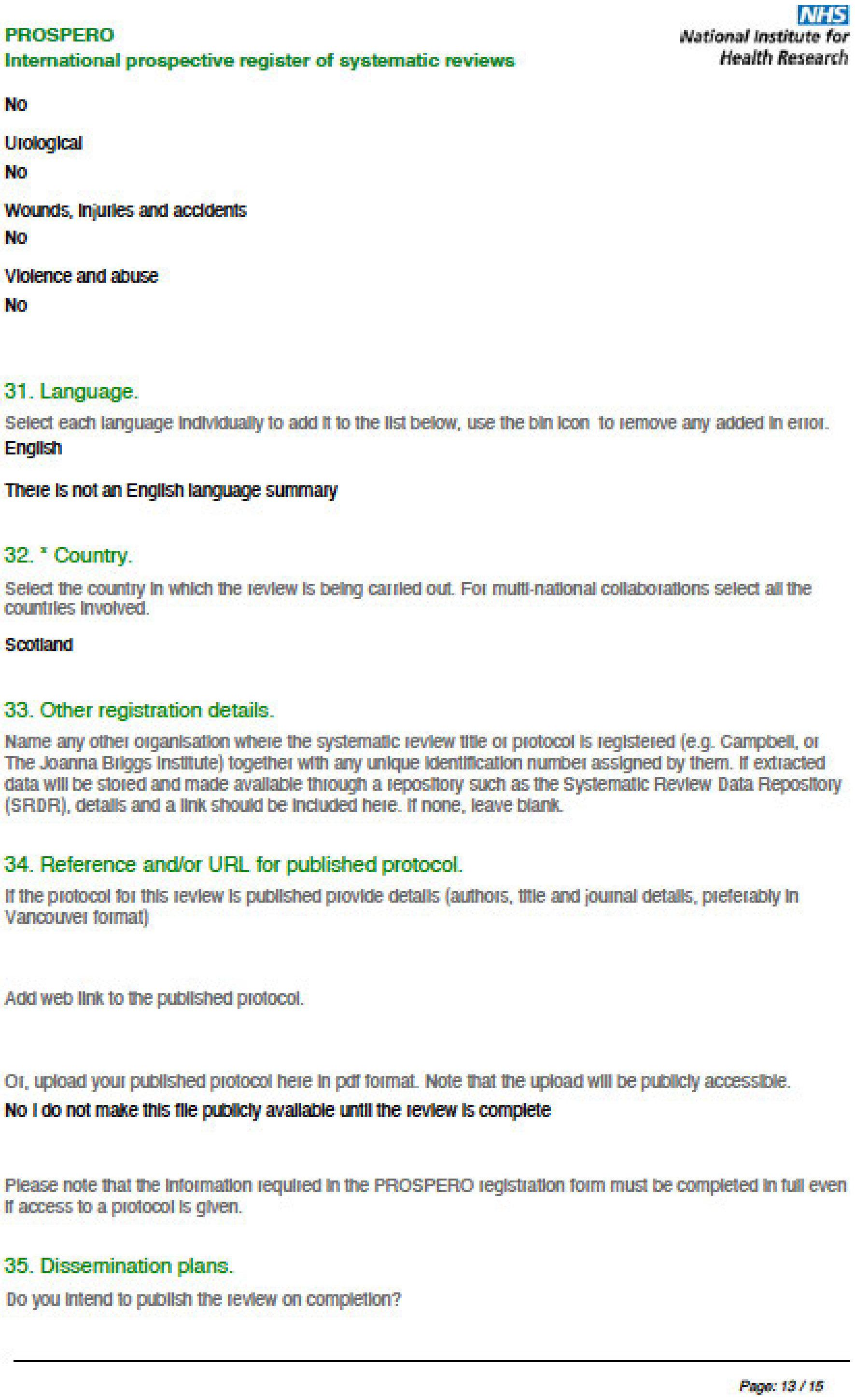
Service delivery
No

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine



No

Urological

No

Wounds, injuries and accidents

No

Violence and abuse

No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.

English

There is not an English language summary

32. * Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

Scotland

33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them. If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)

Add web link to the published protocol.

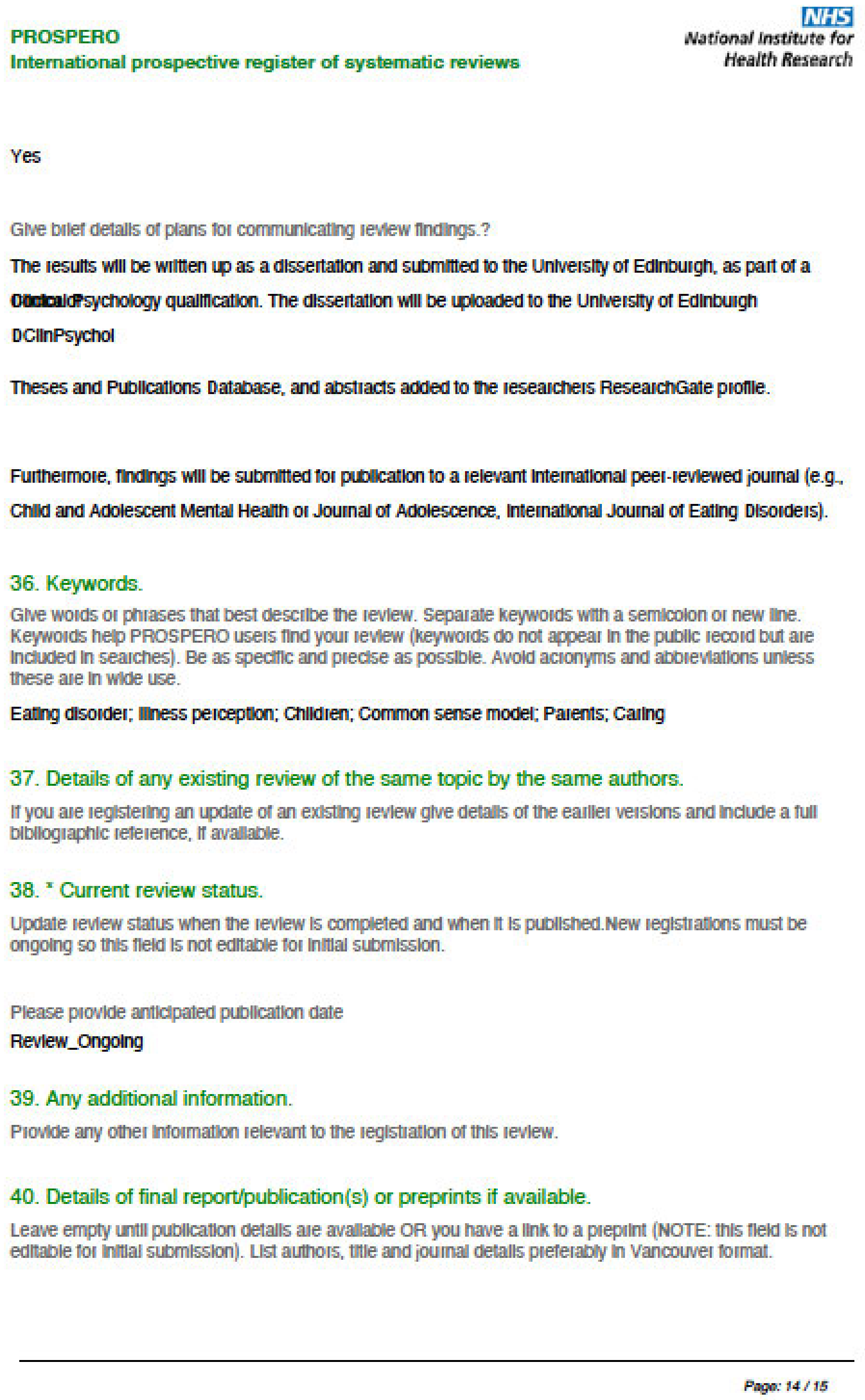
Or, upload your published protocol here in pdf format. Note that the upload will be publicly accessible.

No I do not make this file publicly available until the review is complete

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

35. Dissemination plans.

Do you intend to publish the review on completion?



Yes

Give brief details of plans for communicating review findings.?

The results will be written up as a dissertation and submitted to the University of Edinburgh, as part of a Clinical Psychology qualification. The dissertation will be uploaded to the University of Edinburgh

DClinPsychol

Theses and Publications Database, and abstracts added to the researchers ResearchGate profile.

Furthermore, findings will be submitted for publication to a relevant international peer-reviewed journal (e.g., Child and Adolescent Mental Health or Journal of Adolescence, International Journal of Eating Disorders).

36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Eating disorder; Illness perception; Children; Common sense model; Parents; Caring

37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

38. * Current review status.

Update review status when the review is completed and when it is published.New registrations must be ongoing so this field is not editable for initial submission.

Please provide anticipated publication date

Review_Ongoing

39. Any additional information.

Provide any other information relevant to the registration of this review.

40. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission). List authors, title and journal details preferably in Vancouver format.

Appendix C. Ethical Approval from the Research Ethics Committee (REC; 21/YH/0287)

Health Research
Authority

Yorkshire & The Humber - Sheffield Research Ethics Committee
NHS Blood and Transplant Blood Donor Centre
Holland Drive
Newcastle upon Tyne
Tyne and Wear
NE2 4NQ

Telephone: 0207 104 8388

13 December 2021

Dr Vilas Sawrikar
Lecturer in Clinical Psychology
The University of Edinburgh
Doorway 6, Old Medical School, Teviot Place
School of Health in Social Science
Edinburgh
EH8 9AG

Dear Dr Sawrikar

Study title:	**Using the common sense model of illness to understand parents' experiences of caring for a child with an Eating Disorder.**
REC reference:	**21/YH/0287**
Protocol number:	**CAHSS2109/17**
IRAS project ID:	**304323**

Thank you for your letter of 10 December 2021, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

On behalf of the Research Ethics Committee (REC), I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

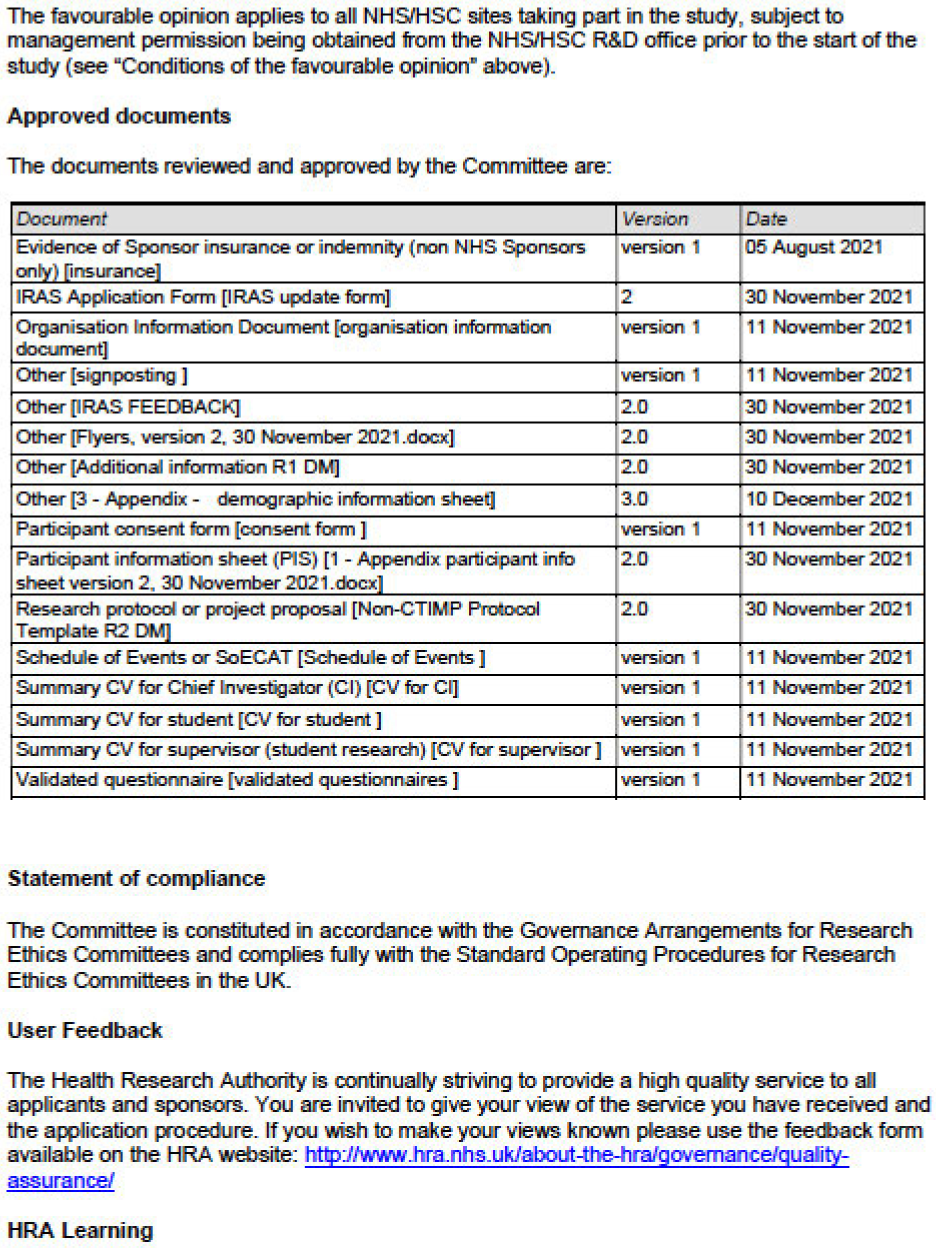
After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites



The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [insurance]	version 1	05 August 2021
IRAS Application Form [IRAS update form]	2	30 November 2021
Organisation Information Document [organisation information document]	version 1	11 November 2021
Other [signposting]	version 1	11 November 2021
Other [IRAS FEEDBACK]	2.0	30 November 2021
Other [Flyers, version 2, 30 November 2021.docx]	2.0	30 November 2021
Other [Additional information R1 DM]	2.0	30 November 2021
Other [3 - Appendix - demographic information sheet]	3.0	10 December 2021
Participant consent form [consent form]	version 1	11 November 2021
Participant information sheet (PIS) [1 - Appendix participant info sheet version 2, 30 November 2021.docx]	2.0	30 November 2021
Research protocol or project proposal [Non-CTIMP Protocol Template R2 DM]	2.0	30 November 2021
Schedule of Events or SoECAT [Schedule of Events]	version 1	11 November 2021
Summary CV for Chief Investigator (CI) [CV for CI]	version 1	11 November 2021
Summary CV for student [CV for student]	version 1	11 November 2021
Summary CV for supervisor (student research) [CV for supervisor]	version 1	11 November 2021
Validated questionnaire [validated questionnaires]	version 1	11 November 2021

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 304323	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

On Behalf Of
Mrs Yvonne Stephenson
Chair

Email: sheffield.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Please note, the standard conditions referenced in your REC favourable opinion letter has being attached ("After ethical review – guidance for researchers") can now be accessed through the HRA website. HRA website.

After ethical review guidance for sponsors and investigators –
Non CTIMP Standard Conditions of Approval]

Copy to:

Lead Nation

England: approvals@hra.nhs.uk
Scotland: gram.nrspcc@nhs.scot
Wales: research-permissions@wales.nhs.uk
Northern Ireland: research.gateway@hscni.net

NHS
Health Research
Authority

Yorkshire & The Humber - Sheffield Research Ethics Committee
NHS Blood and Transplant Blood Donor Centre
Holland Drive
Newcastle upon Tyne
Tyne and Wear
NE2 4NQ

Tel: 0207 104 8388

01 July 2022

Miss Doriana Marchetti
School of Health in Social Science
The University of Edinburgh
Edinburgh
EH8 9AG

Dear Miss Marchetti

Study title:	**Using the common sense model of illness to understand parents' experiences of caring for a child with an Eating Disorder.**
REC reference:	**21/YH/0287**
Protocol number:	**CAHSS2109/17**
Amendment number:	**Substantial Amendment 1**
Amendment date:	**22 May 2022**
IRAS project ID:	**304323**

The above amendment was reviewed by the Sub-Committee in correspondence.

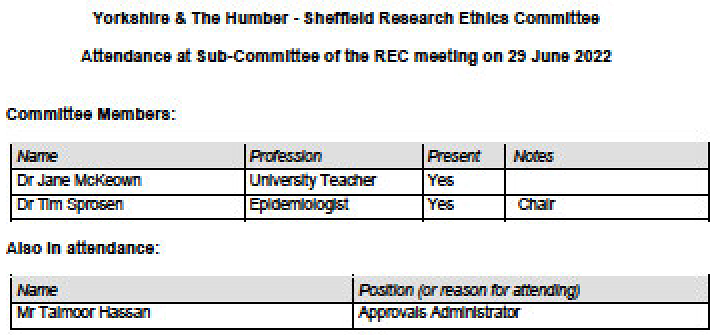
Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*



Yorkshire & The Humber - Sheffield Research Ethics Committee

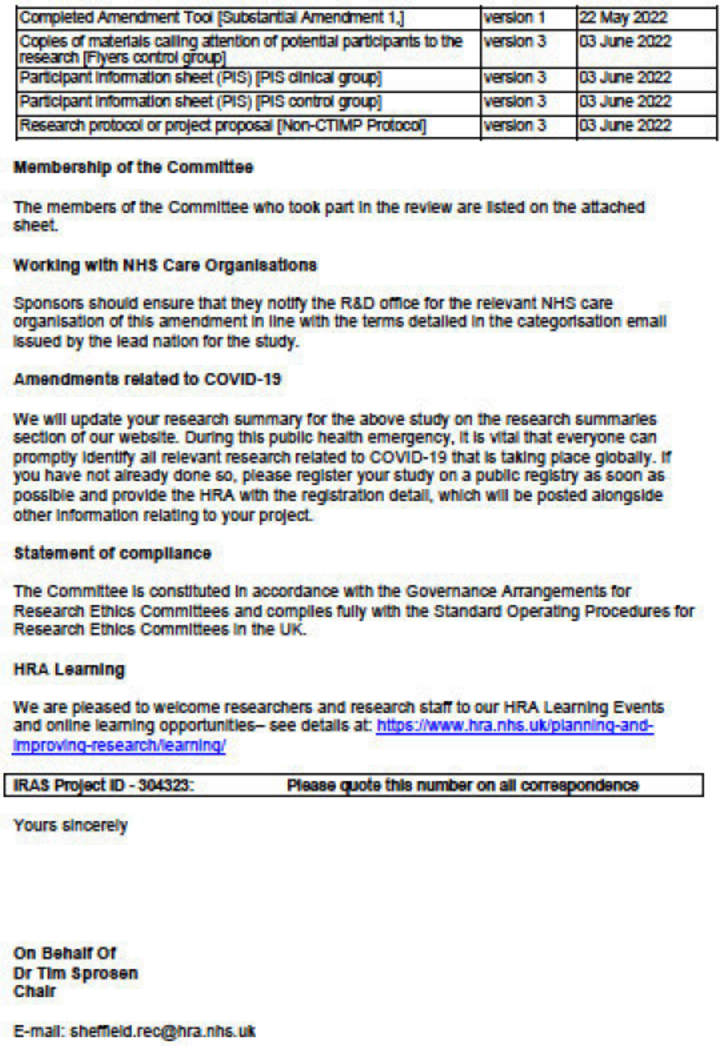
Attendance at Sub-Committee of the REC meeting on 29 June 2022

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Jane McKeown	University Teacher	Yes	
Dr Tim Sprosen	Epidemiologist	Yes	Chair

Also in attendance:

Name	*Position (or reason for attending)*
Mr Taimoor Hassan	Approvals Administrator



Completed Amendment Tool [Substantial Amendment 1,]	version 1	22 May 2022
Copies of materials calling attention of potential participants to the research [Flyers control group]	version 3	03 June 2022
Participant information sheet (PIS) [PIS clinical group]	version 3	03 June 2022
Participant information sheet (PIS) [PIS control group]	version 3	03 June 2022
Research protocol or project proposal [Non-CTIMP Protocol]	version 3	03 June 2022

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 304323:	**Please quote this number on all correspondence**

Yours sincerely

On Behalf Of
Dr Tim Sprosen
Chair

E-mail: sheffield.rec@hra.nhs.uk

Appendix D. Ethical Approval from the Research and Development (R&D) Department

Research and Development

Foresterhill House Annexe
Foresterhill
ABERDEEN
AB25 2ZB

NHS
Grampian

Miss Doriana Marchetti
NHS Grampian/ University of Edinburgh
School of Health in Social Science
University of Edinburgh

Date 28/01/2022
Project No 2021CL001E

Enquiries to Linda Leith
Extension 53846
Direct Line 01224 553846
Email gram.randdpermissions@nhs.scot

Dear Miss Marchetti

Management Permission for Non-Commercial Research

STUDY TITLE: Using the common sense model of illness to understand parents' experiences of caring for a child with an Eating Disorder.
PROTOCOL NO: V1, 11.11.21
REC REF: 21/PR/1586
IRAS REF: 304323

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the UK Policy Framework for Health and Social Care Research (2017 v3), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

R&D Permission is granted on condition that:

1) **The R&D Office will be notified and any relevant documents forwarded to us if any of the following occur:**
    - **Any Serious Breaches in Grampian (Please forward to pharmaco@abdn.ac.uk).**
    - **A change of Principal Investigator in Grampian or Chief Investigator.**
    - **Any change to funding or any additional funding**

2) **When the study ends, the R&D Office will be notified of the study end-date.**

3) **The Sponsor will notify all amendments to the relevant National Co-ordinating centre. For single centre studies, amendments should be notified to the R&D office directly.**

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

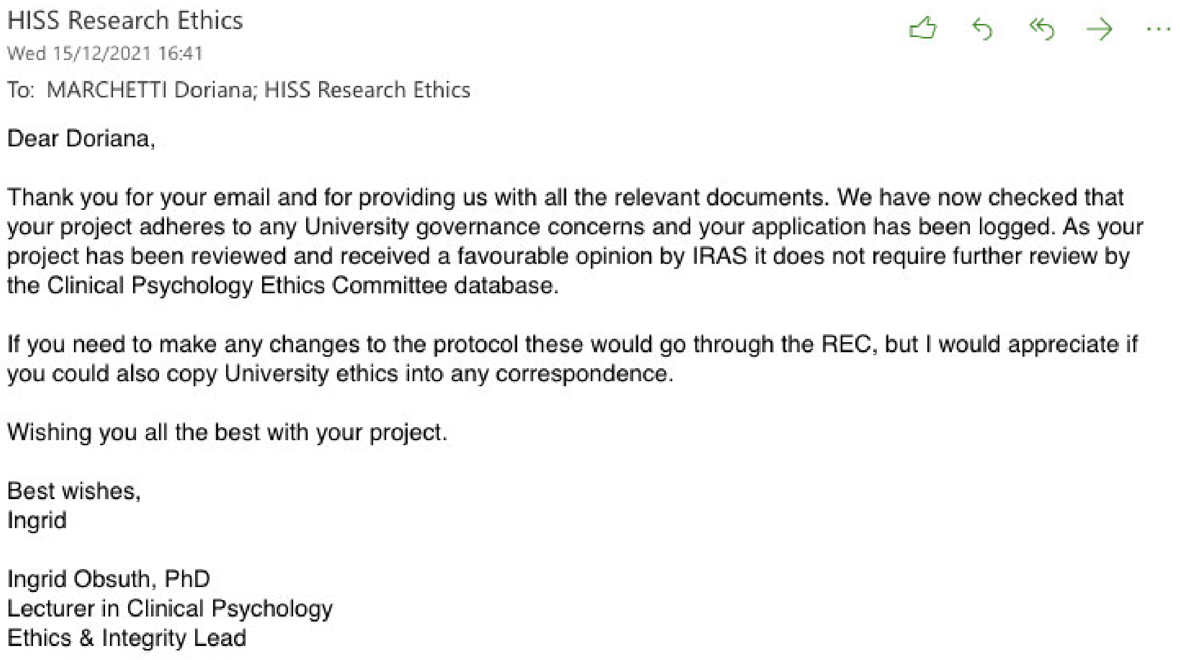
Yours sincerely

Susan Ridge
Non-Commercial Manager

cc: CI Dr Vilas Sawrikar
Research Monitor
Dr Rachael Smith
Ms Charlotte Smith
Ms Carol Ball
Dr Nicola Price
Dr Rituka Richardson
Ms Louise Milne

Sponsor: Edinburgh University

Appendix E. Ethical Approval from the School of Health in Social Science



HISS Research Ethics
Wed 15/12/2021 16:41
To: MARCHETTI Doriana; HISS Research Ethics

Dear Doriana,

Thank you for your email and for providing us with all the relevant documents. We have now checked that your project adheres to any University governance concerns and your application has been logged. As your project has been reviewed and received a favourable opinion by IRAS it does not require further review by the Clinical Psychology Ethics Committee database.

If you need to make any changes to the protocol these would go through the REC, but I would appreciate if you could also copy University ethics into any correspondence.

Wishing you all the best with your project.

Best wishes,
Ingrid

Ingrid Obsuth, PhD
Lecturer in Clinical Psychology
Ethics & Integrity Lead

Appendix F. Participant Information Sheet (PIS): clinical sample

PARTICIPANT INFORMATION SHEET (PIS)

Understanding parents' experiences of caring for child with an Eating Disorder

You are being invited to take part in research on understanding parents' experiences of having a child with an Eating Disorder (ED). Doriana Marchetti, a trainee Clinical Psychologist at the University of Edinburgh is leading this research. Before you decide whether to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

What is the purpose of this study?
The purpose of the study is to understand parental experiences when caring for child with ED. The emotional toll of caring for a child with ED is not well-understood making it challenging to provide adequate support and coping skills for parents. Therefore, in order to understand how best to support parents, we would like to undertake this study to better understand the wellbeing of parents caring for children with ED.

Why have I been invited to take part?
You are invited to participate in this study because you are a parent or a guardian caring for a child aged between 12-18 years who is struggling with eating difficulties.

Do I have to take part?
No – it is entirely up to you. If you decide to take part, you are still free to stop at any time, without giving a reason, whilst completing the questionnaires. This will not impact on the clinical care you or your child receives. However, as participation in the research study is anonymous, it will not be possible to withdraw your data once you have submitted your questionnaires.

What will happen if I decide to take part?
If you do decide to take part, please keep this Patient Information Sheet, and follow the link below.

You will be asked several questions regarding your personal information about yourself (e.g., gender and occupation) and about your child (e.g., age and gender). You will also be asked to complete some questionnaires about your thoughts, feelings, and behaviours towards yourself and your child.

These questionnaires are recommended to be done in a safe environment at a time that is convenient to you. These personal information and questionnaires should take around 40 minutes maximum to complete. Your data will only be saved once the entire questionnaire is submitted. Given that this study is anonymous, there is no mechanism to prevent duplication. Therefore, the questionnaires need to be completed in one run.

What are the possible benefits of taking part?
There are no direct benefits, but by sharing your experiences with us you will be helping Doriana Marchetti, the NHS, future families, and the University to create the best possible intervention for future parents with children suffering from eating difficulties.

Are there any risks or disadvantages associated with taking part?
There are no significant risks associated with participation although the expected time commitment for the four requested questionnaires is 40 minutes. If you experience any distress completing these questionnaires, please contact one of the support services listed at the end of this information sheet. We will also provide these details at the end of the study.

Will my taking part be kept confidential?
All the information we collect during the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. The research process is organised so that all data which is collected about you will be anonymous and kept completely confidential, which means the research team will never be able to identify you.

How will we use information about you?
Your information will be anonymised in our records. Your data will only be viewed by the researcher and the research team. Your data will be destroyed once they have been analysed.

We will keep all information about you safe and secure. All electronic data will be stored on a password-protected computer file that meets the encryption standards used throughout the NHS. Your consent information will be kept separately from your responses to minimise risk.

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

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Anonymised data from the study will be stored for a minimum of 3 years and may be used in future ethically approved research.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, whilst completing the questionnaires. However, as participation in the research study is anonymous, it will not be possible to withdraw your data once you have submitted your questionnaires.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

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

- at https://www.ed.ac.uk/records-management/privacy-notice-research
- at https://www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to the University of Edinburgh Data Protection Officer at dpo@ed.ac.uk

What will happen with the results of this study?
The research will initially be published as a thesis as part of the University of Edinburgh's Doctorate in Clinical Psychology. The results of the research will also be made into a leaflet and a poster explaining the findings. You will be given the opportunity to read a summary of the findings if you wish. We may also publish the results in scientific journals and present the results at conferences. This will likely be made available by September 2023. No patient identifiable information will be made public.

Who is organising and funding this research?
The project is part of Doriana Marchetti's training as part of the Doctorate in Clinical Psychology at the University of Edinburgh. The University of Edinburgh is the sponsor for this study. There is no additional funding in place for this research.

Who has reviewed this study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee. A favourable ethical opinion has been obtained from the PR Committee. NHS Management Approval has also been given.

Who can I contact?
If you have any further questions or concerns about the study, please contact the lead researcher, Doriana Marchetti at

If you would like to discuss this study with someone independent of the study, please contact Dr Angus Macbeth on

If you wish to make a complaint about the study, please contact Matthias Schwannauer, the head of school and professor of clinical psychology on headofschool health@ed.ac.uk

Conclusion

- Thank you for taking the time to read about this research.
- If you wish to take part, please follow, and click on the link below, which will take you to the study.
- If you do not wish to participate, please exit this page.

Taking part in this study means that you confirm that you have read and understood the Participant Information Sheet (Version 2 dated 30/11/2021) for the above study

Are you interested in taking part in this study?
Please follow this link: https://edinburgh.eu.qualtrics.com/jfe/form/SV_8evX1eYYQMZ80mO

Are you interested in receiving a summary of the study results?
Please, follow this link: https://psychologyofparents.blogspot.com/ This will likely be made available by September 2023.

Appendix G. Demographic questionnaire

Demographic information about parents

About you…

- **What age category do you fall into?**
  - o 18-24
  - o 25-34
  - o 35-45
  - o 45-54
  - o 55-64
  - o 65 and over
  - o Prefer not to say

- **How would you describe your gender?**
  - o Male
  - o Female
  - o Transgender
  - o Non-binary
  - o Prefer not to say

- **How would you describe your ethnicity?**
  - o White
  - o Asian
  - o Black
  - o Mixed
  - o Other…
  - o Prefer not to say

- **What is your education level?**
  - o Primary studies
  - o Secondary studies
  - o Professional education
  - o University studies
  - o Other…
  - o Prefer not to say

- **What is your relationship status?**
  - o Married/cohabiting
  - o Single with partner
  - o Single without partner
  - o Widowed
  - o Divorced
  - o Other…
  - o Prefer not to say

- **What is your employment status?**

    - Student
    - Carer
    - Part-time employed
    - Full-time employed
    - Unemployed
    - Other…
    - Prefer not to say

- **Do you have a current mental health diagnosis?**
    - Yes
    - No
    - Prefer not to say

- **Do you have a learning disability?**
    - Yes
    - No
    - Prefer not to say

- **Are you comfortable continuing these questionnaires in English?**
    - Yes
    - No
    - Prefer not to say

Demographic information about their child

About your child

- **How old is your child?**
  - o Under 12
  - o 12-14
  - o 14-16
  - o 16-18
  - o 18 or over
  - o Prefer not to say

- **How would you describe the gender of your child?**
  - o Male
  - o Female
  - o Transgender
  - o Non-binary
  - o Prefer not to say

- **What symptoms is your child experiencing? My child is experiencing symptoms of…**
  - o Anorexia
  - o Bulimia
  - o Binge eating
  - o Not specified
  - o Mixed
  - o Others…
  - o N/A
  - o Prefer not to say

- **When did your child start having eating difficulties?**
  - o Under 3 months ago
  - o 3-6 months ago
  - o 6-12 months ago
  - o Over 12 months ago

- **Are you currently referred to a mental health service for your child’s eating difficulties?**
  - o Yes
    - o NHS
    - o BEAT
    - o Others
  - o No
  - o Prefer not to say

Appendix H. Brief illness Perceptions Questionnaire (Brief IPQ)

It is common to have negative thoughts about our children, especially when they experience emotional and behavioural difficulties. This questionnaire will explore some of these thoughts, so please be as honest as you can when completing these questions. Please rate these items on a scale from 0-10.

1. **How much does the eating disorder of your child affect your life?**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No affect at all										**Severely affect my life**

2. **How long do you think the eating disorder of your child will continue?**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
A very short time										**Forever**

3. **How much control do you feel you have over the eating disorder of your child?**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Absolutely no control										**Extreme amount of control**

4. **How much do you think her/his treatment can help your child's eating disorder?**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Not at all										**Extremely helpful**

5. **How much does your child experience symptoms from his/her eating disorder?**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No symptoms at all										**Many severe symptoms**

6. **How concerned are you about your child’s eating disorder?**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Not at all concerned										**Extremely concerned**

7. **How well do you feel you understand your child’s eating disorder?**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
I don’t understand at all										**I understad very clearly**

8. **How much does the eating disorder of your child affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?**

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Not at all affected emotionally										**Extremely affected emotionally**

9. **Please list in rank-order the three most important factors that you believe caused the eating disorder of your child. The most important causes for me:**

____

____

____

Appendix I. Brief Coping Orientation to Problems Experienced (Brief COPE)

It is difficult to be a parent and we do not always know what to do and how to deal with our children's difficulties. This questionnaire is going to explore some of these behaviours, so please try to be as honest as possible when answering these questions. Please rate each statement on a scale from 1-4.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

	QUESTIONS				
1	I've been turning to work or other activities to take my mind off things.	1	2	3	4
2	I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3	I've been saying to myself "this isn't real".	1	2	3	4
4	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5	I've been getting emotional support from others	1	2	3	4
6	I've been giving up trying to deal with it.	1	2	3	4
7	I've been taking action to try to make the situation better.	1	2	3	4
8	I've been refusing to believe that it has happened	1	2	3	4
9	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10	I've been getting help and advice from other people	1	2	3	4
11	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4

13	I’ve been criticizing myself.	1	2	3	4
14	I've been trying to come up with a strategy about what to do.	1	2	3	4
15	I've been getting comfort and understanding from someone.	1	2	3	4
16	I've been giving up the attempt to cope	1	2	3	4
17	I've been looking for something good in what is happening.	1	2	3	4
18	I've been making jokes about it.	1	2	3	4
19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20	I've been accepting the reality of the fact that it has happened	1	2	3	4
21	I've been expressing my negative feelings.	1	2	3	4
22	I've been trying to find comfort in my religion or spiritual beliefs	1	2	3	4
23	I’ve been trying to get advice or help from other people about what to do.	1	2	3	4
24	I've been learning to live with it	1	2	3	4
25	I've been thinking hard about what steps to take	1	2	3	4
26	I’ve been blaming myself for things that happened.	1	2	3	4
27	I've been praying or meditating.	1	2	3	4
28	I've been making fun of the situation.	1	2	3	4

Appendix J. Depression, Anxiety and Stress Scale (DASS)

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree, or a good part of time
3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3

17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

Appendix K. Eating Disorder Examination Questionnaire - Short (EDE-QS)

My child's weight: _______ My child's height: ________

	ON HOW MANY OF THE PAST 7 DAYS…	0 days	1-2 days	3-5 days	6-7 days
1	My child has been deliberately trying to limit the amount of food she/he eats to influence her/his weight or shape (whether or not she/he has succeeded)?	0	1	2	3
2	My child has gone for long periods of time (e.g., 8 or more waking hours) without eating anything at all in order to influence her/his weight or shape	0	1	2	3
3	Has her/his thinking about food, eating or calories made it very difficult to concentrate on things she/he is interested in (such as working, following a conversation or reading)?	0	1	2	3
4	Has her/his thinking about your weight or shape made it very difficult to concentrate on things she/he is interested in (such as working, following a conversation or reading)?	0	1	2	3
5	Has your child have a definite fear that she/he migh gain weight?	0	1	2	3
6	Has your child have a strong desire to lose weight?	0	1	2	3
7	Had your child tried to control her/his weight or sh by making herself/himself sick (vomit) or taking laxatives?	0	1	2	3
8	Has your child exercised in a driven or compulsive way as a means of controlling her/his weight, shape or body fat, or to burn off calories?	0	1	2	3

9	Has your child had a sense of having lost control ov her/his eating (at the time that she/her was eating)?	0	1	2	3
10	On how many of these days *(i.e. days on which* s*he/he had a sense of having lost control over your eating*) did she/her eat what other people would regard as an unusually large amount of food in one go?	0	1	2	3
	OVER THE PAST 7 DAYS…	Not at all	Slightly	Moderately	Markedly
11	Has your child's weight or shape influenced how she/he thinks about (judge) herself/himself as a pers	0	1	2	3
12	How dissatisfied has she/he been with her/his weig or shape?	0	1	2	3

Appendix L. Social media content

Survey Responses Needed

Your chances to help with mental health research!

Online survey for parents caring for a child aged 12-18
about mental health and food related thoughts

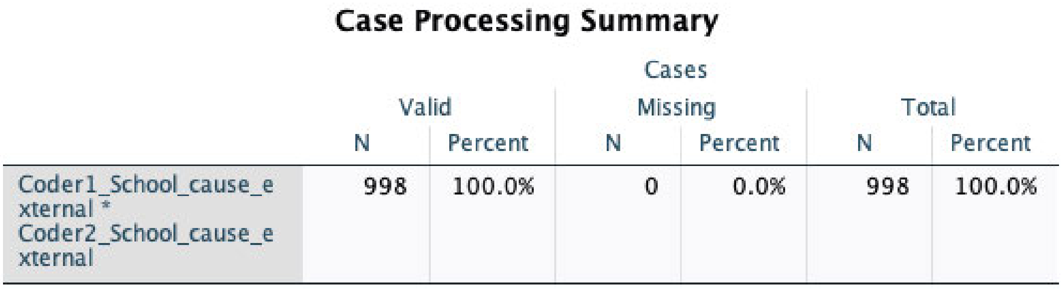
THE UNIVERSITY of EDINBURGH

NHS

Appendix M. Raw calculation of cohen's kappa Coefficient

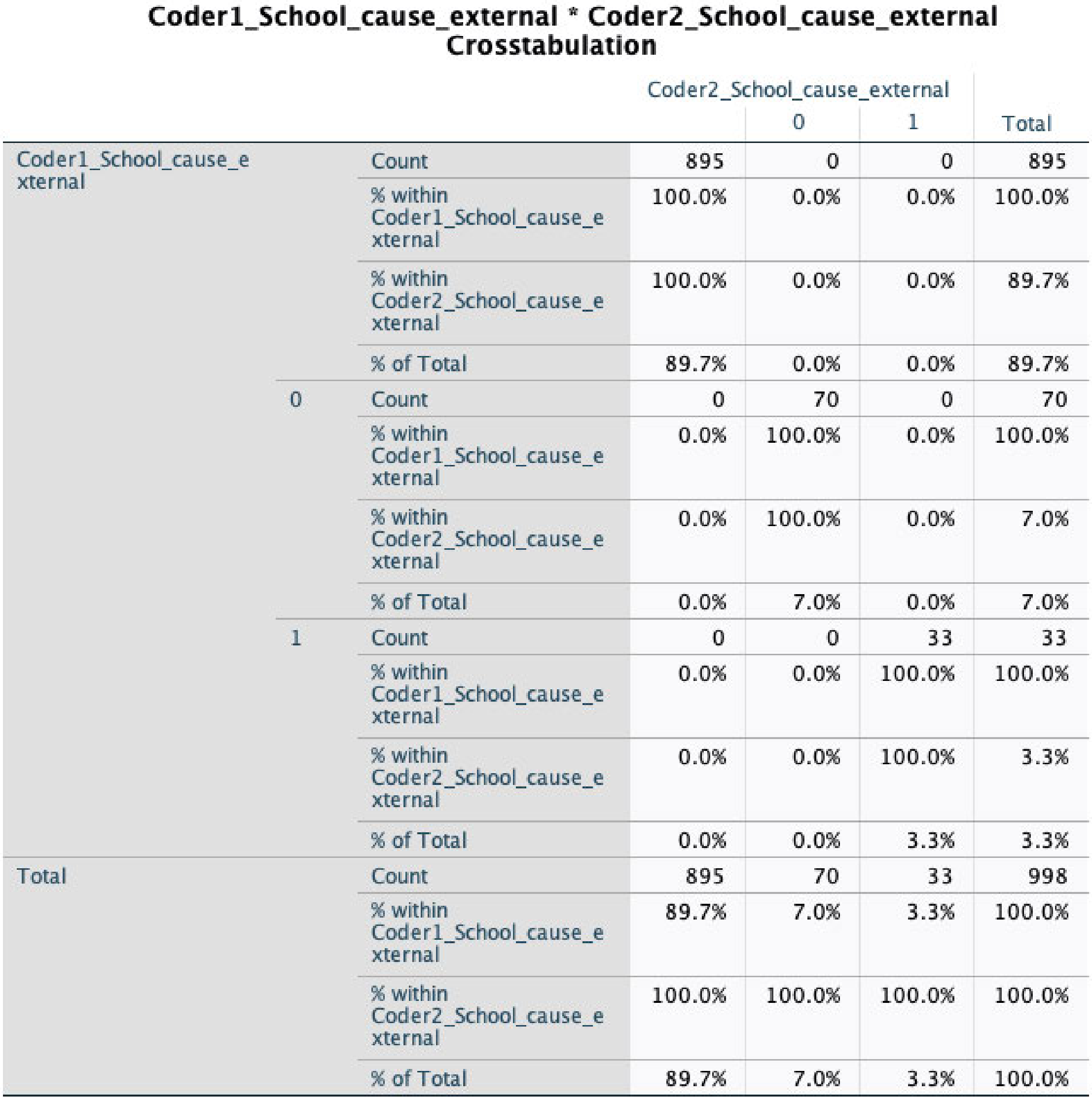
1. External causes

1.1 School



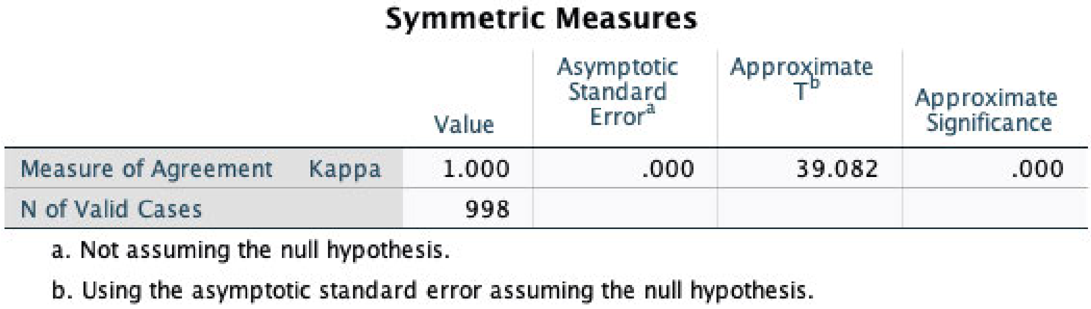
Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Coder1_School_cause_external * Coder2_School_cause_external	998	100.0%	0	0.0%	998	100.0%



Coder1_School_cause_external * Coder2_School_cause_external Crosstabulation

			Coder2_School_cause_external			
				0	1	Total
Coder1_School_cause_external		Count	895	0	0	895
		% within Coder1_School_cause_external	100.0%	0.0%	0.0%	100.0%
		% within Coder2_School_cause_external	100.0%	0.0%	0.0%	89.7%
		% of Total	89.7%	0.0%	0.0%	89.7%
	0	Count	0	70	0	70
		% within Coder1_School_cause_external	0.0%	100.0%	0.0%	100.0%
		% within Coder2_School_cause_external	0.0%	100.0%	0.0%	7.0%
		% of Total	0.0%	7.0%	0.0%	7.0%
	1	Count	0	0	33	33
		% within Coder1_School_cause_external	0.0%	0.0%	100.0%	100.0%
		% within Coder2_School_cause_external	0.0%	0.0%	100.0%	3.3%
		% of Total	0.0%	0.0%	3.3%	3.3%
Total		Count	895	70	33	998
		% within Coder1_School_cause_external	89.7%	7.0%	3.3%	100.0%
		% within Coder2_School_cause_external	100.0%	100.0%	100.0%	100.0%
		% of Total	89.7%	7.0%	3.3%	100.0%



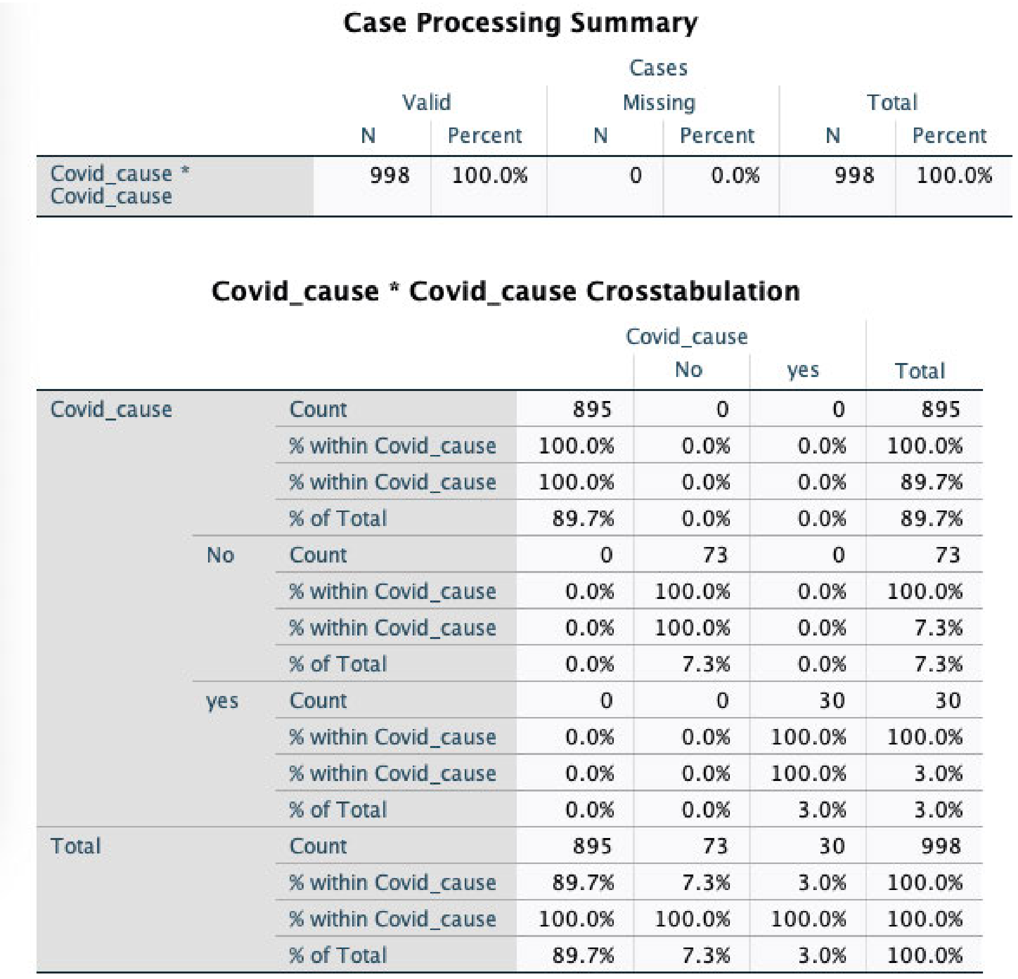
Symmetric Measures

		Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	39.082	.000
N of Valid Cases		998			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

2.2 Covid-19

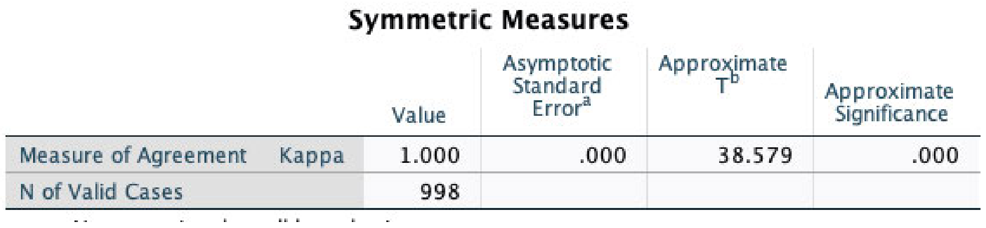


Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Covid_cause * Covid_cause	998	100.0%	0	0.0%	998	100.0%

Covid_cause * Covid_cause Crosstabulation

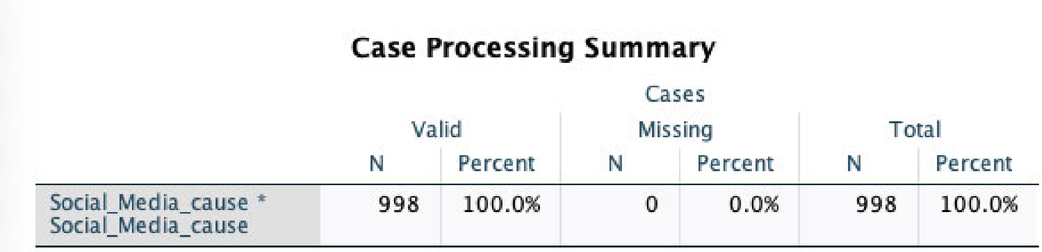
			Covid_cause			
				No	yes	Total
Covid_cause		Count	895	0	0	895
		% within Covid_cause	100.0%	0.0%	0.0%	100.0%
		% within Covid_cause	100.0%	0.0%	0.0%	89.7%
		% of Total	89.7%	0.0%	0.0%	89.7%
	No	Count	0	73	0	73
		% within Covid_cause	0.0%	100.0%	0.0%	100.0%
		% within Covid_cause	0.0%	100.0%	0.0%	7.3%
		% of Total	0.0%	7.3%	0.0%	7.3%
	yes	Count	0	0	30	30
		% within Covid_cause	0.0%	0.0%	100.0%	100.0%
		% within Covid_cause	0.0%	0.0%	100.0%	3.0%
		% of Total	0.0%	0.0%	3.0%	3.0%
Total		Count	895	73	30	998
		% within Covid_cause	89.7%	7.3%	3.0%	100.0%
		% within Covid_cause	100.0%	100.0%	100.0%	100.0%
		% of Total	89.7%	7.3%	3.0%	100.0%



Symmetric Measures

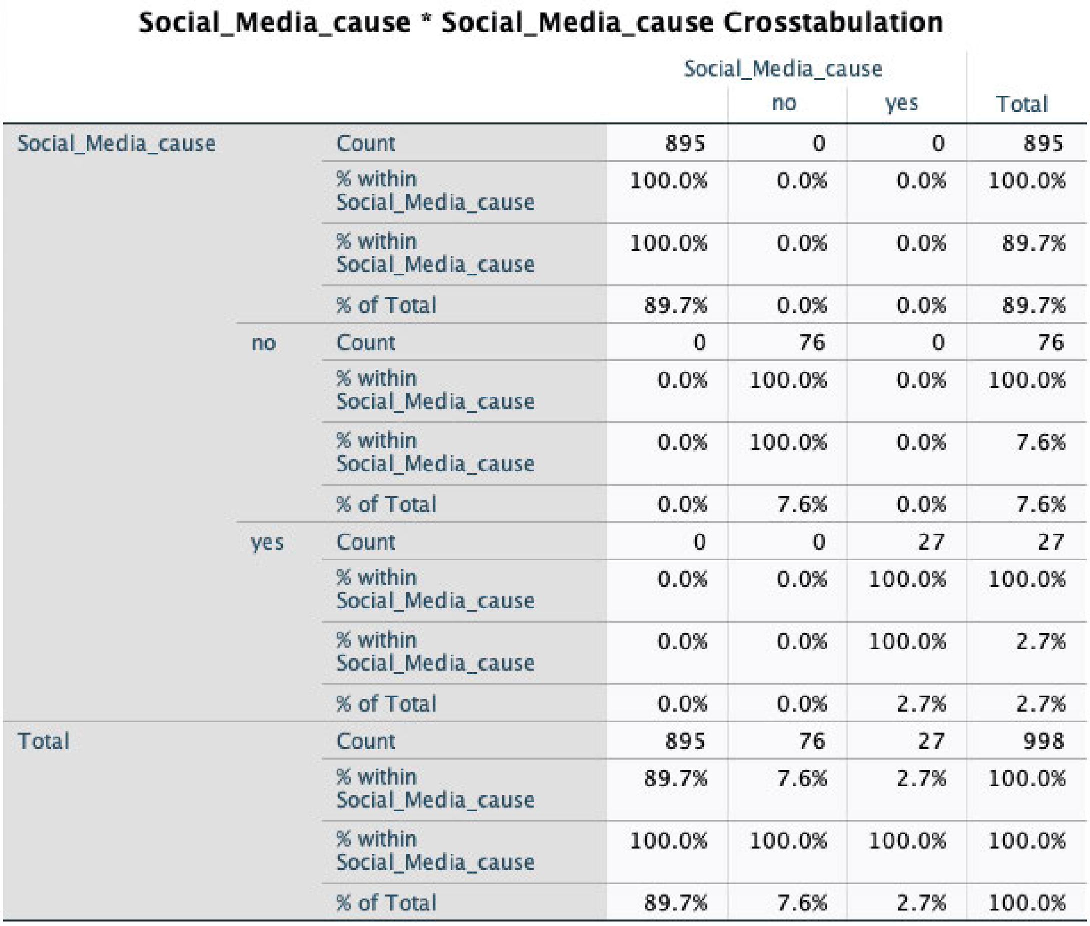
		Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	38.579	.000
N of Valid Cases		998			

1.3 Social media



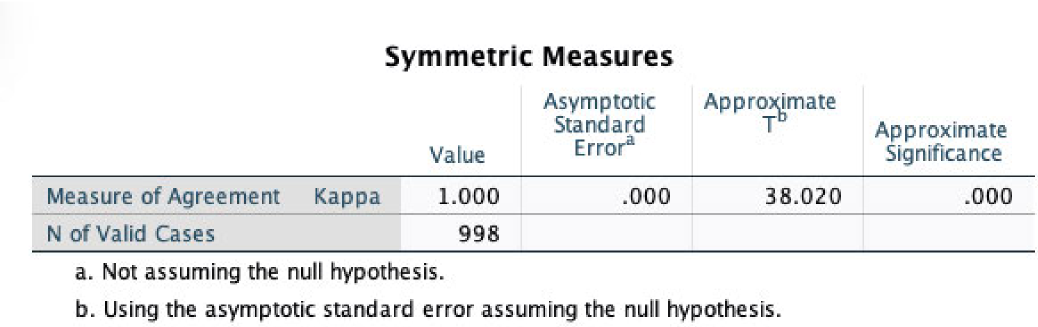
Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Social_Media_cause * Social_Media_cause	998	100.0%	0	0.0%	998	100.0%



Social_Media_cause * Social_Media_cause Crosstabulation

			Social_Media_cause			
				no	yes	Total
Social_Media_cause		Count	895	0	0	895
		% within Social_Media_cause	100.0%	0.0%	0.0%	100.0%
		% within Social_Media_cause	100.0%	0.0%	0.0%	89.7%
		% of Total	89.7%	0.0%	0.0%	89.7%
	no	Count	0	76	0	76
		% within Social_Media_cause	0.0%	100.0%	0.0%	100.0%
		% within Social_Media_cause	0.0%	100.0%	0.0%	7.6%
		% of Total	0.0%	7.6%	0.0%	7.6%
	yes	Count	0	0	27	27
		% within Social_Media_cause	0.0%	0.0%	100.0%	100.0%
		% within Social_Media_cause	0.0%	0.0%	100.0%	2.7%
		% of Total	0.0%	0.0%	2.7%	2.7%
Total		Count	895	76	27	998
		% within Social_Media_cause	89.7%	7.6%	2.7%	100.0%
		% within Social_Media_cause	100.0%	100.0%	100.0%	100.0%
		% of Total	89.7%	7.6%	2.7%	100.0%



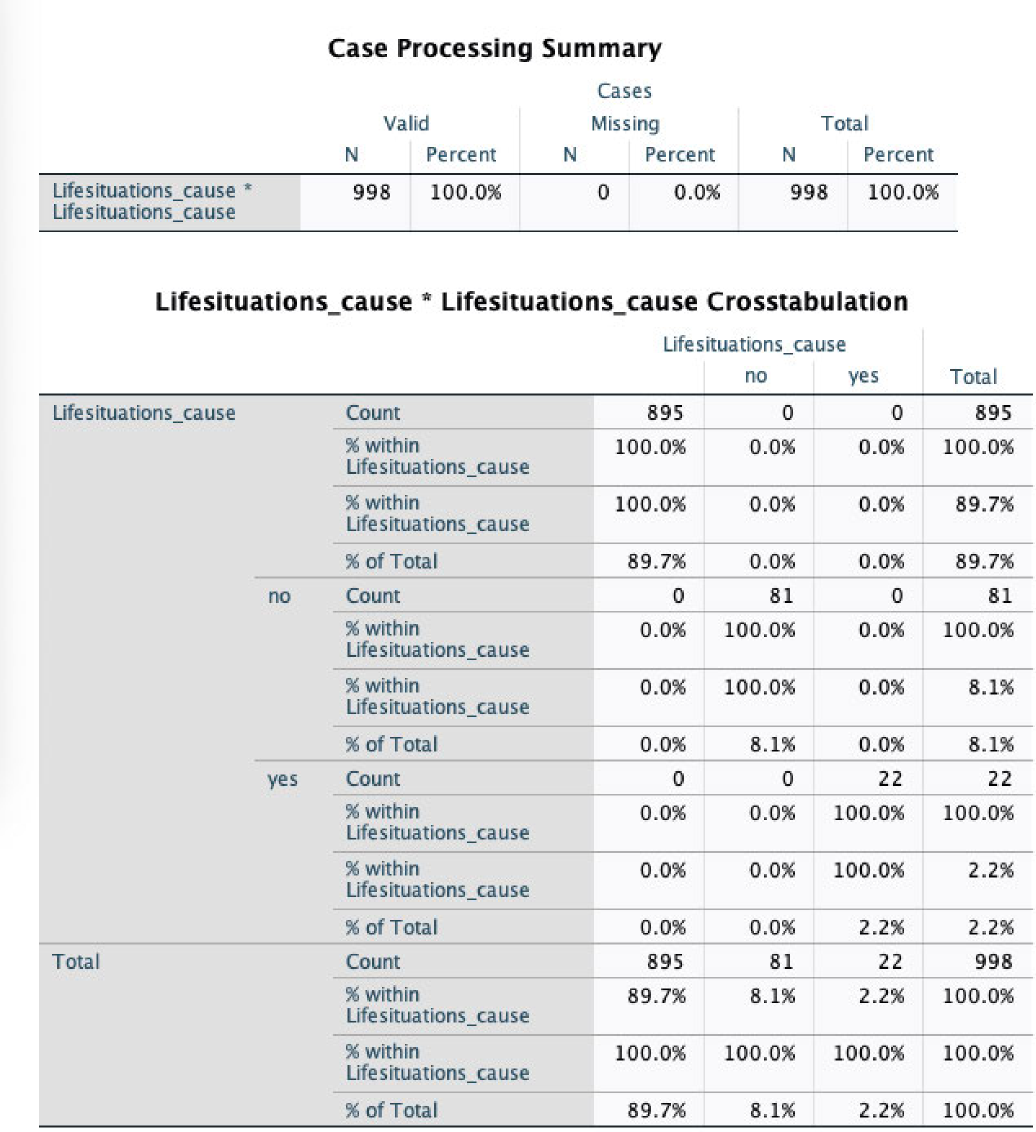
Symmetric Measures

		Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	38.020	.000
N of Valid Cases		998			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

1.4 Life situations

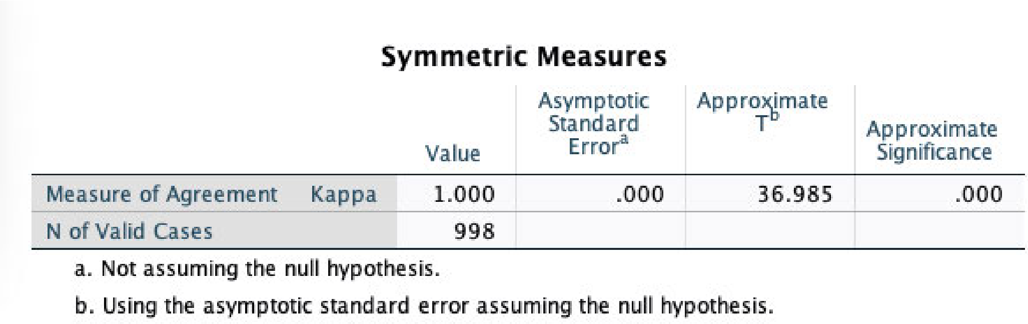


Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Lifesituations_cause * Lifesituations_cause	998	100.0%	0	0.0%	998	100.0%

Lifesituations_cause * Lifesituations_cause Crosstabulation

			Lifesituations_cause			
				no	yes	Total
Lifesituations_cause		Count	895	0	0	895
		% within Lifesituations_cause	100.0%	0.0%	0.0%	100.0%
		% within Lifesituations_cause	100.0%	0.0%	0.0%	89.7%
		% of Total	89.7%	0.0%	0.0%	89.7%
	no	Count	0	81	0	81
		% within Lifesituations_cause	0.0%	100.0%	0.0%	100.0%
		% within Lifesituations_cause	0.0%	100.0%	0.0%	8.1%
		% of Total	0.0%	8.1%	0.0%	8.1%
	yes	Count	0	0	22	22
		% within Lifesituations_cause	0.0%	0.0%	100.0%	100.0%
		% within Lifesituations_cause	0.0%	0.0%	100.0%	2.2%
		% of Total	0.0%	0.0%	2.2%	2.2%
Total		Count	895	81	22	998
		% within Lifesituations_cause	89.7%	8.1%	2.2%	100.0%
		% within Lifesituations_cause	100.0%	100.0%	100.0%	100.0%
		% of Total	89.7%	8.1%	2.2%	100.0%



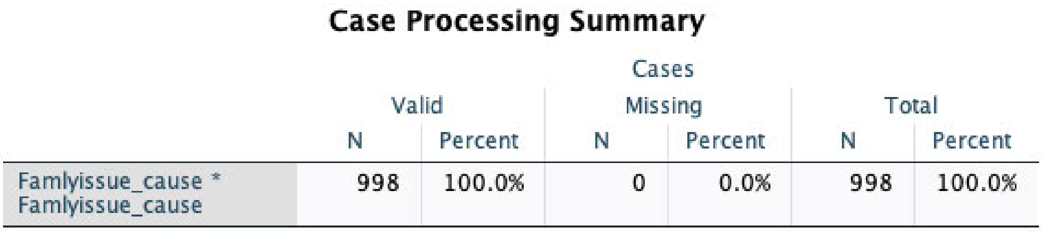
Symmetric Measures

		Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	36.985	.000
N of Valid Cases		998			

a. Not assuming the null hypothesis.

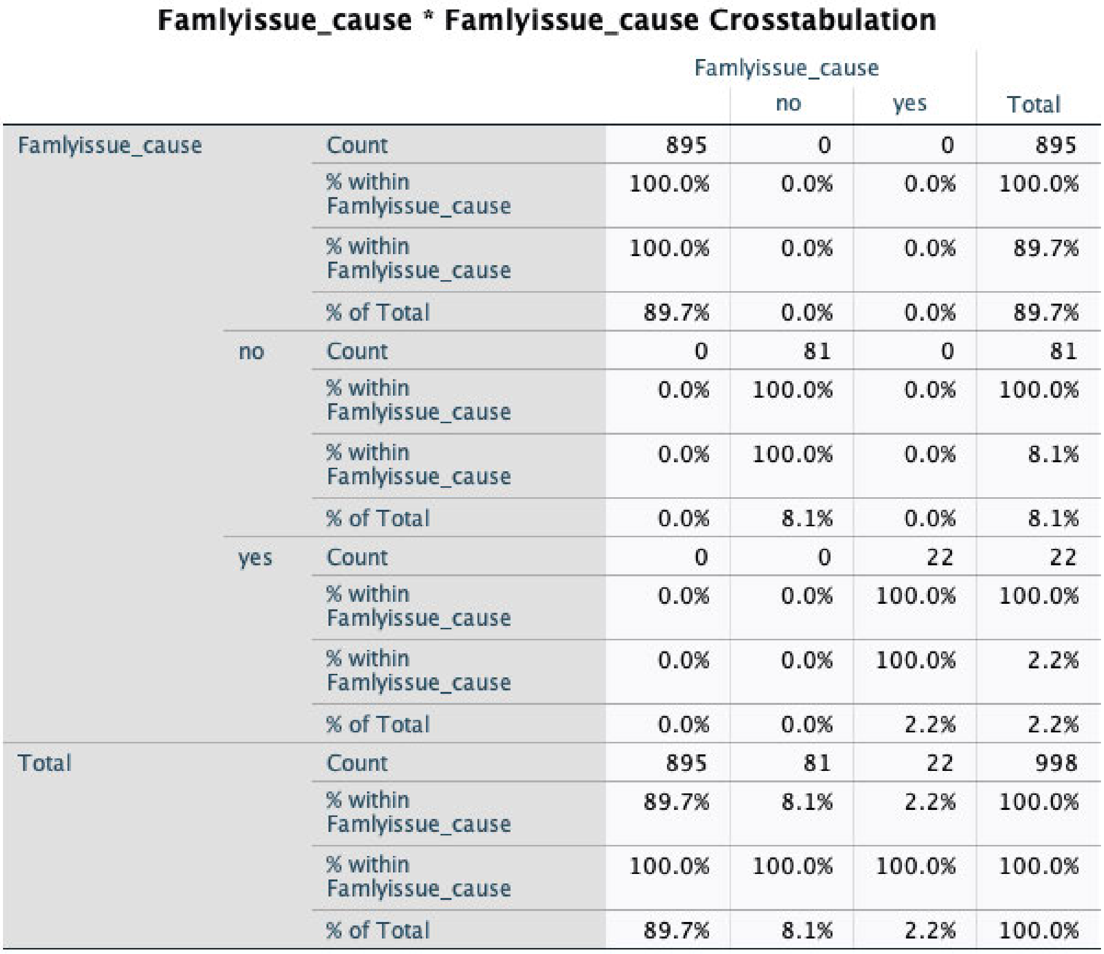
b. Using the asymptotic standard error assuming the null hypothesis.

1.5 Family problems



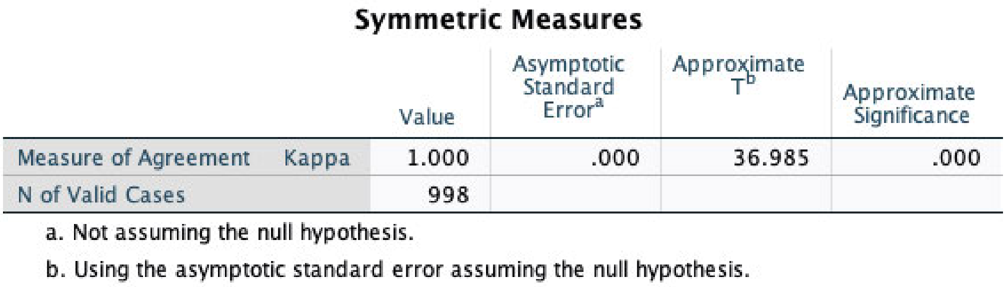
Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Famlyissue_cause * Famlyissue_cause	998	100.0%	0	0.0%	998	100.0%



Famlyissue_cause * Famlyissue_cause Crosstabulation

			Famlyissue_cause			
				no	yes	Total
Famlyissue_cause		Count	895	0	0	895
		% within Famlyissue_cause	100.0%	0.0%	0.0%	100.0%
		% within Famlyissue_cause	100.0%	0.0%	0.0%	89.7%
		% of Total	89.7%	0.0%	0.0%	89.7%
	no	Count	0	81	0	81
		% within Famlyissue_cause	0.0%	100.0%	0.0%	100.0%
		% within Famlyissue_cause	0.0%	100.0%	0.0%	8.1%
		% of Total	0.0%	8.1%	0.0%	8.1%
	yes	Count	0	0	22	22
		% within Famlyissue_cause	0.0%	0.0%	100.0%	100.0%
		% within Famlyissue_cause	0.0%	0.0%	100.0%	2.2%
		% of Total	0.0%	0.0%	2.2%	2.2%
Total		Count	895	81	22	998
		% within Famlyissue_cause	89.7%	8.1%	2.2%	100.0%
		% within Famlyissue_cause	100.0%	100.0%	100.0%	100.0%
		% of Total	89.7%	8.1%	2.2%	100.0%



Symmetric Measures

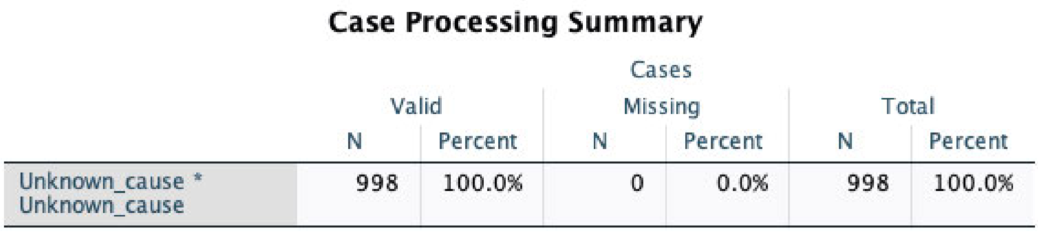
		Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	36.985	.000
N of Valid Cases		998			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

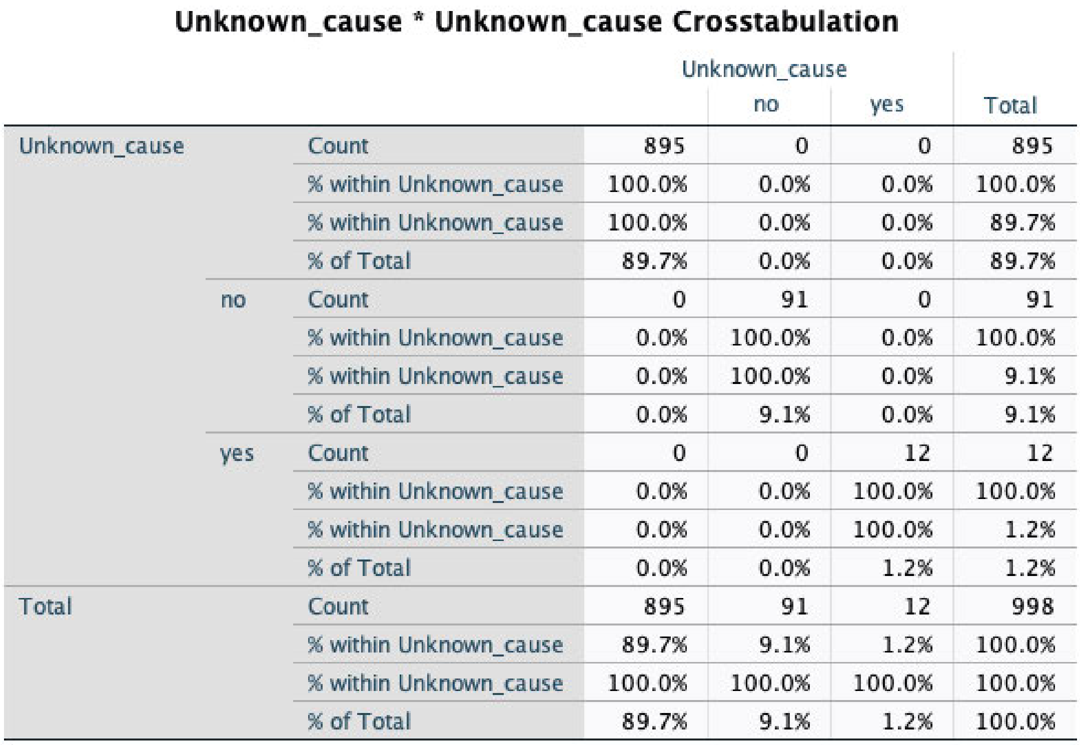
CROSSTABS

1.6 Unknown



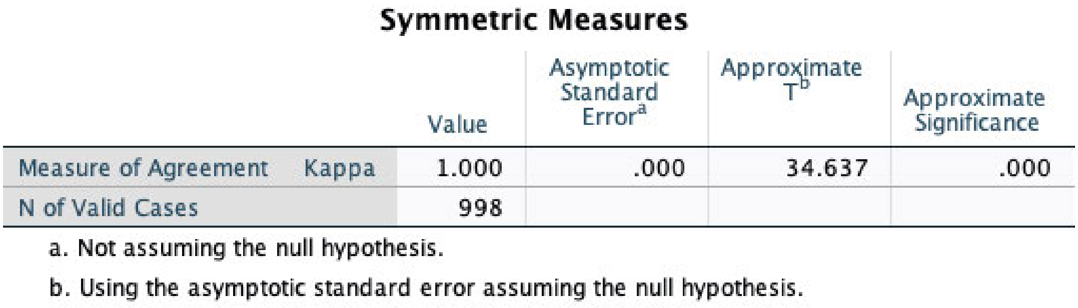
Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Unknown_cause * Unknown_cause	998	100.0%	0	0.0%	998	100.0%



Unknown_cause * Unknown_cause Crosstabulation

			Unknown_cause			
				no	yes	Total
Unknown_cause		Count	895	0	0	895
		% within Unknown_cause	100.0%	0.0%	0.0%	100.0%
		% within Unknown_cause	100.0%	0.0%	0.0%	89.7%
		% of Total	89.7%	0.0%	0.0%	89.7%
	no	Count	0	91	0	91
		% within Unknown_cause	0.0%	100.0%	0.0%	100.0%
		% within Unknown_cause	0.0%	100.0%	0.0%	9.1%
		% of Total	0.0%	9.1%	0.0%	9.1%
	yes	Count	0	0	12	12
		% within Unknown_cause	0.0%	0.0%	100.0%	100.0%
		% within Unknown_cause	0.0%	0.0%	100.0%	1.2%
		% of Total	0.0%	0.0%	1.2%	1.2%
Total		Count	895	91	12	998
		% within Unknown_cause	89.7%	9.1%	1.2%	100.0%
		% within Unknown_cause	100.0%	100.0%	100.0%	100.0%
		% of Total	89.7%	9.1%	1.2%	100.0%



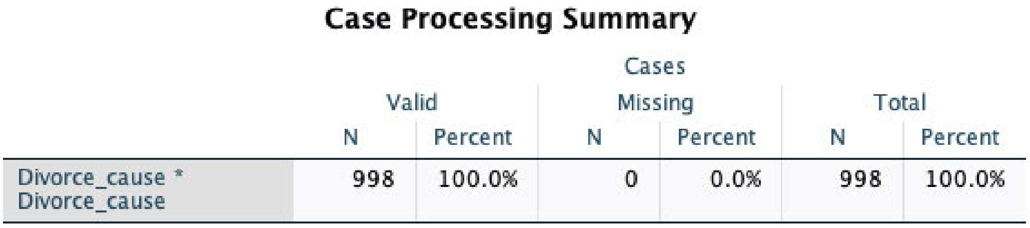
Symmetric Measures

		Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	34.637	.000
N of Valid Cases		998			

a. Not assuming the null hypothesis.

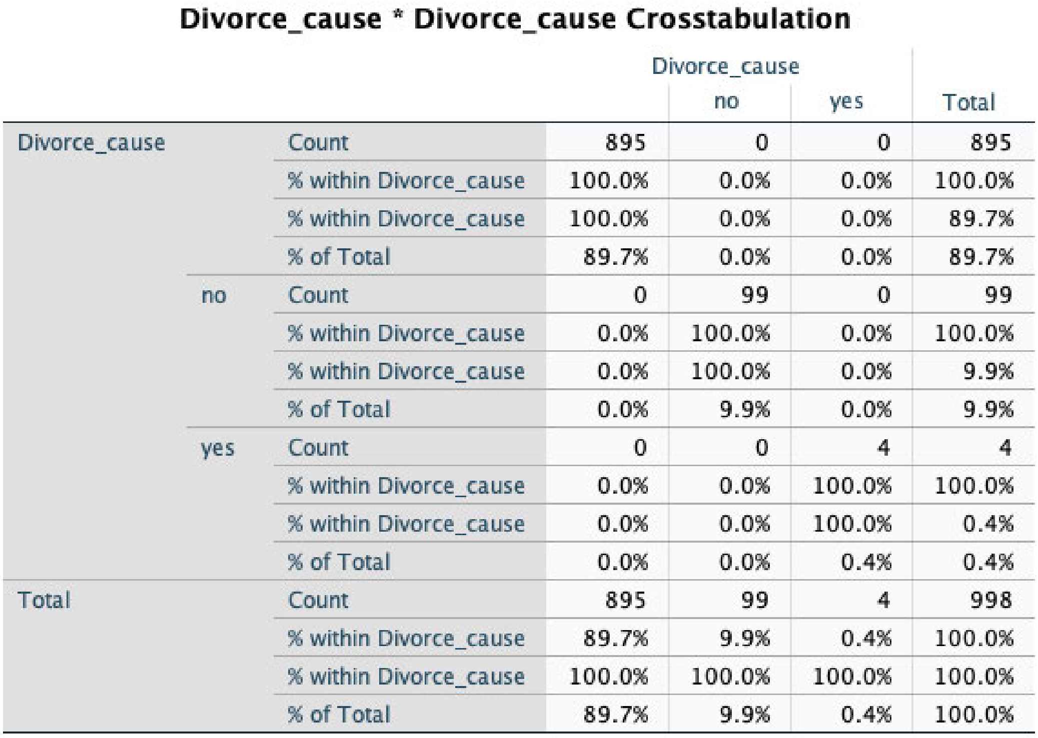
b. Using the asymptotic standard error assuming the null hypothesis.

1.7 Parental divorce



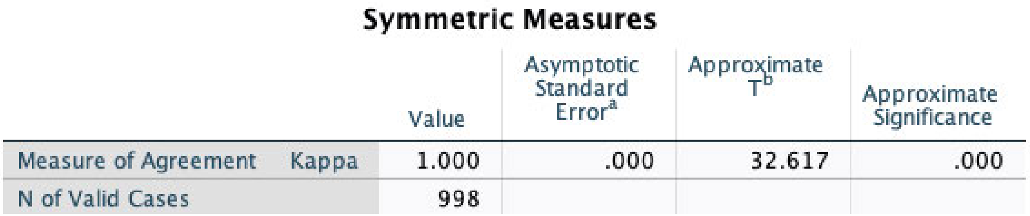
Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Divorce_cause * Divorce_cause	998	100.0%	0	0.0%	998	100.0%



Divorce_cause * Divorce_cause Crosstabulation

			Divorce_cause			
				no	yes	Total
Divorce_cause		Count	895	0	0	895
		% within Divorce_cause	100.0%	0.0%	0.0%	100.0%
		% within Divorce_cause	100.0%	0.0%	0.0%	89.7%
		% of Total	89.7%	0.0%	0.0%	89.7%
	no	Count	0	99	0	99
		% within Divorce_cause	0.0%	100.0%	0.0%	100.0%
		% within Divorce_cause	0.0%	100.0%	0.0%	9.9%
		% of Total	0.0%	9.9%	0.0%	9.9%
	yes	Count	0	0	4	4
		% within Divorce_cause	0.0%	0.0%	100.0%	100.0%
		% within Divorce_cause	0.0%	0.0%	100.0%	0.4%
		% of Total	0.0%	0.0%	0.4%	0.4%
Total		Count	895	99	4	998
		% within Divorce_cause	89.7%	9.9%	0.4%	100.0%
		% within Divorce_cause	100.0%	100.0%	100.0%	100.0%
		% of Total	89.7%	9.9%	0.4%	100.0%

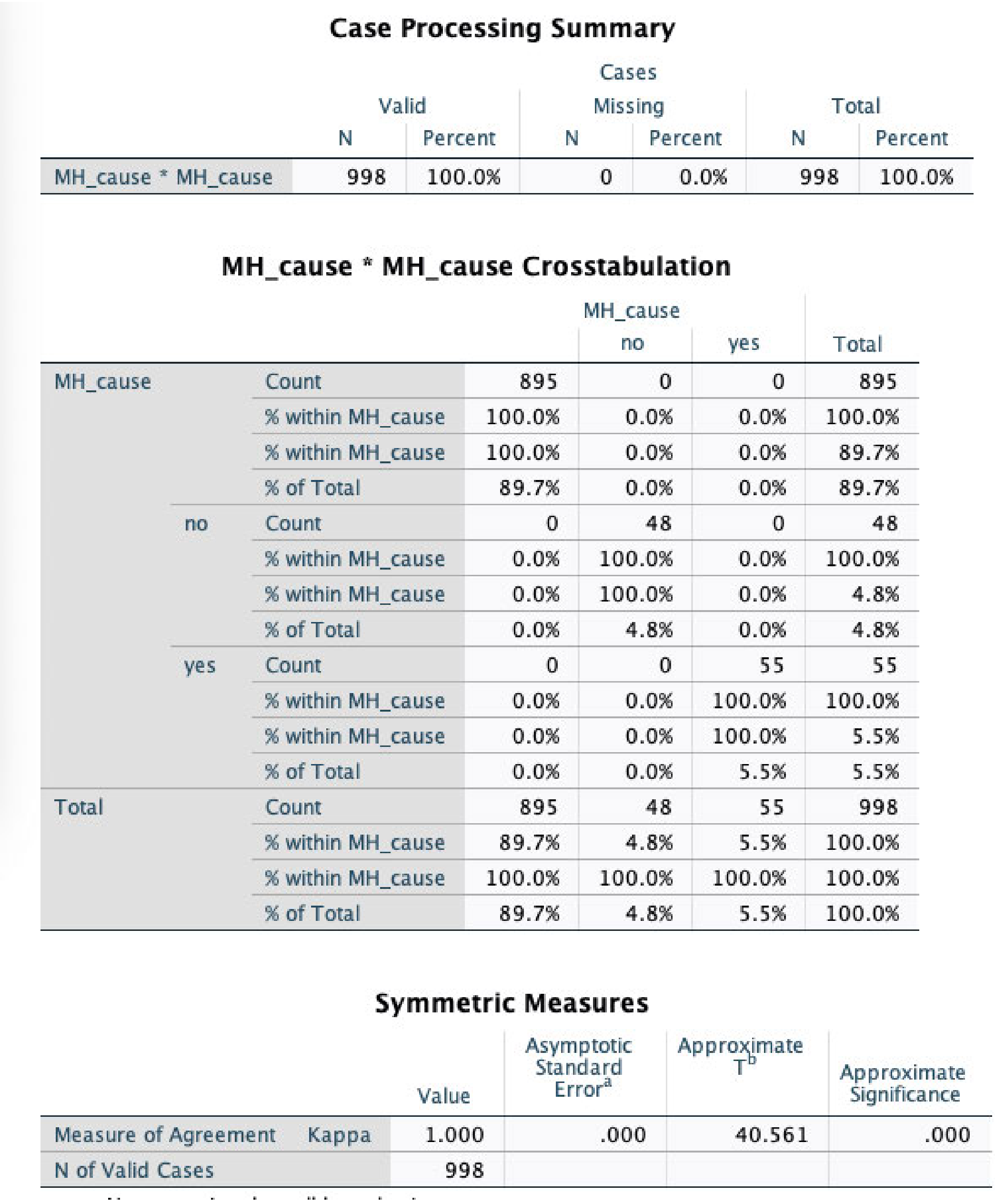


Symmetric Measures

		Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	32.617	.000
N of Valid Cases		998			

2. Child referent attributions

2.1 My child's mental health



Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
MH_cause * MH_cause	998	100.0%	0	0.0%	998	100.0%

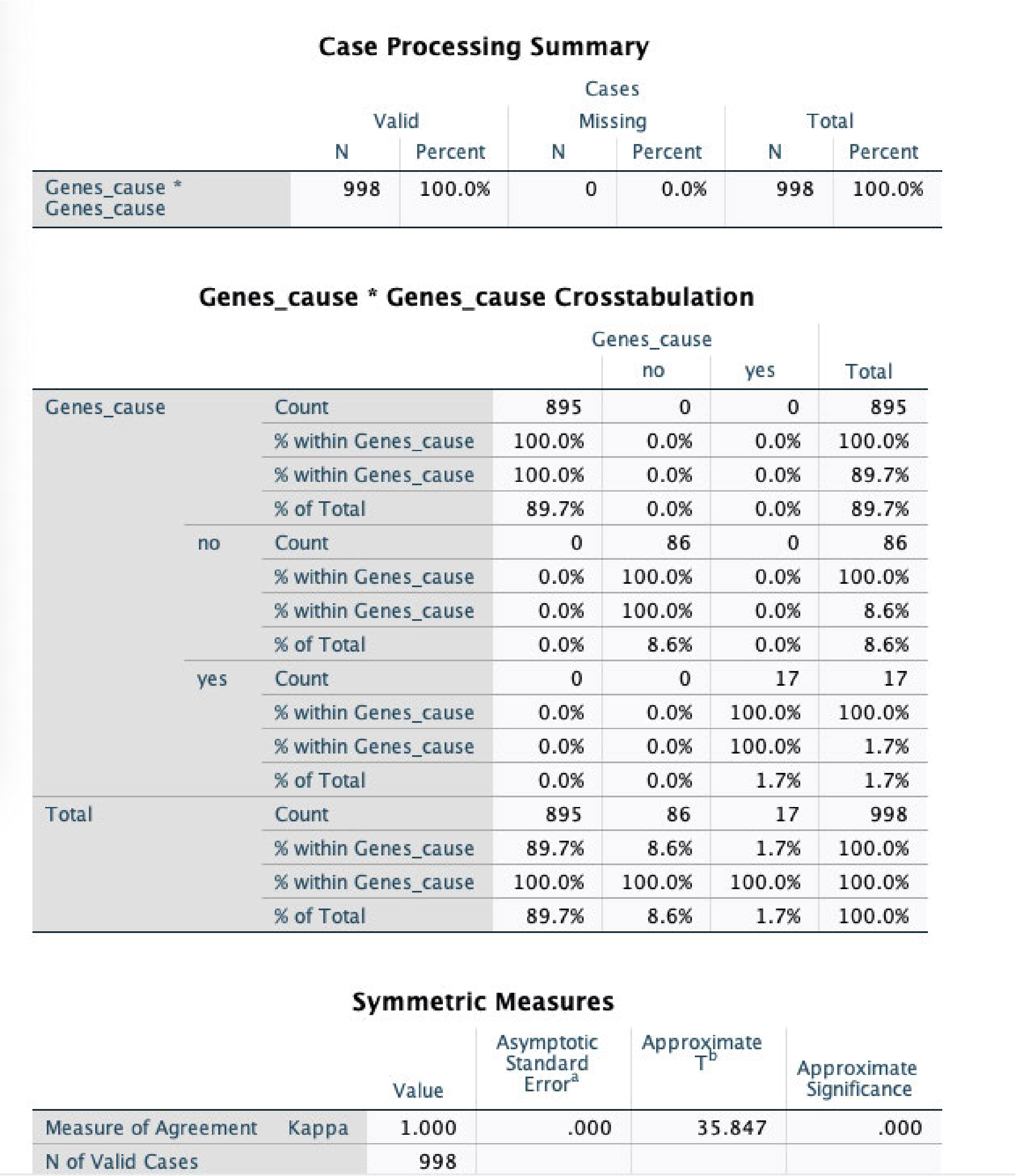
MH_cause * MH_cause Crosstabulation

			MH_cause			Total
				no	yes	
MH_cause		Count	895	0	0	895
		% within MH_cause	100.0%	0.0%	0.0%	100.0%
		% within MH_cause	100.0%	0.0%	0.0%	89.7%
		% of Total	89.7%	0.0%	0.0%	89.7%
	no	Count	0	48	0	48
		% within MH_cause	0.0%	100.0%	0.0%	100.0%
		% within MH_cause	0.0%	100.0%	0.0%	4.8%
		% of Total	0.0%	4.8%	0.0%	4.8%
	yes	Count	0	0	55	55
		% within MH_cause	0.0%	0.0%	100.0%	100.0%
		% within MH_cause	0.0%	0.0%	100.0%	5.5%
		% of Total	0.0%	0.0%	5.5%	5.5%
Total		Count	895	48	55	998
		% within MH_cause	89.7%	4.8%	5.5%	100.0%
		% within MH_cause	100.0%	100.0%	100.0%	100.0%
		% of Total	89.7%	4.8%	5.5%	100.0%

Symmetric Measures

		Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	40.561	.000
N of Valid Cases		998			

2.2 My child's genes



Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Genes_cause * Genes_cause	998	100.0%	0	0.0%	998	100.0%

Genes_cause * Genes_cause Crosstabulation

			Genes_cause			
				no	yes	Total
Genes_cause		Count	895	0	0	895
		% within Genes_cause	100.0%	0.0%	0.0%	100.0%
		% within Genes_cause	100.0%	0.0%	0.0%	89.7%
		% of Total	89.7%	0.0%	0.0%	89.7%
	no	Count	0	86	0	86
		% within Genes_cause	0.0%	100.0%	0.0%	100.0%
		% within Genes_cause	0.0%	100.0%	0.0%	8.6%
		% of Total	0.0%	8.6%	0.0%	8.6%
	yes	Count	0	0	17	17
		% within Genes_cause	0.0%	0.0%	100.0%	100.0%
		% within Genes_cause	0.0%	0.0%	100.0%	1.7%
		% of Total	0.0%	0.0%	1.7%	1.7%
Total		Count	895	86	17	998
		% within Genes_cause	89.7%	8.6%	1.7%	100.0%
		% within Genes_cause	100.0%	100.0%	100.0%	100.0%
		% of Total	89.7%	8.6%	1.7%	100.0%

Symmetric Measures

		Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	35.847	.000
N of Valid Cases		998			