

**Understanding Mental health literacy: Socio-demographic correlates and its association with trauma responses among caregivers of children with eating disorders<sup>1</sup>**

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<sup>1</sup> This thesis will bear resemblance to a Thesis proposal previously submitted by Nabirinde (2023) as part of the Doctorate in clinical Psychology course requirements.

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## **Thesis portfolio Abstract**

### **Background**

Mental health literacy (MHL) has been linked to positive mental health outcomes such as improved coping skills, increased access to mental health services and reduced community mental health symptoms. Research has shown that caregivers of children/young people (CYP) with eating disorders will experience psychological distress, namely post-traumatic stress symptoms (PTSS). A growing area of research within MHL is eating disorder mental health literacy (ED-MHL). While there are good foundations in both MHL research and research on caregivers' psychological well-being in this population, little is known about their association.

### **Aims**

This thesis portfolio contains a systematic review, which aimed to synthesize data on sociodemographic factors associated with mental health literacy, and an empirical paper, which aimed to explore the association of ED-MHL, caregiver stressors and post-traumatic stress symptoms in caregivers to child/young people with eating disorders.

### **Methods**

The systematic review used a meta-analytic approach to synthesise data from 23 studies reporting on correlations between mental health literacy and sociodemographic factors.

The empirical paper used a cross-sectional design with 123 caregivers providing substantial care to a CYP with an ED. Participants completed a survey comprising demographic information, the Post-Traumatic Stress Disorder Checklist for DSM-5 (PCL-5), and the Eating Disorder–Mental Health Literacy Scale (ED-MHL).

## **Results**

The meta-analysis indicated that higher education levels and female gender were associated with greater MHL. Findings from the cross-sectional study revealed that many caregivers met the threshold for probable PTSD, trauma symptoms were more likely among caregivers with lower levels of ED-MHL and among those whose child had been hospitalised in a general hospital.

## **Conclusions**

This thesis contributed to knowledge of MHL and its association with mental health difficulties. It highlights the importance of sociodemographic factors in MHL and it draws attention to the need for psychoeducational interventions—not only for individuals with EDs but also for their caregivers.

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## **Chapter One: General Introduction**

Word count: 2000



This thesis portfolio focuses on mental health literacy (MHL). The portfolio will examine the association between MHL and sociodemographic factors and the relationship between MHL and traumatic symptoms in caregivers of children/young people (CYP) with an eating disorder (ED). This introductory chapter provides a foundation for the systematic review (Chapter Two) and the empirical paper (Chapter Four), both of which are briefly outlined below.

Several abbreviations are used within this thesis portfolio. Please see a list of abbreviations below for a full overview of all abbreviations used within the portfolio.

#### **List of abbreviations**

ED	Eating disorders
ED-MHL	Eating disorder mental health literacy
PTSD	Post-traumatic stress disorder
PTSS	Post-traumatic stress symptoms
MHL	Mental health literacy
CYP	Child or Young person

#### **Definition of key terms**

##### *Mental health literacy (MHL)*

The definition of MHL that is most accepted by the academic community is by Jorm et al. (1997, p182), part of which is quoted below and then further explored in this and the Chapters that follow:

“...we have coined the term "mental health literacy" to refer to knowledge and beliefs about mental disorders which aid their recognition, management and prevention.”

Subsequent research has either simplified or adapted this original definition. For this research, we use Jorm et al. (1997) definition above. Jorm and colleagues' concept of mental health literacy includes five components, a) knowledge of how to prevent mental health difficulties, b) recognition of when a disorder is developing, c) knowledge of help-seeking options and available treatments, d) knowledge of effective self-help strategies for milder problems, and e) first aid skills to support others who are developing a mental disorder or are in a mental health crisis (Jorm et al., 1997).

### *Sociodemographic factors*

Sociodemographic factors refer to a population's characteristics related to social and demographic aspects of life. For example: age, gender, education, ethnicity, location, marital status, religion, work status. The involvement of sociodemographic factors in research helps research contextualise and understand how individual differences affect study results.

In this thesis portfolio, the factors to be researched will be age, gender, and education. The rationale for this will be provided in Chapter Two.

### *Post-traumatic Stress Symptoms (PTSS) and Post-traumatic Stress Disorder (PTSD)*

While post-traumatic stress symptoms (PTSS) refer to individual symptoms related to PTSD, such as intrusive thoughts or hypervigilance, post-traumatic stress disorder (PTSD) is a diagnosable condition characterized by a cluster of symptoms that significantly impair daily

functioning. The DSM-5 states that there are four symptoms (criteria) that need to be present for a PTSD diagnosis (American Psychiatric Association, 2013). These criteria are:

Criterion A: stressor

Criterion B: intrusion symptoms

Criterion C: avoidance

Criterion D: negative alterations in cognition and mood

### *Eating disorders*

Eating disorders are a group of mental health conditions where a person displays disturbances in eating behaviour, in some cases, they might be worried about health, weight or appearance and control their food intake because of these concerns.

The eating disorders researched in this thesis portfolio include anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), other specified feeding or eating disorders (OSFED), avoidant/restrictive food intake disorder (ARFID). Further details on eating disorders can be found in Chapter Four.

### **Mental health literacy literature**

Defining MHL requires first understanding health literacy (HL), as the former concept originated from the latter. Health literacy refers to an individual's ability to access, understand, and use information to make informed healthcare decisions. HL is a concept that has received growing interest over the years, including its relation to increased access to health services and decreased mortality rates (Berkman et al., 2011).

Mental health literacy was introduced to increase individuals' awareness of mental healthcare, increase the positive discourse on mental illnesses and avoid negative

narratives that deter people from accessing treatment (Jorm, 2012). In the mid-1990s, Jorm and colleagues noted a contrast between the community's efforts to address access to treatment for physical illnesses versus mental illnesses (Jorm, 2012) and they began to advocate for an increased awareness of mental health. Since MHL is linked to actions that benefit one's mental health or that of others, identifying barriers to help-seeking serves as a key justification for its importance. Research over the years has noted barriers to seeking support for mental health problems that include lack of recognition (Gulliver, Griffiths, & Christensen, 2010), and stigma around mental health (Henderson et al. 2013; Salaheddin & Mason, 2016; Schnyder et al, 2017). Community surveys in Australia (Jorm et al., 2005), the United Kingdom (Holman, 2015), Japan (Jorm et al., 2005), India (Kermode et al., 2009) and Sweden (Dahlberg, Waern, & Runeson, 2008) have presented individuals with vignettes giving details of a person struggling with a mental illness and asked them to identify what might be wrong. These studies consistently found that many individuals were unable to identify common mental health conditions when presented with detailed case descriptions.

The World Health Organization (WHO) emphasize the need for early intervention to improve outcomes for individuals with mental health conditions (WHO, 2021). A delay in recognition of a mental health condition can exacerbate symptoms, reduce treatment efficacy, and increase the likelihood of crises requiring emergency intervention. A study by Thompson et al. (2008) found an average of 1.3 years between recognition and help-seeking. Additionally, in a study consisting of over sixteen thousand adults from across the UK, 20.5% reported that they would significantly delay or never seek mental healthcare (Wang et al., 2024). This reluctance is often attributed to stigma, a lack of awareness about mental health services, or cultural misconceptions about mental health treatment (Henderson et al., 2013; Schnyder et al., 2017). By improving MHL, individuals can better

recognize the signs of mental illness, reduce stigma, and access appropriate care sooner.

These outcomes have driven the continued development of MHL over time to guide interventions at both individual and community levels.

### *MHL as a multi-construct theory*

Over the years, researchers have developed and modified the original definition of MHL with suggestions to include stigma and positive mental health in its definition (Kutcher et al., 2016; Wei et al., 2015). However, it is widely acknowledged that reaching a consensus on which concepts to include in the definition is challenging. This debate prompted Spiker and Hammer (2018) to propose redefining MHL as a multi-construct theory rather than a multidimensional construct. As a construct, MHL is simply a combination of variables, which can lead to ambiguity regarding relationships between its components. As a theory, MHL provides a structured framework that articulates how the components of MHL interact and influence specific outcomes. Spiker and Hammer (2018) conclude that MHL, as a theory, provides clarity, coherence, and applicability in the research field.

### *Summary of current research on MHL*

MHL has been studied concerning different age groups (Farrer et al., 2008; Piper et al., 2018), cultures (Atilola, 2015; Liu et al., 2018), genders (Reavley et al., 2012; Kaneko & Motohashi, 2007), and environments such as schools (Kutcher et al., 2015) and healthcare settings (Wang et al., 2023). Additionally, its association with outcomes such as help-seeking behaviours (Wei et al., 2017) and stigma (Ma et al., 2023) has also been explored. Studies have also looked at MHL of specific disorders (Furnham & Lousley, 2013; Melas et al., 2013). The evidence has shown that sociodemographic factors such as being female and having higher education levels are associated with higher MHL (Kaneko & Motohashi,

2007). The findings have also concluded that MHL programs in schools have improved mental health outcomes. Additionally, higher levels of MHL have been associated with reduced stigma and increased help-seeking behaviours which means earlier and greater access to MH services (Yang et al., 2024). Although previous MHL research has produced many important findings, it has also raised questions that warrant further investigation into how sociodemographic factors collectively influence MHL. Building on these findings, one of the aims of the present thesis is to explore the relationship between MHL and sociodemographic factors. Another aim of this thesis is to explore the relationship between MHL and mental health symptoms, focusing specifically on levels of caregiver trauma.

### **PTSD in caregivers of CYP with eating disorders**

Evidence indicates that victims of a traumatic event are not the only ones susceptible to PTSD. Witnessing, being involved in, or even being informed of a traumatic event involving a loved one may trigger its onset (Carmassi et al., 2021). The psychological impact of caregiving for children with terminal or chronic illnesses has been widely researched, with particular attention to the prevalence of PTSD in caregivers. A meta-analysis by Cabizuca et al. (2009) found that one in four parents of a child with a chronic disease met the criteria for PTSD.

Research has used terms such as caregiver burden, caregiver stress, post-traumatic stress symptoms (PTSS), and caregiver burnout to describe the mental health strain experienced by caregivers of individuals with physical or mental illness. Rady et al. (2021) found significant stress among caregivers of this population, reporting that over half of their participants met the criteria for PTSD. More specifically, studies have identified PTSD in caregivers of individuals with psychosis (Loughland et al., 2009; Kingston et al., 2016),

schizophrenia, and bipolar disorder (Rady et al., 2021). However, research has not clearly distinguished between caregivers of children and caregivers of adults with mental illness, an issue also identified by Carmassi et al. (2021).

While most of the existing literature has focused on caregivers of individuals with chronic illnesses or some mental health conditions, less attention has been paid to caregivers of individuals with eating disorders, and even less to caregivers of children with eating disorders. Factors commonly associated with PTSD in caregivers to populations with severe physical and mental illnesses include challenging behaviours in patients, illness uncertainty (Carmassi et al., 2021), and younger age (Rady et al., 2021), all of which are present in children with eating disorders. In the context of eating disorders, caregivers need to manage disruptive behaviours such as secretive eating habits, emotional dysregulation at mealtimes, and coping with the uncertainty of recovery outcomes. A systematic review by Anastasiadou et al. (2014) confirmed results from previous reviews reporting difficulties with the caregiving experience of children with eating disorders. They report that the caregiving experience was considered negative, and found that there were high levels of anxiety, stress and depression in caregivers. This thesis aims to contribute to the understanding of PTSD in this specific caregiver population.

Building on the existing research exploring caregiver stress, Möller-Leimkühler and Wiesheu (2012) examined predictors of caregiver well-being and psychological distress in chronic mental illness. Their findings show that chronic and severe caregiving demands may lead not only to stress and burden but also to PTSS. Their research was based on Lazarus and Folkman's (1984) transactional stress model, which suggests that stress occurs when an individual is exposed to a challenging event. The individual appraises the demands of the event, evaluates their resources to manage those demands, and then initiates a

coping strategy. Their sample, which predominantly consisted of mothers of children with schizophrenia, revealed factors such as neuroticism that influenced caregiver appraisal and predicted caregiver well-being and psychological distress.

This model is relevant to this thesis as it highlights how caregivers' appraisal of stressors and their chosen coping strategies may influence their psychological outcomes. Möller-Leimkühler and Wiesheu (2012) offer a platform for exploring other factors that may be associated with or predict caregiver stress, burden or, for this thesis, caregiver trauma. This thesis will investigate whether the mental health literacy of caregivers is associated with the level of trauma in caregivers of children with eating disorders. Findings from this research could inform psychoeducation initiatives and family interventions aimed at supporting caregivers and improving treatment outcomes for children.

### **Thesis Portfolio Overview**

Given the gaps identified in previous research on mental health literacy (MHL), this thesis portfolio aims to synthesise data on sociodemographic factors associated with MHL and explore whether MHL is linked to trauma in caregivers of children and young people (CYP) with eating disorders (EDs).

The portfolio consists of five chapters, including this general introduction, and a set of appendices. Chapters Two and Four present the secondary and primary research findings, while Chapters Three and Five provide critical appraisals and summaries of the research.

Table 1 gives a brief outline of each chapter.



**Table 1***Overview of Thesis portfolio chapters*

Chapter Two	Presents a meta-analysis examining the sociodemographic correlates of MHL.
Chapter Three	Bridges the meta-analysis findings to the empirical study in Chapter Four.
Chapter Four	Outlines a cross-sectional quantitative study investigating trauma in caregivers of CYP with EDs and its association with caregiver stressors and Eating Disorder–Mental Health Literacy (ED-MHL).
Chapter Five	Offers a general discussion, summarizing key findings from both studies, critically appraising the research methodology, and discussing broader implications for the field.

## **Chapter Two: Systematic Review**

### **Demographic factors associated with mental health literacy: a systematic review and meta-analysis**

*To be sent for publication in the Journal of Mental Health – Should be no more than 6000*

*(excluding abstracts, tables and references) words, APA-& referencing style*

[Submit to Journal of Mental Health \(see appendix A for journal author guidelines\)](#)

Word Count (excl. excluding abstract, tables and references): 4,364

## **Abstract**

### ***Background***

Mental health literacy (MHL) was introduced to address access to treatment of mental health conditions and to advocate for an increased awareness of mental health in communities. MHL has been linked to improved mental health outcomes such as reduced stigma and greater access to support. Additionally, several studies have identified associations between MHL and various sociodemographic factors.

### ***Aim***

This meta-analysis aims to examine the relationship between MHL and sociodemographic factors by synthesizing correlations reported in previous studies.

### ***Methods***

Following PRISMA guidelines, data from 23 studies were systematically reviewed and analysed using meta-analytic techniques.

### ***Results***

The analysis revealed that the pooled effect size between age and MHL was non-significant ( $r = 0.011$ ,  $p > .05$ ). In contrast, significant associations were found for gender ( $r = 0.139$ ,  $p < .05$ ) and education ( $r = 0.232$ ,  $p < .05$ ), indicating that higher MHL is associated with being female and having a higher level of education.

### ***Conclusion***

This meta-analysis supports previous research by confirming the relationship between certain sociodemographic factors and MHL. The findings highlight the importance of incorporating tailored mental health awareness messages for different demographic groups to aid better mental health outcomes.

Keywords: mental health literacy, sociodemographic factors, age, gender, education

## Introduction

Health literacy (HL) is crucial in improving health outcomes (Kutcher et al., 2016). Studies have shown that low HL is associated with higher rates of chronic illness, reduced use of healthcare services, poorer overall health, and increased mortality (Berkman et al., 2011). An increase in HL empowers communities to manage their physical health better.

Traditionally, HL has focused on physical well-being, while mental health literacy (MHL) — an extension of HL — addresses understanding mental health disorders. A widely accepted definition is that MHL is the knowledge and beliefs individuals hold about mental health disorders, which shape their ability to recognize, manage, and respond to these conditions (Jorm et al., 1997). Over time, this definition has expanded to include the influence of such knowledge on one's ability to support others experiencing mental health challenges (Kutcher et al., 2016).

Evidence has shown that mental health literacy is a significant factor in mental health outcomes, and influences areas such as symptom reduction, reduced stigma and coping mechanisms (Kutcher et al., 2016; Jorm, 2012). Jorm (2012) emphasized that MHL is fundamentally about translating knowledge into practical actions that benefit both the individual and community mental health. Early intervention has also been evidenced to improve recovery rates and reduce symptom severity. Kutcher et al. (2016) showed the effectiveness of MHL-based interventions in school settings, reporting that MHL school programs improved recognition and increased help-seeking behaviours.

Consequently, findings have consistently shown that low levels of mental health literacy are a barrier to accessing mental health services, resulting in increased symptoms of mental illness (Jorm et al. 1997). Individuals with low MHL may struggle to identify signs and

symptoms of mental health illness, both in themselves and others, increasing the risk of misdiagnosis. This misattribution of signs and symptoms contributes to reluctance to seek professional help, delays in initiating treatment, and ultimately poorer mental health outcomes (Jorm et al. 1997; Kelly et al. 2007). Additionally, low MHL can perpetuate negative stereotypes around mental illness, further discouraging help-seeking behaviours and reinforcing neglect within communities. By contrast, higher levels of MHL can increase proactivity in addressing mental health conditions.

Building on evidence that MHL significantly influences mental health outcomes, it is important to consider how sociodemographic factors play a role in the variation of MHL across different populations. Research has shown that MHL can vary significantly across demographic groups, with specific sociodemographic factors being associated with poorer MHL.

Regarding gender, evidence suggests that males tend to have lower levels of MHL compared to females (Cheng et al. 2018; Kaneko & Motohashi, 2007). This gap contributes to the underutilization of mental health services among men, and is linked to poorer mental health outcomes, including vulnerability to suicide (Kaneko & Motohashi, 2007).

Older age has also been associated with lower levels of MHL (Farrer et al., 2008; Piper et al., 2018). This may be due to generational differences in mental health attitudes or greater stigma surrounding mental health issues in older generations. Research has suggested that age-appropriate mental health messages are necessary to improve MHL across the lifespan, for both younger and older populations (Farrer et al., 2008).

Another factor linked to poorer MHL is lower educational attainment (Kaneko & Motohashi, 2007). The association has been attributed to learning ability (Kaneko &

Motohashi, 2007) which affects their ability to engage with mental health information, affecting their ability to recognise mental health issues and seek appropriate support. Additionally, studies indicate that ethnic minority groups often have lower levels of MHL compared to majority populations (Lee et al., 2020; Jorm, 2012). Lee et al. (2020) found underutilization of mental health services among Korean American women and urged that increasing mental health literacy in his population may change attitudes or willingness to seek help for mental health difficulties.

College students represent another key population with unique mental health literacy challenges. Despite being a group with a relatively high risk for mental health difficulties, many college students do not seek help, often because they do not perceive a need for it (Blanco et al., 2008; Czyz et al., 2013).

In summary, improving MHL across these diverse demographic groups requires targeted mental health messaging. Studies have concluded that efforts should focus on increasing mental health education for males, creating age-appropriate messaging, considering strategies for creating accessibility for individuals with lower educational backgrounds and developing culturally sensitive materials for ethnic minority communities (Kaneko & Motohashi, 2007; Lee et al., 2020; Farrer et al., 2008).

While several studies have reported on the demographic correlates of MHL, few have conducted in-depth analyses to explore these relationships thoroughly. This study aims to fill that gap by providing a quantitative review, synthesizing data from multiple studies to better understand both the strength and direction of the associations between MHL and key sociodemographic factors.

- ***Objective of meta-analysis***

The objective of this study was to conduct a quantitative meta-analysis of studies that reported on a correlation between demographic variables and mental health literacy. Specifically, we aimed to examine associations between mental health literacy and key demographic factors, including, age, gender, ethnicity and education. This quantitative review will provide both practical and theoretical insights for mental health organisations, professionals and public sector initiatives to increase mental health awareness. The findings are expected to emphasise the importance of designing gender and age-appropriate mental health awareness initiatives. Additionally, mental health professionals may apply these insights to inform and develop psych-educational programs and interventions tailored to the needs of different demographic groups.

## **Methodology**

The study protocol was registered on an international prospective register of systematic reviews (PROSPERO). Registration number - CRD42024480249.

### **- *Data sources and search strategy***

The search was conducted between April and June 2024 and updated in October 2024 to include any articles published after the initial search. Four electronic databases were searched with no publication year restriction: PsychINFO, PsycARTICLES, Web of Science and PubMed. These databases offer extensive coverage of mental health, psychological and health science literature, ensuring a comprehensive search across studies on MHL across diverse populations.

The following search terms were used in each database: "mental health literacy" or "mental health education" or "mental health knowledge" OR "Multiple-Choice Knowledge of Mental Illnesses Test" OR "Mental Health Knowledge Schedule" OR "Knowledge of

Mental Disorders" OR "Mental Health Knowledge Questionnaire" OR "Mental Health Literacy Questionnaire" OR "Mental Health First Aid Knowledge Test" OR "Multidimensional Mental Health Literacy Scale". The search terms included commonly used mental health literacy measures and synonyms of mental health literacy.

- ***Study selection***

After the initial search, EndNote reference manager software was used to store the initial 5,567 studies found and to remove duplicate studies. After duplicate studies were removed, 4,631 studies remained (see Figure 1). Rayyan.ai was then used to screen the remaining titles and abstracts using the inclusion and exclusion criteria (details of this below). After the title and abstract screening, 156 studies remained. The full texts of the remaining 156 studies were screened against inclusion/exclusion criteria, and 23 studies met all criteria and were included in the meta-analysis.

*Inclusion and exclusion criteria*

A two-stage screening process was implemented to determine eligibility for inclusion in the meta-analysis. The first stage was title and abstract screening and the second was a full-text screen. At the title and abstract stage, studies were included if they clearly stated that they measured mental health literacy (MHL) in a specific population. As this was a quantitative review, only quantitative studies were included. The abstract also had to specify that the study used a validated MHL measure such as those named in the search terms.

Some research has focused on measuring the MHL of a specific mental illness, and over time tools have been developed that measure the literacy of these mental illnesses. Examples include depression literacy (Griffiths et al., 2004; Reavley et al. 2014), and eating



disorder mental health literacy scale (Feldhege, 2022). The purpose of this meta-analysis was to determine if there was an association between general mental health literacy and demographic characteristics. Thus, to avoid domain-specific associations to demographic variables, studies were included if they measured and reported general mental health literacy and not literacy specific to one area of mental health. Additionally, if it was clear at this stage of screening that a study measured MHL but only reported subscale scores, rather than the full-scale MHL score, then it was excluded. Exclusion criteria were also applied to qualitative studies, systematic reviews, meta-analyses and other secondary research studies.

For the full-text screening, studies were rescreened for the MHL measure used to ensure that the study used a standardised tool and the measure included broad domains as described by Jorm et al. (1997). The results section of studies was screened to ensure they reported a whole-scale MHL score, and demographic information, including age, gender, education status, and ethnicity. Additionally, studies needed to have performed a correlation or regression analysis between the MHL score and at least one demographic variable. Studies were also re-screened and excluded if they only reported the scores of subsets. Exclusion criteria were also applied to studies that did not conduct correlation or regression analysis.

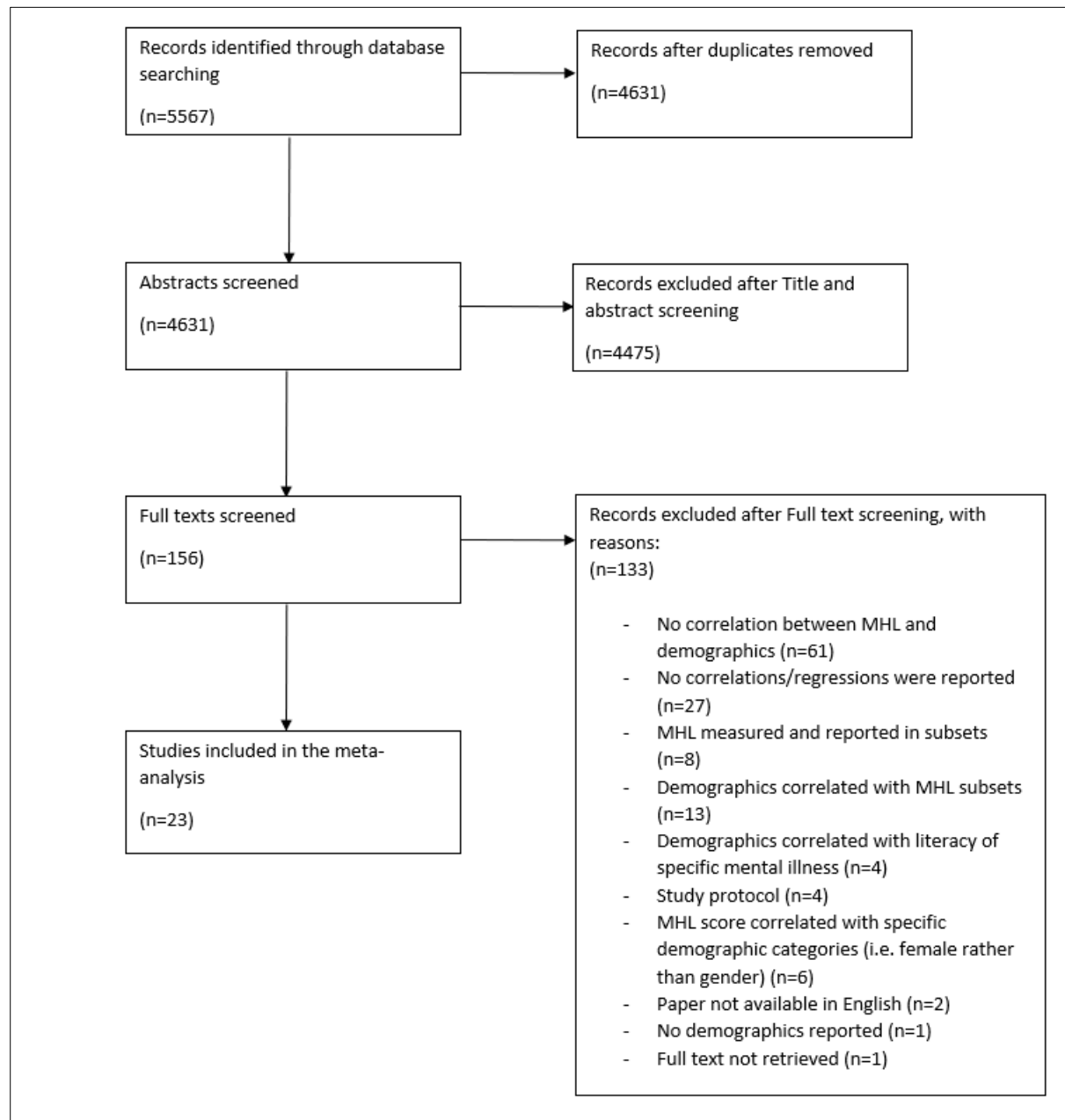
Eligibility was assessed by two independent reviewers. The primary reviewer screened 100% of the studies at both stages. The second reviewer independently screened a random sample of 20% of the studies at each stage. The initial inter-rater agreement between the two reviewers was 97.8% at the title and abstract screening stage and 67.7% at the full-text screening stage, indicating generally strong alignment during the selection process. Any disagreements between the reviewers were resolved through discussion until a consensus

was reached. As consensus was reached in all cases, a third reviewer was not required.

Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) (Moher et al., 2009) were used during the article selection process, as reported in Figure 1.

**Figure 1**

*PRISMA flow diagram of screening and study selection*



Following the full-text screening, all articles were assessed for quality and risk of bias in the study designs, conduct and analyses. Quality assessment was completed by two raters

using the Joanna Briggs Critical Appraisal checklist for cross-sectional studies, version 2020 (Moola et al., 2020). This checklist asks 8 questions to ascertain the quality rating of a study. The full checklist was not relevant for the studies selected in this review. Therefore, only 5 items were used to assess the quality of the studies (Were the criteria for inclusion in the sample clearly defined; Were the study subjects and the setting described in detail; Were objective, standard criteria used for measurement of the condition; Were the outcomes measured in a valid and reliable way; Was appropriate statistical analysis used). Each study was rated on a 5-point scale, depending on how many criteria were fulfilled. The second rater assessed 25% of the studies at random. Inter-rater reliability was calculated and found moderate agreement (66.7%).

- ***Data extraction***

Data were systematically extracted from each study and organized into a standardised extraction form in a database. Extracted data included study authors, publication year, population characteristics, sample size, country, study design (correlational, cross-sectional), MHL measurement tool, reported demographics, type of analysis (e.g. Pearson correlation, regression) and reported associations between MHL and demographic variables. Associations were reported relative to the data reported in the study. To ensure consistency across studies, we reviewed the coding of gender and education in all included studies. Where coding was not obvious, it was inferred from looking at the descriptive statistics, examining the study context and analysing results in figures and tables. Positive correlations for gender were standardized to indicate that females have a higher MHL compared to males. Similarly, positive correlations for education were standardized to indicate that higher education levels are associated with greater MHL.

- ***Data analysis***

Most of the studies used in this meta-analysis reported their results as a correlation coefficient (Pearson's  $r$ ), which was selected to represent effect sizes and could be estimated from other effect size statistics. Where a correlation coefficient was not reported, calculations were made to estimate Pearson's  $r$  from the reported standardised regression coefficients ( $\beta$ ), following guidance from Peterson and Brown (2005). These values were treated as estimates of the strength of association and are not intended to imply that original analyses were correlational. The studies included reported effect sizes for the association between MHL and three socio-demographic factors (age, gender and education). Studies were grouped according to the associations that they reported on and analysed separately; this led to three separate meta-analyses.

Meta-analytic calculations were completed using MAVIS Version 1.1.3 (Hamilton, 2017). A random effects model (Hedges & Vevea, 1998) was used in each of the meta-analyses, effect sizes and their 95% confidence intervals including measures of heterogeneity reporting  $I^2$  statistic and Q test results were also reported. The  $I^2$  index estimates the proportion of total variability across studies that is due to heterogeneity, while the Q statistic tests whether the variability between studies is greater than what would be expected due to random sampling error. Higgins and Thompson (2002) suggested that values of  $I^2$  above 75% represent high heterogeneity. Subgroup analyses were conducted to help identify possible sources of heterogeneity and any methodological issues that may skew results. The subgroup analyses separated studies by measures used, number of participants and type of analysis.

## **Results**

### *Study characteristics*

23 studies were included in the review. Study characteristics are reported in Table 1. The selected studies were conducted in 11 different countries with a range of populations. Age of participants ranged from 10-90 years old. Samples used in these studies ranged in size, with a minimum of 80 and a maximum of 3478 with a median sample size of 351 participants; the total sample size was 17,875. Most studies used a cross-sectional design ( $k=17$ ) with the remaining studies using either a correlation design, mixed-methods approach or secondary data. The instruments used to measure mental health literacy are summarized in Table 1. The most used MHL scale in the studies was the Mental health literacy scale developed by O'Connor and Casey (2015). A list of all measures used by included studies can be found in Appendix K.

As shown in Table 1, the studies collected various demographic data, namely gender, age, ethnicity, education level, and marital status. The meta-analyses focus on the relationship between age, gender, and education (as independent variables) and mental health literacy (MHL) as the dependent variable.

**Table 1**

*Study Characteristics*

Author	Year	Population	Sample	Country	Study design	Mental Health Literacy measure	Demographics reported
Alshehri et al.	2021	Female undergraduate students	351	Saudi Arabia	Correlational and cross-sectional	Mental health literacy scale (MHLS)	age; marital status; college attended; academic level;

							place of residence; and personal history, family history, and relative history of mental disorder
Anbesaw et al.	2024	Traditional healers > 18years	343	Ethiopia	Cross-sectional	Mental health literacy scale (MHLS)	faith; marital status; ethnicity; educational qualification; occupation; traditional healer type
Kelzie E.	2023	Coaches from National Collegiate Athletics Association	1571	United States of America	Cross-sectional	Mental health literacy scale (MHLS)	age; years coached; ethnicity; gender; highest degree earned
Brandt et al.	2023	Undergraduate students	683	USA	Cross-sectional	Mental Health Literacy Assessment for College Students (MHLA-c)	age; ethnicity; gender; sexual orientation; mental health history

Choi et al.	2022	Korean American Immigrant women	234	USA	Secondary data	Adapted version of the Epps et al. scale (2010)	age; marital status; education; English proficiency; social support
D’Cunha, A	2015	Adults, 18-76	203	USA	Secondary data	Adaptation of 14 items from two subscales of the MHLS	gender; age; zip code; level of education; income category, ethnicity
Furnham and Sjekvist	2017	Adults, 18-56	129	UK	Cross-sectional	Vignette identification and character adjustment.	age; psychological education, gender
Kumar et al.	2020	Children, 13-18	3478	India	Cross-sectional	Mental Health Knowledge Questionnaire (MHKQ)	gender; age; family history of mental illness
Moss et al.	2022	PGR students	241	UK	Cross-sectional	Mental health literacy scale (MHLS)	sex; gender identity; sexual orientation; marital status; ethnicity; diagnoses MH

							condition (self/relative)
Mutiso et al.	2017	Health workers	104	Kenya	Cross- sectional, comparative	Mental Health Knowledge Schedule (MAKS)	age, gender, religious affiliation, participant type, number of years of practice, highest level of education, self- rating of current health status, self- rating of current life satisfaction, self-rating of current mental status, self-rating of current sense of belonging to the community and socioeconomic status



Nobre et al.	2022	Adolescents, 10-19	260	Portugal	descriptive, cross-sectional, and correlational stud	Mental Health Knowledge Questionnaire (MHKQ)	age; gender; year of school education; employment status and occupation of father and mother; history of mental health problems; previous contact with people with mental health problems; sleep habits; medication consumption; leisure and exercise activities; eating habits; internet and gadget use; interpersonal relationships; alcohol and
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							tobacco consumption; self-perception of mental and physical health and body image; and self-perception of mental and physical health during confinement due to the COVID-19 pandemic.
Noroozi et al.	2018	Adults 18-65	378	Iran	Cross-sectional	Mental health literacy scale (MHLS)	age, sex, marital status, level of education, employment status, income status, and family/ personal history of mental disorders.

Piper et al.	2018	Australian adults aged 60 years and over	91	Australia	Cross-sectional	Mental health literacy scale (MHLS)	sex; age; education; first language spoken; marital status; proximity to someone with mental ill-health
Simões de Almeida et al.	2023	20-59	928	Portugal	Cross-sectional	Mental Health Knowledge Schedule (Portuguese version)	age; gender; marital status; educational level; occupation; institution
Sin et al.	2016	siblings, aged 16 or over, who were either biologically related, step- or half-siblings, or related through adoption	90	UK	cross-sectional correlational study	Mental Health Knowledge Schedule (MAKS)	age; sex; marital status; ethnicity; vocational status; education; birth order
Sullivan et al.	2019	College coaches	80	Canada	Cross-sectional	Mental health literacy scale (MHLS)	gender; age; experience in

							current position; total experience
Wang A et al.	2023	nurses from public general and psychiatric hospitals	777	China	Cross- sectional	Chinese version of the Mental Health Literacy Scale (MHLS-C)	age; sex; education; marital status; work duration; professional title; sleep quality
Wang J et al.	2013	permanent residents of Shanghai 15 years of age or older	1953	China	Cross- sectional	comprehensive 'Questionnaire of Mental Health Work' developed by the Chinese Ministry of Health	
Wang Z et al.	2019	Adults 18-90	2425	China	Cross- sectional	the Mental Health Knowledge Questionnaire (MHKQ; Chen, Wang, & Phillips	age; gender; marital status; education; smoker; drinker; religious affiliation

Warden et al.	2024	Coaches	184	United Kingdom	mixed-methods approach	Mental Health Literacy Scale (MHLS)	age; gender; sexuality; disability; years of coaching
Yu et al.	2015	Adults 18-60	2052	China	Cross-sectional	Mental Health Knowledge Questionnaire (MHKQ)	
Zhang X et al.	2023	Junior high school students	700	China	Cross-sectional	Adolescent Mental health literacy Assessment Questionnaire (AMHLAQ)	gender; socio-economic status
Zhang Z et al.	2023	Adults 18-60	620	China	Descriptive correlation design	Mental Health Literacy Scale (MHLS)	age; sex; education; marital status; income

Note: MHLS: Mental health literacy scale; MHLA-c: Mental Health Literacy Assessment for College Students; Adapted version of the Epps et al. scale (2010); Adaptation of 14 items from two subscales of the MHLS; Vignette identification and character adjustment; MHKQ: Mental Health Knowledge Questionnaire; MAKs: Mental Health Knowledge Schedule; MHLS-C: Chinese version of the Mental Health Literacy Scale; comprehensive 'Questionnaire of Mental Health Work' developed by the Chinese Ministry of Health; AMHLAQ: Adolescent Mental health literacy Assessment Questionnaire

### *Assessment of study quality and risk of bias*

Most of the studies were rated as high quality (k=21), with most fulfilling all 5 criteria from the Joanna Briggs Critical Appraisal checklist for cross-sectional studies. The remaining (k=2) received a 4 out of 5 rating, with one criterion not being fulfilled from the checklist.

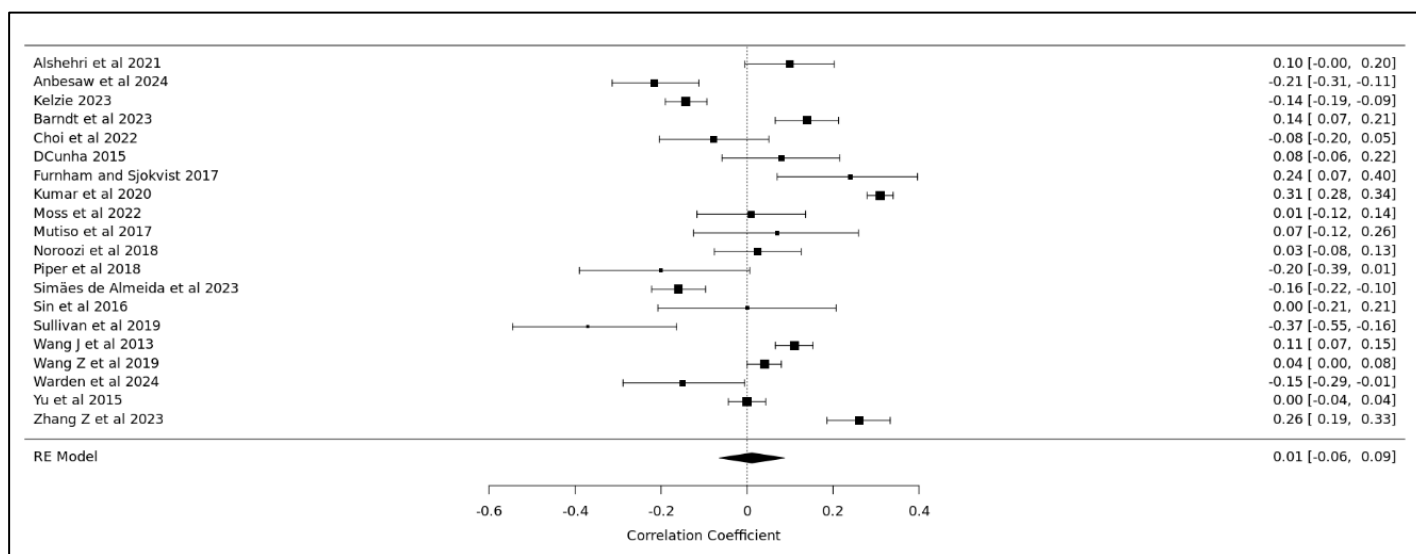
### *Meta-analysis of age and MHL*

Twenty studies examined the relationship between age and MHL, with age measured as a continuous variable. The studies showed an average effect size of 0.004, suggesting minimal overall association across the studies. They reported a mix of positive and negative associations, indicating no single consistent direction of the reported relationships.

There was a close to zero effect size between age and MHL with  $r=0.01$  (95% CI= -0.07, 0.09,  $z=0.29$ ,  $p=.77$ ; for forest plot see Figure 2) with no statistically significant overall effect. The Q test for heterogeneity was statistically significant ( $Q=451.84$ ,  $p < 0.0001$ ), indicating substantial variability between studies.  $I^2$  was also high at 95.11% suggesting a high level of heterogeneity. A funnel plot showed slight visual asymmetry on inspection and suggested no missing studies from the meta-analysis. Nonetheless, Kendall's tau was -0.095,  $p = 0.59$ , indicating no significant publication bias.

### **Figure 2**

*Forest plot for studies reporting a relationship between age and MHL*



### *Meta-analysis of gender and MHL*

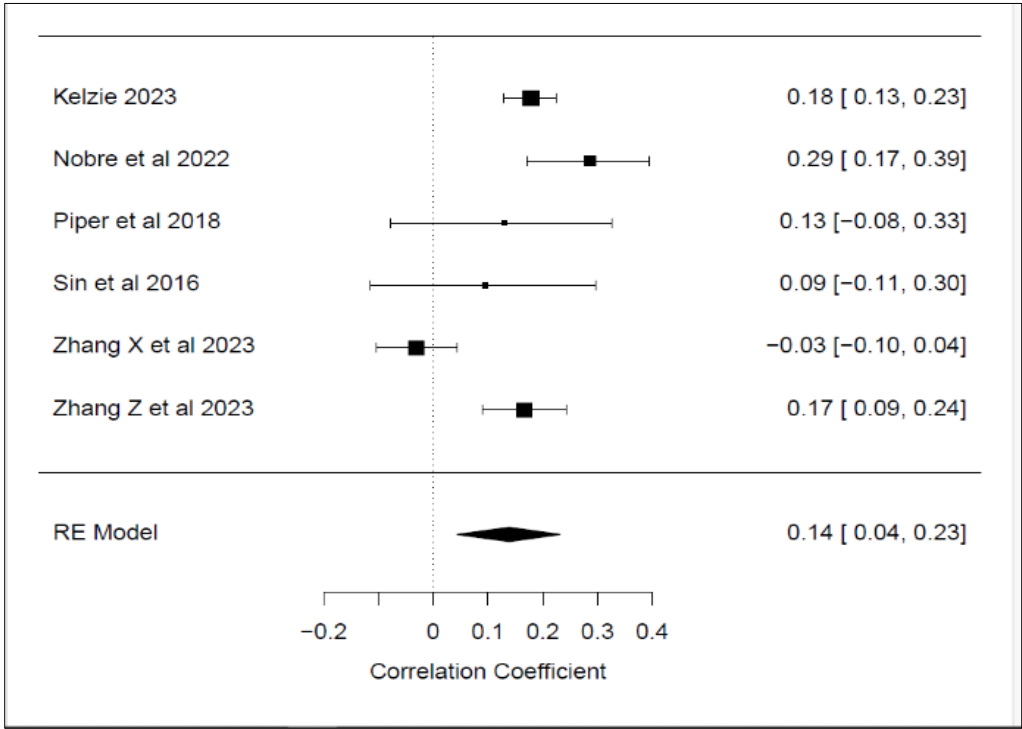
Gender was investigated in six studies, one found a negative association, with males associated with greater MHL than females (Zhang et al, 2023) whilst the rest reported a positive association between gender and MHL, with females associated with a greater MHL than males. In three studies, gender was included in the regression model with a reference category. However, due to the small number of studies and the inconsistent use of reference categories, a meta-analysis using gender reference categories was not conducted. Instead, all the data included in the meta-analysis on gender reported their overall relationship to MHL.

There was a small but statistically significant positive effect between gender and MHL ( $r=0.14$ , 95% CI= 0.04, 0.24,  $z=2.82$ ,  $p=.004$ ; for forest plot see Figure 3). This pooled effect indicates that greater MHL is associated with females. The Q test for heterogeneity was statistically significant ( $Q=29.47$ ,  $p<0.0001$ ), indicating substantial variability between studies and an  $I^2$  of 82.69% suggesting a high level of heterogeneity. A funnel plot showed

approximate visual symmetry on inspection and suggested no missing studies from the meta-analysis. Kendall’s tau was -0.20,  $p = 0.72$  indicating no significant publication bias.

**Figure 3**

*Forest plot for studies reporting a relationship between gender and MHL*



*Meta-analysis of education and MHL*

Eight studies reported on the relationship between education and MHL, with education measured as a categorical variable. The studies all reported a positive relationship, showing that higher education is associated with greater MHL. No studies selected for this analysis reported education in a regression model using a reference category.

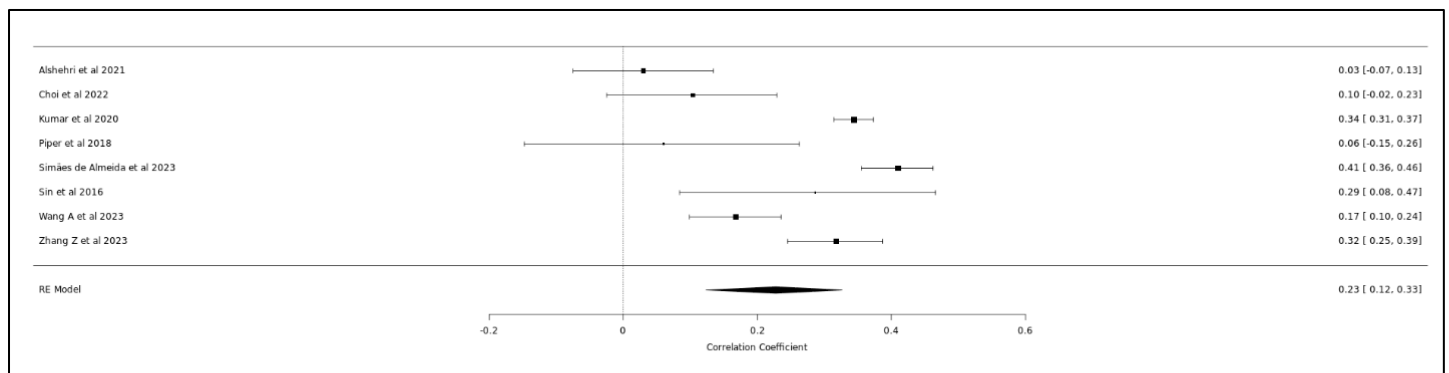
The pooled effect between education and MHL shows a moderate and statistically significant positive effect ( $r=0.23$ , 95% CI= 0.12, 0.33,  $z=4.22$ ,  $p<0.0001$ ; for forest plot see Figure 4). This pooled effect suggests that higher educational attainment is associated with



greater MHL. The Q test for heterogeneity was statistically significant ( $Q=80.80$ ,  $p<0.0001$ ), indicating substantial variability between studies and an  $I^2$  of 92.76% suggesting a high level of heterogeneity. A funnel plot showed visual symmetry on inspection and suggested no missing studies from the meta-analysis. Kendall's tau was  $-0.21$ ,  $p = 0.55$  indicating no significant publication bias.

**Figure 4.**

*Forest plot for studies reporting a relationship between education and MHL*



### ***Subgroup analyses***

Subgroup analyses were conducted to determine whether methodological differences among the individual studies impacted the overall results. The results are reported in Table 2. For age, the subgroup analyses indicated that separating studies by measurement type affected the direction of the relationship with MHL; however, the associations remained not statistically-significant. Notably, studies using the MHKQ showed a significant increase in the strength of the association between age and MHL when analysed separately. For gender, the positive and statistically significant relationship with MHL persisted in studies using the MHKQ and MHLS scales. Subgroup analyses for education revealed that removing studies by measure, sample size, or effect size source did not alter the direction or significance of the association between education and MHL. The smaller number of studies

in some of the meta-analyses may have contributed to the variations in statistical significance due to reduced statistical power.

**Table 2**

*Summary of Subgroup Analyses (incl. results of main analysis)*

	<i>Heterogeneity estimates</i>								
	<i>Estimate</i>	<i>k</i>	<i>u.CI</i>	<i>l.CI</i>	<i>z</i>	<i>p</i>	<i>Q</i>	<i>p</i>	<i>I<sup>2</sup></i>
	<i>(r)</i>								
Age									
<b>Main analysis</b>	0.01	20	0.09	-0.07	0.29	0.77	451.8	<.0001	95.11%
<b>Studies over 100 participants</b>	0.04	17	0.11	-0.04	1.01	0.31	427.4	<.0001	95.11%
<b>MHKQ</b>	0.15	3	0.17	0.13	13.58	<.0001	176.4	<.0001	98.87%
<b>MHLS</b>	-0.05	10	0.07	-0.17	-0.86	0.39	111.4	<.0001	91.53%
<b>Other MHL scale</b>	0.04	7	0.15	-0.07	0.77	0.44	62.7	<.0001	88.67%
<b>Pearson r</b>	-0.03	12	0.07	-0.13	-0.65	0.52	378.6	<.0001	95.25%
Gender									
<b>Main analysis</b>	0.13	6	0.24	0.04	2.82	0.004	29.47	<.0001	82.69%
<b>Studies over 100 participants</b>	0.15	4	0.28	0.02	2.26	0.02	29.3	<.0001	91.41%
<b>MHLS</b>	0.18	3	0.22	0.13	8.34	<.0001	0.236	0.89	0.00%
<b>Other MHL scale</b>	-0.008	2	0.09	-0.10	-0.16	0.87	1.212	0.27	17.51%
<b>Pearson r</b>	0.02	2	0.17	-0.13	0.26	0.79	2.019	0.16	50.47%
Education									

<b>Main analysis</b>	0.23	8	0.34	0.12		<.0001	80.80	<.0001	92.76%
<b>Studies over 100 participants</b>	0.24	6	0.37	0.12	3.76	0.0002	75.04	<.0001	95.09%
<b>MHLS</b>	0.16	4	0.29	0.02	2.24	0.03	22.70	<.0001	86.87%
<b>Other MHL scale</b>	0.31	4	0.45	0.17	4.22	<.0001	20.76	0.0001	92.05%
<b>Pearson r</b>	0.21	5	0.38	0.04	2.45	0.01	62.59	<.0001	95.31%

Note. l.CI refers to the lower limit of the 95% confidence interval; u.CI refers to the upper limit of the 95% confidence interval. (MHLS: Mental health literacy scale; MHKQ: Mental Health Knowledge Questionnaire; MHL: Mental health literacy)

## Discussion

### *Summary of findings*

Twenty-three articles were included in this review. From the total sample of 17,875 participants within the studies selected for this meta-analysis, the following pooled effects were found: 1) a positive but not statistically significant correlation between age and MHL ( $r=0.01$ ), 2) a positive and statistically significant association between gender and MHL ( $r=0.14$ ) and 3) a positive and statistically significant association between education and MHL ( $r=0.23$ ). All meta-analyses reported statistically significant heterogeneity.

At the time of this review, no other meta-analytic studies were available to compare these specific associations. Thus, these findings should be considered preliminary and interpreted with caution. The observed effect sizes are modest and largely reflect trends found in individual studies rather than conclusive relationships. Additionally, the high heterogeneity across studies, likely stemming from differences in sample characteristics, cultural contexts, and MHL measurement tools, may affect the generalizability of the pooled effect sizes. *MHL and age*

In this review, this meta-analysis included the most studies ( $k=20$ ) with the highest total sample size ( $n=16,138$ ), which improves the statistical power and reliability of the effect size estimates (Papakostidis and Giannoudis, 2023).

Previous research often reports the relationship between age and MHL by comparing generational differences (Farrer et al. 2008; Piper et al. 2018), typically noting poorer MHL in older adults (70+ years) (Farrer et al. 2008; Fisher and Goldney 2003). However, the findings from this review showed no significant relationship between age and MHL. The discrepancy may be due to methodological differences; whereas past studies often rely on descriptive analyses such as variations in scores on MHL tools, the present review used correlational analyses to assess the overall relationship between age and MHL without separating by age groups.

Although the pooled effect size was not statistically significant, the observed positive association may still reflect a tendency for MHL to increase with age in some populations. This is consistent with over half of the studies in the review that reported positive correlations. The positive association may imply that knowledge increases with age, but it's essential to recognize that MHL combines various domains, such as knowledge, attitudes, and beliefs—that may relate differently to age. For instance, Wang et al. (2019) found that age was significantly associated with attitudes but not knowledge. This meta-analysis, treating MHL as one variable, provides a foundational understanding of which further analyses can explore these specific facets of MHL and their relationships with age.

#### *MHL and gender*

Although based on a relatively small number of studies ( $k = 6$ ), this meta-analysis found a small but statistically significant positive association between MHL and gender, suggesting

that females tend to exhibit higher MHL scores. This is broadly consistent with previous studies (Cheng et al., 2018; Kaneko & Motohashi, 2007), which report gender differences using group comparisons. Although the studies in this meta-analysis provided regressions from which an  $r$  effect size could be derived, the findings also emphasize inconsistencies in reporting practices across studies, particularly regarding gender reference categories, which limit the precision of this estimate. Future studies that more consistently report gender data would strengthen understanding of gender-specific patterns and enhance the robustness of the findings from this review, additionally gender data including non-binary participants, would make associations more inclusive.

#### *MHL and education*

The association between MHL and education appears intuitive, as health literacy in general is closely linked to educational attainment (Langford et al., 2014). Research has noted that individuals with higher education tend to report greater MHL (Kaneko & Motohashi, 2007), likely due to enhanced cognitive and critical thinking skills and increased exposure to health education. Research also shows that school-based programs are a primary source of mental health information for younger populations (O'Connor et al. 2018; Bjørnsen et al. 2024), further emphasizing the role of education in promoting mental health awareness. The positive relationship observed in this review supports previous conclusions that higher MHL is associated with higher educational attainment.

This relationship between education and age aligns with the observed relationship between MHL and age. If higher education correlates with a higher MHL, then it can be assumed that, as individuals grow older and ideally progress in education, their MHL might also increase. However, this relationship may differ among older generations who often

had limited access to formal education and were less likely to receive mental health information in school, as mental health information in schools is a relatively recent addition to curricula. While the data suggest that both variables are associated with MHL, generational differences in access to mental health education likely play a role. Strengths and limitations

This meta-analysis has several strengths. The study followed a rigorous, PRISMA-guided screening process and addressed a gap in the literature by synthesising quantitative evidence on the relationship between MHL and key demographic variables. The dataset also included a wide range of countries across different cultural, economic and social contexts, with participants ranging from adolescents to older adults, enhancing potential generalisability. By synthesizing data from both high-income and low- to middle-income countries, an initial idea of how sociodemographic variables, such as education, gender, and age, correlate with MHL across different cultural settings. However, the high heterogeneity across studies remains a significant limitation, as cultural attitudes toward mental health, access to education and services, and public stigma levels vary significantly across countries and age cohorts. These contextual factors could moderate the observed relationships between sociodemographic characteristics and MHL, potentially weakening or increasing effect sizes. Future meta-analyses might shed light on these contextual factors by conducting analyses by culture, region, or developmental stage to further explain these relationships. Additionally, all included studies were cross-sectional, and from such findings it is not possible to conclude the causality of the relationship between MHL and these variables. Additionally, as briefly mentioned above, MHL is a combination of domains, the findings from this review do not enable one to draw conclusions on which parts of MHL are associated with these demographics. Over time, domain-specific MHL scales have been

developed, future research might consider examining MHL domains using these scales as a reference point.

The high heterogeneity in the meta-analyses was a noted limitation. This slightly improved in some of the sensitivity analyses, which suggested that different types of MHL scales or the conversion of effect sizes from regression models may partially explain heterogeneity. However, further research using more consistent methodologies would increase confidence in these future meta-analyses and enhance interpretability.

Another limitation of this systematic review is the modification of the Joanna Briggs Institute (JBI) critical appraisal tool. The original tool includes eight items, but only five were used, as the remaining items were not relevant to the included studies. While this adaptation was necessary for the context of this review but, the selection of relevant items involved a degree of subjectivity, which could introduce bias.

Additionally, a limitation of this meta-analysis is its reliance on studies that exclusively categorized participants as male or female, which does not fully reflect the diversity of gender identities. As a result, this review lacks inclusivity in its consideration of non-binary and gender-diverse individuals. While this limitation is briefly acknowledged here, a more detailed discussion of its implications and the need for more inclusive research practices is provided in the final chapter.

## **Conclusion**

Agreeing with previous research, this meta-analysis showed a relationship between MHL and some socio-demographics and highlights the need for tailored mental health messaging for different demographic groups in community settings (Kaneko & Motohashi, 2007; Lee et al. 2020; Farrer et al. 2008). In clinical practice, these findings suggest that

mental health interventions should prioritize psychoeducation, regularly assessing service users' understanding to ensure effective communication and support. Additionally, for caregivers of individuals with mental health conditions, there is evidence that they may experience stress concerning their caregiver responsibilities. Future research should explore how these factors influence caregivers' knowledge and help-seeking behaviours to better support them in their roles and improve their access to mental health resources.

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### **Chapter Three: Bridging Chapter**

Word Count: 439

The meta-analysis presented in Chapter Two examined the associations between MHL and three sociodemographic factors: age, gender and education. The meta-analysis reviewed 23 studies in total with each reporting on correlations between MHL and one or more of the sociodemographic factors of interest. The findings indicated a significant, positive association between higher MHL and both the female gender and higher education, although not increasing age. This suggests that the female gender and those with a higher education will be more able to recognise, manage and prevent mental health difficulties. The research referred to in Chapter One stated that help-seeking behaviours are directly linked to MHL, the results from the meta-analysis show that individuals of the female gender and with a higher education will be more inclined to access mental health services. Additionally, these results highlight the need for targeted mental health awareness efforts across different demographic groups due to the varied levels associated with sociodemographic factors.

Additionally, in clinical settings, this research suggests that to better support service users, professionals should consider varying levels of mental health literacy. Within mental health services, service users include not only individuals living with mental health conditions but also their caregivers. Research has shown that caregivers will experience traumatic stress when their loved one is living with a mental health condition (Loughland et al., 2009; Kingston et al., 2016; Rday et al., 2021). Previous studies have explored contributing factors to this stress, identifying both patient-related and caregiver-specific characteristics (Möller-Leimkühler and Wiesheu (2012).

A mental health condition that has been known to affect caregivers' well-being is eating disorders. Patient-related factors in this population that might contribute to caregiver stress include managing difficult behaviours at mealtimes, secretive eating habits, tube feeding

and hospitalisations. For eating disorders in a child or young person, parents are known to be greatly involved in managing treatment. Parents have identified issues such as delays in identifying eating disorders and accessing eating disorder services (Coelho et al., 2022). These challenges indicate that caregivers of children with eating disorders often struggle with recognizing the condition and accessing appropriate help. Studies have also shown that poor eating disorder mental health literacy negatively affects treatment-seeking for eating disorders (Ali et al., 2017). In addition, the key involvement of parents in their child's treatment would suggest a need for parents to have a good eating disorder-mental health literacy (ED-MHL) to be an effective support system for their child.

Building on these foundations, the following chapter presents an empirical study that will examine the relationships between caregiver stressors, mental health literacy and traumatic stress experienced by caregivers of children and young people (CYP) with eating disorders.

## **Chapter Four: Empirical Study<sup>2</sup>**

**Investigating the relationship between Eating Disorder Mental Health Literacy (ED-MHL),  
caregiver stressors and caregiver trauma responses to children and young people with  
Eating Disorders**

*Journal: Open Psychology Journal*

Word Count (excl. abstract, references, tables or figures): 5,733

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<sup>2</sup> The data in this study was collected jointly with another researcher (Heal-Cohen, 202); however, the analyses were conducted separately to address different research questions. The survey included an additional measure used by the second researcher, which is not included in this study as it is not relevant to the research questions.



## **Abstract**

### ***Objective***

To examine the prevalence of caregiver trauma among those caring for children and young people (CYP) with eating disorders (EDs) and to explore the association between caregiver stressors and caregiver trauma and mental health literacy (MHL).

### ***Methods***

In this cross-sectional study, 123 caregivers (91.9% female) providing substantial care for a CYP with an ED completed a survey comprising demographic information, the Post-Traumatic Stress Disorder Checklist for DSM-5 (PCL-5), and the Eating Disorder–Mental Health Literacy Scale (ED-MHL).

### ***Results***

65.9% of participants met the threshold for probable PTSD. Logistic regression showed that lower ED-MHL, receiving support for their child, and child hospitalisation in a general hospital increased the likelihood of meeting a probable PTSD diagnosis. Exploratory moderation analysis showed that higher ED-MHL was associated with lower post-traumatic stress symptom (PTSS) severity, particularly among those not receiving support.

### ***Discussion***

This research found that caregivers of CYP with EDs meet the threshold for probable diagnosis of PTSD. Our findings also demonstrated that caregiver distress in this context is a multifaceted issue influenced by a combination of ED-MHL and caregiver stressors as defined in this study. The results reinforce the need for integrated interventions that address both caregivers' psychological distress and the contextual factors of their caregiving role.

## Introduction

Eating Disorders (EDs) in the United Kingdom (UK) are estimated to affect over 700,000 people (National Institute for Health and Care Excellence (NICE), 2019), which is likely an underestimate as some charities such as BEAT, estimate that they affect more people. The National Health Service (NHS) of England states that nearly 10,000 children started treatment for EDs between April and December 2021 (NHS, 2022). The onset of EDs usually occurs between the ages of 12 and 30 (Gilbert et al. 2000). Research has shown that the role of caregivers to a child/young person (CYP) with EDs can be challenging (Gilbert et al. 2000; Svensson et al. 2013; Padierna et al. 2013; Timko et al. 2022). Caregivers often report predominantly negative experiences, including disruptions to family relationships (Gilbert et al., 2000), significant emotional distress (Svensson et al., 2013), and post-traumatic stress symptoms (PTSS), anxiety, and depression (Timko et al., 2022; Hazell et al., 2013).

Studies have shown that personal ED history in caregivers and primary caregiving responsibility of CYP with EDs are significant factors that contribute to caregiver stress, anxiety and depression (Stefanini et al., 2019). Individuals caring for a CYP with ED are also exposed to several factors that can affect caregiver burden. Factors include the young person's unwillingness to accept the sick role, visible nature of EDs like anorexia nervosa, managing mealtimes in the home (Treasure, 2009) and poor physical quality of life in the person they are caring for (Padierna et al., 2013).

Overall, research has shown that caregivers of individuals with mental illnesses, not only those with an ED, experience a caregiver burden, which is associated with post-traumatic stress disorder (Rady et al., 2021; Carmassi et al., 2020). This growing body of evidence

suggests that a model of post-traumatic stress may provide a useful framework for understanding and managing the distress experienced by caregivers. While there is extensive research on the trauma symptoms in children and young people with eating disorders (Brewerton et al., 2007; Briere & Scott, 2007), research on the trauma experienced by their caregivers is limited. Studies indicating that caring for an individual with an ED can be traumatic include Hazell et al. (2013) who found that mothers of individuals with anorexia nervosa reported clinically significant post-traumatic stress symptoms (PTSS). Additionally, Timko et al. (2022) found that both mothers and fathers of a child with an ED experience PTSS.

Green's (1990) trauma model confirms this perspective. According to Green, three variables collectively identify a 'trauma': objectively defined events, the individual's subjective interpretation of the event's meaning, and the person's emotional reaction to the event. First, research has given objective definitions of the experience of caregivers to CYP with EDs as a traumatic experience (Hazell et al., 2013; Timko et al., 2022). Second, studies on caregiver experiences provide insight into caregivers' subjective interpretations, often emphasising social disruption and emotional responses such as worry, anger, and guilt (Svensson et al., 2013). Therefore, based on Green's (1990) criteria and the available evidence, caregiving for a CYP with an ED can reasonably be classified as a traumatic experience. However, gaps remain in understanding the specific factors that contribute to caregiver trauma in this population. Additionally, according to cognitive models of PTSD, caregivers' subjective appraisal of stressful events is central to the development and maintenance of trauma symptoms (Ehlers & Clark, 2000). In the context of eating disorders, experiences such as hospitalisation, tube feeding, and prolonged caregiving may represent highly distressing events that shape caregivers' appraisals and, in turn, their vulnerability to

trauma symptoms. This study aims to explore whether these factors and mental health literacy (MHL) are associated with the traumatic stress experienced by caregivers of CYP with EDs.

### *Eating Disorder Mental Health Literacy (ED-MHL)*

Jorm et al. (1997, p.182) define MHL as “knowledge and beliefs about mental disorders which aid their recognition, management or prevention”. Key components of MHL include attitudes and beliefs towards individuals with mental illness, beliefs about the nature, causes, and risk factors, and understanding how to assist others who might be developing a mental illness (Jorm, 2012). Further information on MHL, can be found in Chapters One and Two.

There is evidence for MHL in the context of disorders such as depression (Mond, 2014) however, MHL specific to eating disorders (ED-MHL) has not been greatly investigated. There has been a recent growing interest in the area but primarily focussed on MHL on anorexia nervosa (AN) and bulimia nervosa (BN), leaving gaps in research on other EDs such as binge eating (Bullivant et al. 2020). The importance of ED-MHL lies in its potential to reduce the individual and community health burden of disordered eating and improve the willingness and ability of family and friends to intervene effectively (Mond, 2014).

Despite these findings, no studies have investigated ED-MHL among caregivers of CYP with EDs or the potential of how this might be a protective factor against their negative caregiving experiences. In broader research, MHL has been linked to caregiver resilience. For instance, Zhang et al. (2023) found that higher levels of MHL were associated with lower psychological distress and greater psychological resilience. Similarly, Scholten et al. (2020) conclude that psychological factors such as resilience, appraisal of threat and loss,

and passive coping are important factors in determining the level of psychological distress in caregivers of individuals with spinal cord and acquired brain injury. These findings indicate a potential association between ED-MHL, caregiver burden, and trauma symptoms, suggesting that caregiver knowledge is an important area for further attention. Moreover, enhancing caregivers' understanding of EDs may support their ability to manage challenging behaviours, reduce feelings of helplessness, and foster more adaptive coping strategies. This research is important because it may inform the development of targeted psychoeducational and therapeutic interventions that not only support the mental health of caregivers but also enhance treatment outcomes for CYP with EDs.

### *Present study*

This study aimed to contribute to research on trauma symptoms in caregivers of CYP with an ED and to explore the relationship between ED-MHL and caregiver stressors on caregiver trauma symptom severity and whether or not they meet the threshold for probable diagnosis for PTSD. In order to address these aims, the following research questions and hypotheses were developed:

RQ1: What proportion of caregivers of children with ED meet the cutoff for probable diagnosis of PTSD?

RQ2: Is there a difference in ED-MHL scores between caregivers who meet the cutoff for probable diagnosis of PTSD and those who do not?

RQ3: What factors (e.g., ED-MHL, hospitalisation history, tube feeding, caregiving duration) are associated and/or predict whether a caregiver meets the threshold for probable PTSD diagnosis?

RQ4: Does ED-MHL moderate the relationship between caregiver stressors and PTSS?

## **Method**

### *Participants*

Participants were a non-clinical community sample recruited via social media (X, Facebook and Instagram) and through 13 charity organisations that were contacted via email. The term “eating-related difficulties” was used in the study advertisements to include individuals without a formal diagnosis of an eating disorder (ED). Throughout this paper, the terms “eating-related difficulties” and “eating disorders” are used interchangeably.

To be included in the research, participants needed to be a parent/guardian to a CYP with eating-related difficulties, be over 18 years old, and to currently provide substantial care to a CYP with eating-related difficulties. Substantial care was defined as offering practical and/or emotional support in relation to their CYP’s eating-related difficulties. Eligible participants’ CYP needed to be aged between 5 and 25, reside in the UK, and be either diagnosed with or suspected of having an ED.

A total of 123 participants provided consent and fully completed the online survey. To ensure data validity, the survey included two bot-detecting screening questions.

Ethical approval was granted by the University of East Anglia (UEA) Faculty of Medicine and Health Sciences Research Ethics Committee on 10<sup>th</sup> November 2024 (reference: ETH2324-1470).

### *Measures*

Included in the online survey were the following measures: a researcher-developed set of questions relating to sociodemographic characteristics and ED symptoms (demographics

tool); Posttraumatic stress disorder checklist for DSM-5 (PCL-5) (Weathers et al., 2015); and ED-MHL Scale (Ali, in preparation). Measures can be found in Appendix H, I and J. A detailed overview of each measure can be seen below.

#### *Demographics and illness severity tool*

This tool collected information about the CYP, the caregiver, and the CYP's eating disorder symptoms as reported by the caregiver. Caregiver demographics included gender, ethnicity, age, level of education, relationship to the CYP, and prior experience with eating-related difficulties. CYP demographics included gender, age, and the duration of eating-related difficulties. Caregivers were also asked about support received (options included individual therapy, family-based therapy, support groups, helplines, self-help resources, support from friends and/or family, and an "other" option) and medical treatments experienced in relation to their CYP's ED, and whether their CYP had a formal diagnosis of an ED. Factors such as medical treatment experiences, support received, caregiver history of ED, and duration of eating-related difficulties were referred to as 'caregiver stressors' during data analysis.

An eating behaviours checklist was used to identify the specific eating-related difficulties present in the CYP. The checklist was based on symptoms of binge eating, anorexia nervosa, bulimia nervosa, and other specified feeding and eating disorders (OSFED) as outlined by the National Institute for Health and Care Excellence (NICE, 2024). Respondents could select one or more of the listed behaviours or opt for a "none of the above/not sure" option. This approach, adapted from Goddard et al. (2011), has been used to assess eating behaviours in similar caregiver-focused studies.

#### *Posttraumatic stress disorder checklist for DSM 5 (PCL-5)*

The PCL-5 is a self-report 20-item questionnaire developed by Weathers et al. (2015). It is based on the fifth edition of the Diagnostic and Statistical Manual for Mental Disorders (DSM-5, 2013) criteria for posttraumatic stress disorder (PTSD). It has four subscales: re-experiencing, avoidance, negative alteration in cognition and mood, and hyperarousal. Respondents were asked to rate items using a 5-point Likert scale (0-4) with the descriptors, "Not at all," "A little bit," "Moderately," "Quite a bit," and "Extremely." A total symptom severity score (range: 0–80) was obtained by summing scores of all items, with higher scores indicating greater PTSS severity. The PCL-5 can also be used to determine a provisional PTSD diagnosis; the recommended cut-off score is around 31-33 to meet criteria for probable diagnosis of PTSD. In this study, this is also referred to as a participants PTSS status (above or below cut-off). The cut-off score for this study was 31. The PCL-5 has demonstrated high internal consistency ( $\alpha = .96$ ) in previous studies (Blevins et al., 2015; Bovin et al., 2016).

#### *ED-MHL scale*

To measure the level of ED-MHL, 18 factual statements about symptoms, risk factors, causes, help-seeking, treatment, and recovery of EDs were used. Participants responded to each statement with "true," "false," or "don't know." Of the 18 statements, eight are true and ten are false. Each correct answer scores one point, with higher scores indicating greater ED-MHL (a range of 0-18). The scale has shown good internal consistency ( $\alpha = .79$ ) in previous research (Feldhege et al., 2022) and was found acceptable ( $\alpha = .60$ ) in this study. The ED-MHL is a new, unvalidated measure, but to date, it is the only quantitative measure of ED-MHL. The validation study for this measure is ongoing (Ali et al. *in preparation*).

#### *Statistical analysis*



Data were analysed using IBM SPSS Statistics (version 29.0.2). All variables were screened for outliers and assumptions of normality; when assumptions for parametric tests were violated, non-parametric alternatives were used.

To address research question one, descriptive statistics were used to determine the proportion of caregivers meeting the threshold for probable PTSD diagnosis using the PCL-5. To prepare for subsequent analyses, data on support received and medical treatments were transformed into binary variables, with caregivers who endorsed one or more types of support categorised as “yes,” and each medical treatment option treated as a separate binary variable.

To answer research question two, differences in ED-MHL scores between caregivers who met and did not meet the PTSD threshold were assessed using a Mann-Whitney U test due to the non-normal distribution of ED-MHL scores. Mean, median and interquartile range for each group (below vs above threshold) were also reported. We also undertook a post-hoc exploratory analysis to examine the relationship between responses to recovery and weight-related items and PTSS status, as it was noted that some of these items might reflect caregivers' negative beliefs and attitudes.

Research question three was first addressed through an initial series of exploratory analyses. Given the binary nature of the dependent variable and the non-normal distribution of some predictors, Mann–Whitney U tests were used for the continuous variables (ED-MHL and duration of eating-related difficulties) as a test of difference in scores between the two different PTSS statuses. While chi-square tests were used for categorical predictors (caregiver history of ED, support received, and medical treatment experiences) to determine association with PTSS status. A binary logistic regression was

then conducted to assess whether these variables significantly predicted the likelihood of meeting the threshold for probable PTSD diagnosis. This model served as the primary analysis for RQ3.

Supplementary analyses were conducted using multiple linear regression to examine predictors of PTSS severity (continuous outcome). A backward hierarchical regression was also conducted to identify the most parsimonious set of predictors. This supplementary approach was included to offer a more sensitive analysis of symptom variability.

Research question four was addressed using a univariate general linear model. Interaction terms were computed between ED-MHL and each caregiver stressor. Any significant interaction between ED-MHL and a caregiver stressor was further explored with visual plots to interpret conditional effects. This analysis was exploratory and aimed to generate hypotheses for future research, rather than provide definitive conclusions. This exploratory analysis was also done with the consideration that linear relationships are not always present but can be found in moderation analyses.

## Results

### *Sample characteristics*

**Table 1**

*Participant characteristics (N=123)*

<b>Characteristic</b>	<b><i>n</i></b>	<b>%</b>	<b><i>M (SD)</i></b>
Age (years)	—	—	33.0 (6.4)
<b><i>Gender</i></b>			
Female	113	91.9	

Male	9	7.3
Other (unspecified)	1	0.8
<b><i>Ethnicity</i></b>		
White	120	97.6
Asian	1	0.8
Other (unspecified)	2	1.6
<b><i>Education</i></b>		
High school	11	8.9
Diploma	16	13.0
Bachelor's degree	42	34.1
Master's degree	42	34.1
PhD	8	6.5
Other	4	3.3
<b><i>History of ED</i></b>		
Yes	16	13.0
No	107	87.0

**Table 2**

*Child characteristics (N=123)*

<b><i>Characteristic</i></b>	<b><i>n</i></b>	<b><i>%</i></b>	<b><i>M (SD)</i></b>
Age (years)	—	—	12.6 (3.8)
<b><i>Gender</i></b>			

Female	107	87.0
Male	14	11.4
Non-binary	2	1.6
<b>Caregiver Relationship</b>		
Mother	113	91.9
Father	9	7.3
Other (“mother via surrogacy”)*	1	0.8
<b>Diagnosis</b>		
Formal ED diagnosis	106	86.2
No diagnosis	17	13.8

*Note.*

*\*This participant was categorised as a mother for any grouped analysis.*

Table 3 shows the medical treatments children and young people have experienced as reported by their caregivers. Caregivers were able to pick more than one medical treatment. Of particular interest, overall, there were higher percentages of caregivers who had not experienced these treatment options. Nonetheless, there was still nearly half that indicated they had experienced hospitalisation in a general hospital.

**Table 3**

*Medical treatments experienced by child/young person*

Medical treatments	Yes		No	
	<i>N</i>	<i>Percent</i>	<i>N</i>	<i>Percent</i>
Hospitalised in Mental health or ED unit	44	35.8	79	64.2

Hospitalised in general hospital	57	46.3	66	53.7
Feeding tube	33	26.8	90	73.2
None of the above	54	43.9	69	56.1

114 participants (92.7 %) reported having received support in relation to their child's eating disorder. Participants could select more than one type of support received. Table 4 shows how many participants reported each type. Most participants reported accessing more than one type of support.

**Table 4**

*Frequency of types of support received by caregivers for their CYP*

	<b>N</b>	<b>Percent</b>
Individual therapy	25	20.3
Family-based therapy	22	17.9
Support groups	26	21.1
Helplines	21	17.1
Self-help resources	17	13.8
Support from friends/family	11	8.9
Other	1	0.8

*Child and Young Person (CYP) Diagnoses and Symptoms*

Table 5 shows the diagnosis and perceived diagnoses reported by caregivers. Participants could select multiple options, resulting in a total number of responses per item that exceeds the sample size.

**Table 5**

*CYP diagnoses as reported by caregivers*

<b>Diagnosis</b>	<b>Perceived and formal diagnosis, N (%)</b>	<b>Perceived diagnosis, N (%)</b>	<b>Formal diagnosis, N (%)</b>
Anorexia	98 (79.7%)	96 (90.6%)	2 (11.8%)
Bulimia	7 (5.7%)	7 (6.6%)	-
Binge eating	10 (8.1%)	7 (6.6%)	3 (17.6%)
OSFED	5 (4.1%)	4 (3.8%)	1 (5.9%)
ARFID	23 (18.7%)	12 (11.3%)	11 (64.7%)
None of the above	2 (1.6%)	-	2 (11.8%)

*Note: OSFED - Other Specified Feeding or Eating Difficulty; ARFID - Avoidant/Restrictive*

#### *Food Intake Disorder*

Of the caregivers who reported a formal diagnosis for their child 90 caregivers reported one diagnosis (84.9%), 12 reported two diagnoses (11.3%), and four reported three diagnoses (3.8%).

#### *Caregiver PTSS levels*

Participants had a mean PCL-5 score of 37.8 ( $SD=16.3$ ), with scores ranging from 2 to 80 (for subsequent analysis, this was referred to as PTSS severity). Based on the suggested

cutoff score of 31 (Weathers et al., 2013), 81 participants (65.9%) met the threshold for probable PTSD diagnosis.

#### *ED-MHL in caregivers*

All participants responded to all 18 items on the ED-MHL scale; the mean ED-MHL score was 14.69 ( $SD=2.3$ , 95%  $CI$  [14.3,15.1]). Table 6 displays the percentage of correct answers for each statement separately, based on the 123 participants. Eight participants answered all items correctly. The results showed limited variability, with over half of the items answered correctly by most participants.

**Table 6**

*Percentage of correct responses to statements on ED-MHL scale*

<b><i>Scale item</i></b>	<b><i>Correct (%)</i></b>
1.Eating disorders only affect adolescent girls and young adult women.	99.2
2.Eating disorders have the highest mortality rate among all mental illnesses.	84.6
3.If people seek help for an eating disorder early they will recover faster.	74.0
4.Rapid weight loss in a short period of time can be a symptom of anorexia nervosa.	87.8
5.People have to vomit to have bulimia nervosa.	56.1
6.People with bulimia nervosa can be slightly underweight, normal weight, or overweight.	94.3
7.A person with an eating disorder might find it difficult to ask for help from family and friends.	100

8.It is common for a person with an eating disorder to also experience another mental illness, such as depression.	95.9
9.Rapid weight loss or being very underweight can affect your ability to think	100
10.Once someone has an eating disorder, recovery is very unlikely.	87.8
11.Not everyone with an eating disorder needs to seek help.	67.5
12.Males can develop anorexia nervosa, but not bulimia nervosa.	93.5
13.People who have had an eating disorder will always worry about their weight, even if they have fully recovered.	49.6
14.Most people have experienced binge eating at some point in their life.	48.0
15.Eating disorders are simply caused by western cultural values of thinness.	94.3
16.Genes do not play a role in the development of eating disorders.	70.7
17.People with eating disorders can stop their behaviour if they want to.	90.2
18.Effective treatment for eating disorders is available.	76.4

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#### *Differences in ED-MHL scores based on PTSS status*

Shapiro-Wilk tests showed normality for PCL-5 scores ( $W=0.99$ ,  $p=.71$ ) but not for ED-MHL scores ( $W=0.92$ ,  $p<.001$ ). Therefore, a Mann-Whitney U test was used to examine differences in ED-MHL scores between participants who met the threshold for probable PTSD diagnosis and those who did not. Results indicated no statistically significant difference ( $U=1420.00$ ,  $Z=-1.52$ ,  $p=.13$ ). Descriptives of ED-MHL scores for the different PTSS statuses were as follows; Below threshold (mean=15.1, median=16, IQR=3) and above threshold (mean=14.5, median=15, IQR=3).



Following the main analysis, a post-hoc exploratory analysis was conducted to examine whether endorsement of specific beliefs about eating disorders, as measured by selected ED-MHL items, was associated with the likelihood of meeting the threshold for probable PTSD diagnosis. To increase statistical power, responses to ED-MHL items were dichotomised into correct and incorrect categories (with “Don’t know” categorised as incorrect), and a series of chi-square tests of independence were performed. The original three-category responses (True, False, Don't know) were used for descriptive purposes. Statements on beliefs around recovery (items 3, 10, 13) and weight-related beliefs (items 4, 6, 9, 13) were selected for this analysis. We were unable to perform analysis on ED-MHL item 9 as all participants selected the same response. A significant association was found between the correct vs incorrect responses on Item 13 and PTSS status. Table 7 shows the descriptive distribution of participants who chose each response category (N), and the number (n) and percentage of participants within each category who met the threshold for probable PTSD diagnosis. The table also shows the chi-square and p-values for the statistical test of association between correct vs incorrect responses and PTSS status for each item.

**Table 7**

*Distribution of the percentage of participants above the threshold for probable PTSD diagnosis across item responses*

		<i>n/N (% Above</i>		
		<i>Threshold for PTSD</i>		
<i>Item</i>	<i>Response</i>	<i>symptoms)</i>	<i>Statistical test</i>	
Recovery Beliefs				
3.If people seek help for an eating disorder early, they will recover faster. (Correct response: True)	TRUE	56/91 (61.50%)	$\chi^2=2.89$ , p=.09	
	FALSE	11/14 (78.60%)		
	Don't know	14/18 (77.80%)		
10.Once someone has an eating disorder, recovery is very unlikely. (Correct response: False)	TRUE	5/7 (71.40%)	$\chi^2=1.52$ , p=.22	
	FALSE	69/108 (63.90%)		
	Don't know	7/8 (87.50%)		
13.People who have had an eating disorder will always worry about their weight, even if they have fully recovered. (Correct response: False)	TRUE	23/31 (74.20%)	$\chi^2=5.51$ , p=.02*	
	FALSE	34/61 (55.70%)		
	Don't know	24/31 (77.40%)		
Weight-Related Beliefs				
4.Rapid weight loss in a short period of time can be a symptom of anorexia nervosa. (Correct response: True)	TRUE	70/108 (64.80%)	$\chi^2=0.43$ , p=.51	
	FALSE	6/7 (85.70%)		
	Don't know	5/8 (62.50%)		

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6. People with bulimia nervosa can be slightly	TRUE	75/116 (64.70%)	$\chi^2=1.31, p=.25$
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underweight, normal weight, or overweight. (Correct

response: True)

Don't know 5/7 (71.4%)

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\*  $p < .05$

### *Caregiver stressors, ED-MHL and PTSS status*

Due to violations of the assumption of normality in ED-MHL scores and duration of CYP ED, the Mann-Whitney U test was used to examine the differences in ED-MHL scores and duration of the child's ED between participants who met the threshold for probable PTSD diagnosis and those who did not. No statistically significant difference was observed in both ED-MHL (see statistics above) and duration of the child's eating-related difficulties ( $U=1507.50, Z=-1.04, p=.29$ ) between caregivers who met the threshold for probable PTSD diagnosis and those who did not.

A series of chi-square tests of independence were performed to evaluate the relationship between caregiver stressors and PTSS status. Table 8 presents the associations, based on chi-square tests. Small effect sizes were observed suggesting weak associations; however, none of the variables were statistically significantly associated with meeting the threshold for probable PTSD diagnosis.

**Table 8**

### *Relationship between caregiver stressors and PTSS status*

<i>Variable</i>	<i><math>\chi^2</math></i>	<i>p</i>	<i><math>\Phi</math> (Phi)</i>
Caregiver history of ED	(1, $N=123$ ) = 0.68	.41	.08

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Support received	(1, N=123) = 1.98	.16	.13
Medical treatment – Mental health hospital or ED unit	(1, N=123) = .000	.99	.001
Medical treatment – General Hospital	(1, N=123) = 1.74	.19	.12
Medical treatment – Feeding tube	(1, N=123) = 0.55	.46	.07

### *Logistic regression*

A logistic regression was carried out to assess the effect of ED-MHL, ED duration, caregiver history of ED, support received, and three different types of medical treatment on the caregiver's probable diagnosis of PTSD (PTSS status). The overall model was statistically significant ( $\chi^2(7)=14.49, p<0.05$ ), explaining between 11.1% (*Cox & Snell R Square*) and 15.4% (*Nagelkerke R Square*) of variance in PTSS status and correctly classifying 71.5% of cases. In the model, receiving support was a significant predictor ( $B=2.12, Wald=5.93, p=.02, Exp(B)=8.31, 95\% CI[1.51,45.69]$ ), indicating that the odds of meeting probable PTSD diagnosis criteria were approximately 8.31 times higher among those who received support for their child's ED compared to those who did not. ED-MHL was also a significant predictor ( $B=-0.25, Wald=4.73, p=.03, Exp(B)=0.78, 95\% CI[0.63,0.98]$ ), with each unit increase in ED-MHL leading to a 21.8 % decrease in the odds of probable diagnosis of PTSD. Hospitalisation in a general hospital was also a significant predictor ( $B=1.06, Wald=4.39, p=.04, Exp(B)=2.89, 95\% CI[1.07,7.79]$ ), meaning participants with this experience of medical treatment were about 2.89 times more likely to meet the threshold for PTSD diagnosis as compared to those who did not. No other factors statistically significantly predicted PTSS status.

### *Moderation analysis*

To examine whether ED-MHL moderated the relationships between caregiver stressors and PTSS severity, a univariate general linear model was conducted. Interaction terms between ED-MHL and each stressor were included to test moderation effects.

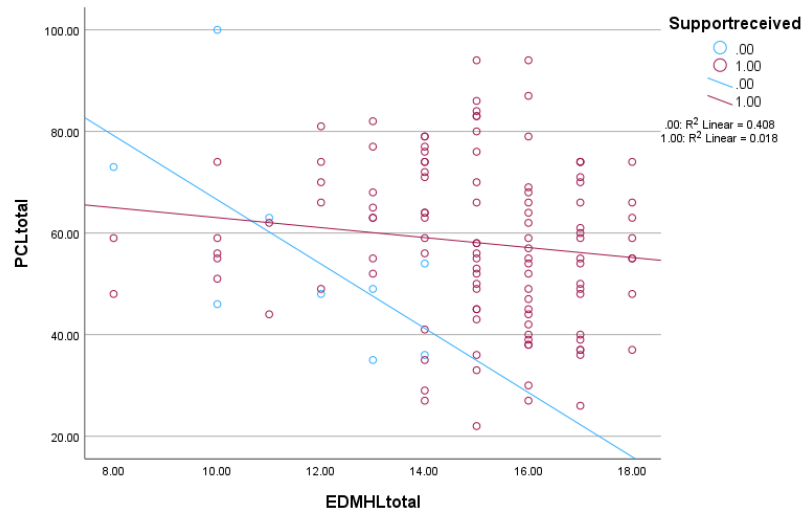
The overall model was not statistically significant,  $F(13, 109)=1.16$ ,  $p=.32$ , *Adjusted R*<sup>2</sup>=.017.

The predictors only accounted for a small variance in PTSS severity. However, a significant main effect of ED-MHL was found,  $F(1, 109)=5.09$ ,  $p=.03$ , indicating that higher ED-MHL scores were associated with lower PTSS severity ( $B=-6.67$ ,  $p=.03$ , 95% *CI*[-12.53, -0.81]). A significant interaction between ED-MHL and support received was also observed,  $F(1, 109)=4.30$ ,  $p=.04$ . Suggesting that the effect of support on PTSS severity differed depending on the level of ED-MHL. No other interactions between ED-MHL and the remaining caregiving stressors reached statistical significance.

To visualise the significant interaction between ED-MHL and support received on PTSS severity, a scatterplot with fitted regression lines was generated (see Figure 1). Among caregivers who did not receive support ( $n=9$ ), higher ED-MHL scores were associated with significantly lower PTSS severity ( $R^2=.408$ ). In contrast, among caregivers who did receive support ( $n=114$ ), ED-MHL was only weakly related to PTSS severity ( $R^2=.018$ ).

### **Figure 1**

*Interaction between ED-MHL and perceived support on PTSS severity*



## Discussion

### *Summary of findings*

This study examined posttraumatic stress symptoms among 123 caregivers of children and young people with eating-related difficulties. The sample was largely composed of white, female caregivers, most of whom were mothers. A majority reported that their child had received a formal diagnosis, most commonly anorexia nervosa or ARFID, and many had experienced some form of support, with nearly half reporting hospitalisation of their child in a general hospital.

Caregivers reported a relatively high level of trauma symptoms, with around two-thirds meeting the threshold for probable PTSD. On average, caregivers demonstrated moderate levels of eating disorder mental health literacy (ED-MHL). Exploratory analyses of individual belief items suggested that caregivers who expressed uncertainty about recovery from eating disorders might be more likely to meet the threshold for probable PTSD.

Across the main analyses, trauma symptoms were more likely among caregivers with lower levels of ED-MHL and among those whose child had been hospitalised in a general hospital. Importantly, the impact of ED-MHL appeared to depend on the support caregivers had received, with the combination of higher ED-MHL and access to support linked to reduced trauma symptoms.

### *Characteristics of caregivers and CYP with eating-related difficulties*

This study followed a similar trajectory to many studies completed in the eating disorder field, where most participants are white females and ethnic minorities are better represented when research is solely focused on a specific ethnic population (Egbert et al. 2022). This lack of diversity highlights a persistent challenge in ED research, despite evidence that eating disorders affect a broad demographic spectrum (Qian et al., 2021). Although the recruitment strategy for this study targeted all demographics, it did not successfully ensure a diverse participant pool. This underscores the need for culturally sensitive recruitment methods and interventions to address barriers to participation among ethnic minorities, particularly within the field of eating disorders. Over the years, studies on eating disorders have struggled to include data on ethnic minorities. One explanation may be the stigmatisation of eating disorders as issues predominantly affecting white women, compounded by clinical failures in culturally sensitive ED assessments and interventions (Alegria et al., 2007; Becker et al., 2003). These factors may discourage disclosure and participation in ED research among ethnic minorities.

Interestingly, anorexia nervosa was the most reported eating disorder in this study, even though the NICE guidelines suggest it is the least common ED (NICE, 2024). This discrepancy may reflect the characteristics of the non-clinical sample studied, as

prevalence rates often vary depending on sample type and recruitment methods.

Additionally, research in ED has an apparent focus on AN whereas AN is a small part of the ED clinical population in services. Among participants whose children did not have a formal diagnosis, ARFID was the most perceived condition. This aligns with NICE (2024) statistics, which identify atypical eating disorders as the most common category.

#### *Role of caregivers to CYP with eating-related difficulties*

This study contributes significantly to the growing body of research highlighting the profound and often negative impact of caregiving on individuals supporting a CYP with an eating disorder (ED). A high mean trauma score was observed among the participants ( $M=37.8$ ,  $SD=16.3$ ), which met the established clinical threshold for probable PTSD. These findings strongly align with prior research indicating that a substantial proportion of caregivers for individuals with EDs often meet full or partial criteria for PTSD diagnoses (e.g., Hazell et al., 2013; Treasure et al., 2015). This highlights the significant psychological toll of caregiving in the context of a severe and complex illness like an ED.

The genesis of such trauma reactions in ED caregivers is often multifaceted. Caregivers frequently witness distressing symptoms, engage in challenging re-feeding efforts, managing medical crises, and face the constant threat to their child's life, which can constitute potentially traumatizing experiences (Treasure et al., 2015). The chronic nature of many eating disorders, coupled with the intensive and often intrusive nature of care required, can create an environment of sustained stress, helplessness, and perceived threat, all of which are antecedents to traumatic stress.

A key contextual factor in this study was the severity of illness among the CYPs, evidenced by many participants reporting experiences with hospitalization and tube feeding. These



indicators strongly allude to a group of CYPs who were moderately to severely ill, requiring intensive medical and psychological intervention. The impact noted on caregivers can be interpreted with significant consideration of this fact. Dealing with a child requiring such high levels of care, including repeated hospitalizations and invasive procedures like tube feeding, inevitably escalates caregiver burden beyond general stress. Severity of symptoms as a predictor of caregiver burden and stress is a finding that has been evidenced in previous studies (Padierna et al., 2013; Martin et al., 2011). The significant association found in this study, between general hospitalisation and caregiver PTSS, further supports the interpretation that greater illness severity contributes to elevated caregiver burden beyond general stress.

These findings reinforce the critical need for comprehensive support for caregivers of CYPs with EDs, moving beyond focusing solely on the patient. Interventions might consider proactively screening caregivers for psychological distress, including PTSD, and offer tailored support such as trauma-informed therapy, stress management techniques, and psychoeducation on coping with the emotional challenges of caregiving.

#### *ED-MHL in caregivers*

Results from the ED-MHL measure should be interpreted with caution due to its unvalidated status in this specific caregiver population and context. Additionally, this study noted low variability in responses to several statements, with some being answered correctly by all or nearly all participants. This lack of variability suggests a potential ceiling effect, where the measure might not have been sufficiently sensitive to capture nuances in knowledge or beliefs, particularly among a disproportionately highly educated sample. The binary (True/False) format may have further allowed participants to rely on general

reasoning, test-taking strategies, or prior knowledge, rather than demonstrating a deeper, more practical understanding of ED-MHL, including the application of knowledge and awareness of support systems. Although this study contributes to the limited objective and quantitative research on ED-MHL among caregivers, extending beyond specific eating disorder diagnoses, these findings underscore the critical need for further validation and development of more robust measurement tools for this population. Previous studies have largely relied on qualitative measures such as interviews and focus groups, or self-report measures using vignettes (Bullivant et al., 2020), highlighting the importance of developing validated quantitative tools.

Despite the exploratory nature and the limitations, the overall analysis of the ED-MHL revealed no statistically significant differences in total ED-MHL scores between participants who did and did not meet the threshold for probable PTSD diagnosis. This absence of a significant association might be influenced by the limited variability in responses and the potential ceiling effect, which could obscure genuine differences if they exist.

An exploratory analysis of individual ED-MHL statements, distinguishing between weight-related and recovery-related beliefs, provided further descriptive insights into attitudes and beliefs irrespective of the full-scale score. As detailed in the results, specific patterns were observed regarding the distribution of probable PTSD among those endorsing different response options. For statements pertaining to recovery-related beliefs, a consistent descriptive pattern emerged where caregivers who expressed uncertainty ("Don't know" response) were most frequently among those meeting the PTSD threshold. This trend could suggest that a lack of clear conviction or understanding regarding the prospects and processes of eating disorder recovery may be associated with increased psychological distress in caregivers. This finding is particularly noticeable as it points towards an area

beyond simple knowledge deficits, potentially reflecting a state of ambivalence, information overload, or emotional exhaustion common in caregiving roles, which could be exacerbated by or contribute to PTSD symptoms. Such experiences of chronic stress and emotional burden, frequently documented among caregivers of individuals with chronic illnesses (Rady et al., 2021; Carmassi et al., 2020; Hazell et al., 2013), can impact cognitive processing and the ability to assimilate complex information, potentially leading to greater uncertainty in responses. The descriptive observation that agreement with the statement about recovery being "very unlikely" (Item 10) also coincided with a high percentage of probable PTSD participants further underscores a potentially pessimistic outlook within this distressed caregiver group.

Collectively, these exploratory, descriptive patterns, while not all statistically significant, identify potential areas where the ED-MHL of caregivers with probable PTSD might differ from those without. These observations offer a basis for generating specific hypotheses for future research concerning the interplay between caregiver distress, their understanding of eating disorders, and how this might impact their caregiving experience or the recovery journey of their CYP.

#### *ED-MHL, caregiver stressors and trauma in caregivers*

The logistic regression revealed an overall model that was statistically significant, suggesting that a combination of the included ED-MHL factors and caregiver stressors, or at least one of these factors, significantly contributes to explaining PTSS status. While the proportion of variance explained by the model was modest (between 11.1% and 15.4%), this should be considered within the context of complex psychological outcomes, which are often influenced by numerous complex and unmeasured factors. Furthermore, the model

demonstrated a good predictive capability, correctly classifying 71.5% of cases, representing an improvement over chance classification.

Beyond the overall model fit, specific predictors within the model significantly contributed to meeting a probable PTSD diagnosis. These were lower ED-MHL scores, experience with hospitalization in a general (non-specialized) hospital and receiving support. The finding that lower ED-MHL was a significant predictor of probable PTSD aligns with the descriptive patterns observed in the exploratory analysis, where uncertainty ("Don't know" responses) on some ED-MHL items was more prevalent among those with probable PTSD. This suggests that a reduced level of knowledge or increased ambiguity in understanding key eating disorder beliefs (both recovery and weight-related) is a distinct factor associated with heightened trauma symptoms in caregivers.

It was particularly interesting to observe that among the various medical treatments, experience with hospitalization in a general hospital was a significant predictor of probable PTSD, while hospitalization in an ED or mental health unit, or tube feeding, were not. This finding is counter-intuitive if one assumes severity of intervention directly correlates with caregiver stress. However, this could be attributed to the differing environments and expertise encountered. Additionally, subjective appraisal theory (Lazarus & Folkman, 1984) suggests that it is not only the objective features of an event, but also how caregivers interpret and appraise those experiences, that shape psychological outcomes. In specialized medical environments, where treatment is focused on eating disorders and professionals are equipped to manage ED-specific behaviours and medical complications, caregivers may appraise the situation as more controlled and supportive, fostering perceptions of safety. Conversely, in general hospitals with non-specialized care, caregivers might face situations where their child's complex needs are less understood, leading to

feelings of uncontained stress and heightened anxiety due to a perceived lack of expertise. This is consistent with research indicating that perceived lack of support or competence in medical settings can exacerbate caregiver distress (Determeijer et al., 2024; Reinhard et al., 2008).

The finding that receiving support was a significant predictor of probable PTSD diagnosis might also initially appear counter-intuitive, as one might expect that receiving support for your child's ED would correlate with a lower probability of a PTSD diagnosis, acting as a protective factor. One potential explanation for this unexpected positive association is the possibility of reverse causality. It is plausible that caregivers who are already experiencing greater psychological distress and are at a higher risk for PTSD are inherently more likely to actively seek out, or be identified as needing, support. Therefore, the support received might be a consequence of their heightened distress rather than a direct preventive or mitigating factor against it. Another critical consideration for this positive association is the likely target and nature of the support. While one might intuitively assume that effective support for the patient would indirectly alleviate caregiver burden and thus reduce PTSD risk, it is important to consider that patients requiring more intensive and sustained support are often those with more severe or chronic EDs. Caregivers of these CYPs are inherently exposed to higher levels of chronic stress and trauma, thereby increasing their vulnerability to PTSD symptoms, regardless of the patient-focused support provided. In this study, there was no qualitative exploration to investigate the nature, source, or perceived helpfulness of the support received by caregivers, making it challenging to differentiate between support acting as a protective factor versus an indicator of the severity and complexity of the ED that the caregiver is managing. This limitation suggests that while

support is undoubtedly vital, its impact on caregiver well-being in the context of PTSD is nuanced and requires deeper investigation.

The exploratory analysis did not find an overall significant model but reported a significant interaction between ED-MHL and support received on PTSS. As noted in the results, this moderation showed that with participants who did not receive support, a higher ED-MHL was associated with lower PTSS severity. This would suggest that ED-MHL serves as a protective factor when caregivers are not receiving support.

### *Strengths & Limitations*

A strength of this study was that it represented a non-clinical population allowing for the inclusion of caregivers whose children do not have a formal diagnosis. While studies that focus on clinical populations with diagnosed eating disorders can be valuable, they may limit the generalizability of the findings. In contrast, this study's approach allows for broader conclusions about caregiver experiences. Another strength is the method used for participants to report their child's eating difficulties. This approach allowed participants to report symptomatology without being constrained by clinical labels, capturing a broader range of caregiver experiences.

Some limitations are noted in this study. Anxiety and depression were not measured in this study and their potential as confounding variables was not controlled for which limits our ability to draw definitive conclusions about their role in observed relationships.

A major methodological limitation of this study is the use of the newly developed, unvalidated ED-MHL questionnaire. While the measure was carefully developed and based on established MHL frameworks, the lack of established psychometric properties means that the true accuracy and reliability of the scores cannot be definitively determined. This

issue restricts the generalizability and interpretation of the findings; therefore, the observed association between ED-MHL and PTSS should be viewed as tentative until a dedicated psychometric study confirms the measure's validity. Future research on ED-MHL should aim to establish the scale's validity and reliability through factor analysis and larger, more diverse samples.

Additionally, this research primarily examines the experiences of white females and is not able to offer a culturally sensitive and inclusive perspective. Future research on caregiver experiences of CYP with eating-related difficulties might consider specific research into a wider range of experiences.

## **Conclusion**

This research demonstrates that caregivers of children and young people with eating disorders experience a substantial psychological burden, frequently meeting criteria for probable PTSD. Factors such as lower ED-MHL, hospitalisation in a general hospital, and receiving support are associated with probable PTSD diagnosis. These findings reinforce the urgent necessity for integrated interventions that address both the patient's ED and the mental health needs of their caregivers. Clinically, professionals should be aware of the specific vulnerabilities faced by caregivers in general hospital settings and consider the potential implications of caregivers seeking support as an indicator of increased distress. Future research is crucial to build upon these exploratory findings, with a particular emphasis on qualitative exploration to unravel the nuanced "why" behind these associations. Further validation of ED-MHL measures tailored for caregivers is also essential to deepen our understanding of this critical aspect of caregiving.

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## **Chapter Five: General Discussion**

Word Count: 3,140

This chapter will review the findings from both the meta-analysis and the empirical paper, highlighting key takeaways from each study. It will examine the contribution of mental health literacy to the ED field and critically appraise the existing literature considering the findings from both studies. Additionally, this chapter will discuss the strengths and limitations of both studies and explore further clinical implications beyond those covered in Chapters Two and Four.

## **Overview of findings**

### *Meta-analysis*

The meta-analysis revealed that higher education and female gender were associated with MHL. A detailed discussion of these findings can be found in Chapter Two, here I would like to focus on a major takeaway message from this study, which was noted due to the high heterogeneity observed across studies examining age, gender, and education, with  $I^2$  values exceeding 80% in all three meta-analyses. A key factor contributing to this heterogeneity may be the variability in MHL measurement tools, as the included studies used ten different measures (see full list of measures in Appendix K). The lack of consistency in how MHL is measured likely contributed to the variation in findings.

Although this debate is not explicitly explored in this research, the variability in studies raises an important discussion about whether MHL should be conceptualized as a multi-construct theory rather than a multi-dimensional construct, as a clearer framework could improve measurement reliability and validity. However, even when studies were separated by measurement type in subgroup analyses, heterogeneity remained high. This suggests measurement variability might not be the only reason for study variability, though the



limited number of studies used in subgroup analyses makes it difficult to draw firm conclusions.

In addition to variability in measurement tools, another challenge is that many existing MHL assessments do not fully capture the construct in its entirety, further complicating efforts to establish standardized measurement approaches. Many studies were excluded from this meta-analysis because their tools assessed only one component of MHL, such as recognition or help-seeking behaviour. Additionally, Kutcher et al. (2016) argue that many MHL tools lack sufficient psychometric validation, making it difficult to assess the reliability of findings. This may have also contributed to the high variability observed in the studies included in these meta-analyses.

#### *Empirical study*

The findings from the empirical paper present a nuanced picture of the caregiver experience, moving beyond a simple assessment of individual factors to reveal a complex interplay of knowledge, environment, and support in predicting caregiver PTSS. The study confirmed that caregivers of CYP with eating disorders experience a psychological burden, frequently meeting the clinical threshold for probable PTSD as indicated in previous literature (Hazell et al., 2013; Timko et al., 2022). While initial analysis did not find a significant difference in ED-MHL scores between the two different PTSS statuses (below vs above threshold for PTSD diagnosis), the subsequent logistic regression demonstrated that a combination of factors, including ED-MHL and caregiver stressors, collectively and significantly contributed to explaining PTSS status. This highlights that the relationship is not a simple linear one but rather is tied to several variables.

Specifically, the model identified three significant predictors of probable PTSD: lower ED-MHL, experiences with hospitalisation in a general (non-specialized) hospital, and receiving support. The finding that lower ED-MHL was a significant predictor of PTSS suggests that a reduced level of mental health literacy is a risk factor for caregiver distress. This could be interpreted as an inability to navigate the complexities of ED management, or perhaps a reflection of a deeper uncertainty about the illness and recovery process, as highlighted by the descriptive patterns of "Don't know" responses. The significance of general hospitalisations illustrated how the care environment impacts caregivers' mental health. Caregivers in non-specialised settings may experience heightened stress due to a perceived lack of professional competence and control, which could contribute to a sense of helplessness and trauma. Finally, the positive association between receiving support and PTSS, a finding that at first appears counter-intuitive, likely points to a pattern of reverse causality. This suggests that caregivers are more likely to seek or be identified as needing support because they are experiencing greater psychological distress and are managing a more severe or complex illness, rather than support acting as a direct protective factor against PTSS. The relationship between receiving support and PTSS was found to be moderated by ED-MHL. This finding provides a nuanced lens through which to view caregiver support and its efficacy. It suggests that the benefits or risks associated with receiving support may be contingent on a caregiver's level of mental health literacy.

Collectively, these findings highlight that ED-MHL, caregiver stressors, and PTSS are interwoven. While ED-MHL may not serve as a direct buffer against trauma-related distress, a deficit in it appears to be a risk factor, alongside caregiver stressors. This emphasises that to effectively support caregivers, interventions must move beyond simple psychoeducation

and address the full spectrum of their needs, including trauma-informed care and support in navigating a complex and often stressful medical system.

### **Contribution to main research fields**

The findings of this research give a new and specific insight into the complex relationship between MHL, caregiver stressors, and psychological distress experienced by caregivers of children and young people (CYP) with eating disorders (EDs). Previous studies have shown that increased MHL is associated with better recognition of poor mental health symptoms (Coles et al., 2016), increased help-seeking behaviours, and earlier access to mental health services (Wei et al., 2017; Yang et al., 2024). Although not directly assessing for these outcomes, our study found that while a simple association between overall ED-MHL scores and PTSS was not present, its contribution is better understood within a multivariate context alongside other caregiver stressors. It highlights that deficits in specific knowledge and beliefs, when combined with other stressors, may increase the risk of caregiver distress.

Furthermore, this research makes a crucial contribution to the field of caregiver mental health by identifying specific stressors that are associated with the development of probable PTSD. The finding that hospitalisation in a general hospital is a significant predictor of PTSS highlights the importance of the care environment itself. This suggests that caregivers' trauma may be influenced not only by the child's illness severity but also by contextual factors within healthcare settings, potentially including variations in perceived professional expertise and support, highlighting an important area for further investigation and service improvement.

While increased MHL may enhance a caregiver's ability to recognise mental health issues and seek support, it does not directly address maladaptive cognitive appraisals and emotion dysregulation that contribute to persistent distress. This presents a need for caregiver support in mental health services to go beyond psychoeducation and promote emotional regulation, self-compassion, and trauma-informed care. Targeted therapeutic approaches for caregivers that address the way they interpret their experiences and regulate their emotions in response to stress are important and more suited to their caregiver needs. In line with cognitive models of PTSD (Ehlers & Clark, 2000) and trauma models (Green, 1990), interventions that address maladaptive appraisals and support emotional regulation may be particularly effective in reducing trauma symptoms and improving caregivers' coping capacities. This research thus contributes a new perspective by emphasising that while MHL plays an important role in early recognition and help-seeking, it must be complemented by psychological and emotional support strategies to address the full spectrum of caregiver needs.

### **Critical appraisal of existing literature**

#### *Mental health literacy*

One notable limitation observed in the field of MHL research is that while many studies collect demographic data, not all these variables are analysed in relation to MHL. This lack of correlational analysis across the studies limited the ability to perform a comprehensive meta-analysis on other key sociodemographic factors such as ethnicity.

On the other hand, a strength of MHL research is its robust exploration of its components as independent factors of MHL. Previous research (Reavley & Jorm, 2011; Wei et al., 2015) has been able to explore recognition, help-seeking, and stigma/attitudes stating that there

is an application of measures for different components. This distinction in measurements of components of MHL versus MHL as a whole construct allowed the meta-analysis in this thesis to have clear inclusion and exclusion criteria, ensuring that relevant studies were easily identified. Additionally, the ongoing debate about whether MHL should be viewed as a multi-component construct or a multi-construct theory (Spiker and Hammer, 2018) has meant that many studies are explicit about whether they are examining specific components of MHL (e.g., knowledge, recognition, help-seeking attitudes) or referring to MHL as a whole construct.

The meta-analysis also revealed that MHL is studied across many different countries, highlighting that it is not a country-specific issue. Among the twenty-three studies analysed, research was conducted across eleven different countries. This raises the question of whether the sociodemographic factors associated with MHL are universal or dependent on cultural context. There have been challenges noted concerning MHL in developing countries, including factors such as higher rates of general illiteracy and economic constraints in developing countries (Ganasen et al., 2008). Implying that the association between MHL and education, for example, may depend on how mental health is integrated into educational curricula across different countries. Furthermore, gender differences in MHL might be more pronounced in societies with rigid gender norms. Jorm et al. (1997) state that MHL should begin to be seen as a goal of health policies and noted the inception of changes in policy plans in some countries but not others. This further emphasises the diversity in MHL across countries not only in its association with the culture but also in the development of efficient strategies to increase prevention and early intervention. Future studies should consider how sociodemographic factors interact with cultural differences in shaping MHL.

### *PTSD in caregivers of CYP with ED*

A noted limitation in the ED field is the lack of transcultural perspectives when examining PTSD in caregivers of CYP with EDs. Yet, previous research by Anastasiadou et al. (2014) demonstrated varying levels of caregiver burden across different countries, suggesting that cultural norms and attitudes toward caregiving play a significant role in shaping experiences. In cultures where caregiving is more widely accepted as a familial duty, the burden may be perceived differently, potentially leading to different outcomes in studies on caregiver distress. This highlights the need for a representation of the differences rather than assuming a universal caregiving experience. Future research should explore how culture influences caregivers' appraisal of their role and response to their child's ED as well as how interventions can be tailored to meet the needs of different cultural contexts.

In addition, a persistent and well-documented issue in ED research is the overwhelming representation of white females and low participation from ethnic minority communities (Halbeisen et al., 2022; Cheng et al., 2019). This has had significant implications as the findings predominantly reflect the experiences of white women, limiting their generalisability to other racial and gender groups (Halbeisen et al., 2022). Plus, clinical assessments and interventions are based on research that lacks diversity making them less inclusive and potentially inapplicable to minority populations. Halbeisen et al. (2022) conclude that there is a need for adjustment in recruitment strategies assessment and reporting practices in clinical trials to address the role of diversity in treatment experiences and differences in outcomes. For these reasons, many ethnic minorities may feel discouraged from participating in research because they do not see their experiences reflected in existing literature. Even when research efforts specifically target diverse populations, white participants often dominate recruitment pools, reinforcing this

imbalance (Halbeisen et al., 2022; Burnette et al., 2022). This can be seen in the empirical study conducted as part of this thesis as white female participants dominated the recruitment pool. This suggests that for research to truly capture the experiences of ethnic minorities, studies may need to focus exclusively on these populations rather than including them alongside white participants, where they remain underrepresented.

### **Strengths and Limitations**

While the meta-analysis and cross-sectional study in this thesis provided valuable insights into MHL and its relationship to PTSS in caregivers of individuals with eating disorders (EDs), there are key limitations and areas for improvement that should be considered when interpreting the findings.

#### *Measuring Help-Seeking Behaviour and Mental Health Service Access*

A major limitation of the cross-sectional study was the lack of direct measurement of caregivers' help-seeking behaviours and access to mental health services concerning their trauma. One widely recognized outcome of higher MHL is increased help-seeking and earlier access to mental health support (Wei et al., 2017; Yang et al., 2024). However, in this study, the outcomes were assumed, which makes it difficult to determine whether the high MHL levels observed in caregivers translated into practical benefits, such as accessing services or seeking psychological support for their distress. Future research should explicitly assess whether caregivers with higher ED-MHL engage in more proactive mental health help-seeking behaviours and whether this affects their trauma symptoms.

One methodological decision that could be debated is the use of an ED-specific MHL scale instead of a more generic MHL measure. While the focus on EDs justified the selection of an ED-MHL tool, it is important to acknowledge that this research was focused on caregiver

trauma and not the child's ED. A more general MHL tool or PTSD focussed MHL tool might have provided different results in relation to caregiver trauma. While the ED-specific tool ensured precise assessment of ED-related knowledge, it limited the ability to explore caregivers' mental health literacy regarding PTSD, including beliefs, attitudes, and access to support. The findings would be able to provide evidence as to whether a higher MHL about PTSD would be related to the caregiver's trauma level.

### *MHL Domains and Demographics*

The meta-analysis excluded studies that examined associations between subsets of MHL and sociodemographic factors. On reflection, including these studies would have offered insights into which specific domains of MHL have stronger associations with different socio-demographics. For example, while education may be associated with knowledge, factors such as age and gender may be more related to help-seeking attitudes or stigma. Future research using meta-analytical approaches could consider exploring the demographic associations to the components of MHL.

### *Country-specific analysis*

One strength of the meta-analysis was that it included studies from multiple countries. However, the analysis did not include an examination of how MHL and its association with sociodemographic factors varies across the different socioeconomic contexts. Further analysis of these differences might reveal interesting factors that consider whether access to education and healthcare systems in different countries change the statistical significance of MHL and its demographic correlates. A deeper exploration of how different education systems impact MHL across countries could have provided more clarity on whether education is a universally significant or context-dependent demographic.



### *Controlling for Anxiety and Depression in Caregiver Trauma*

Previous research has shown that caregivers of individuals with EDs are at high risk for anxiety and depression (Anastasiadou et al., 2014). However, in the cross-sectional study, anxiety and depression were not directly measured or controlled for in relation to caregiver trauma. This presents a limitation because it is unclear whether caregivers' PTSD symptoms are a direct result of their caregiving experience or whether underlying anxiety and depression contribute to the severity of their trauma.

### *The Evolving Definition of Sociodemographic Factors*

Another important consideration is that traditional sociodemographic categories—such as gender—are changing. Many studies in the meta-analysis treated gender as a binary variable, which may not reflect the current understanding of gender diversity and its role in shaping mental health experiences. As definitions of sociodemographic variables evolve, research needs to move beyond conservative classifications and adopt more inclusive frameworks that capture the diversity of lived experiences. Future research should ensure that gender is examined in a way that reflects contemporary understanding rather than relying on outdated binary classifications.

## **Clinical and practice implications**

### *Improving caregiver support and interventions*

The findings from this thesis suggest that interventions for caregivers should extend beyond psychoeducation to include coping strategies that address their distress. This research confirms that caregivers of CYP with EDs frequently meet the diagnostic criteria for PTSD, highlighting the significant stress they experience. Mental health services should

acknowledge the impact of EDs not only on the person with the diagnosis but also on their caregivers.

In this study, caregivers who had substantial caring responsibility for their child's ED were recruited. Mental health services should consider collecting similar information to identify and reach out to caregivers who might need support. The high ED-MHL scores suggest that many participants in this study are likely to engage in help-seeking, but it's unclear whether this is for their child's ED or their own distress. Regardless, given the evidence that caregivers of this population are at high risk of PTSD, there is a need for dedicated caregiver support.

A systematic review by Hannah et al. (2021) found that interventions for caregivers had a positive impact on both caregiver and patient outcomes. Additionally, the NICE guidelines (2021) emphasize the importance of working with caregivers and assessing their needs.

The findings from the empirical study reinforce the necessity of integrating caregiver-specific support into ED services. Furthermore, given the high levels of trauma symptoms observed in this research, clinicians should consider providing trauma-informed care when needed, especially in general non-specialized hospitals providing care for CYP with ED. The NICE guidelines for eating disorders (2020) recommend family therapy as a key psychological treatment for CYP with EDs. This form of support can provide an environment where caregivers can increase their knowledge on EDs, address uncertainties about their child's ED and feel supported whilst caring for their child. This research highlights the importance of addressing caregiver trauma within family therapy sessions, ensuring that interventions offer targeted support.

Overall, clinicians should actively encourage caregivers to seek mental health support while caring for a child with an ED. Given the findings of this study, trauma-informed support may be particularly beneficial in addressing the unique psychological needs of caregivers in this population.

### **Overall conclusion**

In summary, both the meta-analysis and cross-sectional study have contributed to the field of MHL by reinforcing knowledge and identifying new research directions. The meta-analysis has confirmed previously studied associations between MHL and sociodemographic factors, in this case, age, gender and education. The meta-analysis has provided a statistical understanding of the relationships between these sociodemographic factors and MHL. The findings show that there is potential for further exploration of other sociodemographic factors' relationships with MHL. However, such progress also depends on the standardization of MHL tools across studies. In the same spirit, the cross-sectional study highlights the need for a validated and factor-analysed measure for ED-MHL. The lack of a well-studied psychometric tool limits the ability to draw consistent conclusions across studies. Additionally, a validated measure would ensure that all the key components of MHL are accurately assessed using the tool. The cross-sectional study contributes to the growing recognition that MHL research must move beyond a fragmented approach and toward a unified, psychometrically rigorous framework. There were also noted methodological limitations that meant it was hard to interpret what the level of MHL in this population meant. Nonetheless, this research has emphasized the global relevance of MHL, it has also provided insights into caregivers' experiences.

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## Appendices

### Appendix A: Author guidelines for the Journal of Mental Health (Systematic review)

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- Conflict of interest
- Acknowledgements
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research/study', 'performed research/study', 'contributed important reagents', 'collected data', 'analyzed data', 'wrote paper' etc. This information must be included in the submitted manuscript as a separate paragraph under the heading 'Authors' Contribution'. The corresponding author is responsible for obtaining permission from all co-authors for the submission of any version of the manuscript and making any changes in the authorship.

**IMPORTANT:** An Author Contribution/[CRediT \(Contributor Roles Taxonomy\)](#) statement is now a strict requirement for all submissions to "The Open Psychology Journal". This policy aims to address past inconsistencies in the provision of "Author Contribution" statements by authors. Authors are encouraged to clearly define and document their contributions to promote transparency and accountability in the research process.

## HUMAN AND ANIMAL RIGHTS

### Research Involving Humans

All clinical investigations should be conducted according to the [Declaration of Helsinki](#) principles. For all manuscripts reporting data from studies involving human participants, formal review and approval by an appropriate institutional review board or ethics committee are required.

### Patient Consent

Compliance with the guidelines of the International Committee of Medical Journal Editors <http://www.icmje.org/recommendations/browse/roles-and-responsibilities/protection-of-research-participants.html>) is recommended, in accordance with the patient's consent for research or participation in a study as per the applicable laws and regulations regarding the privacy and/or security of personal information, including, but not limited to, the Health Insurance Portability and Accountability Act of 1996 ("HIPAA") and other U.S. federal and state laws related to confidentiality and security of personally distinguishable evidence, the General Data Protection Regulation (GDPR) (EU) 2016/679, member state implementing legislation, the Personal Information Protection and Electronic Documents Act of Canada, and Information Technology Act of India and related Privacy Rules (along with "Data Protection and Privacy Laws").

Furthermore, it is the responsibility of the author to ensure that:

- Patients' names, initials, or hospital numbers are not mentioned anywhere in the manuscript (including figures).
- Authors are responsible for obtaining the consent-to-disclose forms for all recognizable patients in photographs, videos, or other information that may be published in the journal, in derivative works, or on the journal's website and for providing the manuscript to the recognizable patient for review before submission.
- The consent-to-disclose form should indicate specific use (publication in the medical literature in print and online, with the understanding that patients and the public will have access) of the patient's information and any images in figures or videos, and must contain the patient's signature or that of a legal guardian along with a statement that the patient or legal guardian has been offered the opportunity to review the identifying materials and the accompanying manuscript.
- If the manuscript has an individual's data, such as personal details, audio-video material, *etc.*, consent should be obtained from that individual. In the case of children, consent should be obtained from the parent or the legal guardian.

- A specific declaration of such approval and consent-to-disclose form must be made in the copyright letter and a stand-alone paragraph at the end of the article, especially in the case of human studies, where the inclusion of a statement regarding obtaining the written informed consent from each subject or subject's guardian is essential. The original form should be retained by the guarantor or corresponding author. On the other hand, editors may request to provide the original forms by fax or email.
- All such cases require obtaining proper consent prior to publishing. Please refer to COPE guidelines available at <https://publicationethics.org/resources/guidelines/journals%E2%80%9999-best-practices-ensuring-consent-publishing-medical-case-reports>

Editors may request that authors provide documentation of the formal review and recommendation from the institutional review board or ethics committee responsible for oversight of the study. Additionally, the editors reserve the right to reject manuscripts that do not comply with the above-mentioned requirements, and the authors will be held accountable for false statements or failure to fulfill the requirements mentioned above.

#### **Non-identifiable Images**

Anonymous images that do not identify the individual directly or indirectly, such as through any identifying marks or text, do not require formal consent, for example, X-rays, ultrasound images, pathology slides, or laparoscopic images.

In case consent is not obtained, concealing the identity through eye bars or blurring the face would not be acceptable.

#### **Research Involving Animals**

For research involving animals, the authors should indicate whether the procedures followed were in accordance with the standards set forth in the eighth edition of the “Guide for the Care and Use of Laboratory Animals” ( [https://grants.nih.gov/grants/olaw/guide-for-the-care-and-use-of-laboratory-animals\\_prepub.pdf](https://grants.nih.gov/grants/olaw/guide-for-the-care-and-use-of-laboratory-animals_prepub.pdf), published by the National Academy of Sciences, The National Academies Press, Washington, D.C.).

Research work on animals should be carried out in accordance with the NC3Rs ARRIVE Guidelines. For *in vivo* experiments, please visit <https://www.nc3rs.org.uk/arrive-guidelines>.

Authors should clearly state the name of the approval committee, highlighting that legal and ethical approvals were obtained prior to the initiation of the research work carried out on animals, and that the experiments were performed in accordance with the relevant guidelines and regulations stated below:

- US authors should cite compliance with the US National Research Council's " [Guide for the Care and Use of Laboratory Animals](#)".
- The US Public Health Service's " [Policy on Humane Care and Use of Laboratory Animals](#)" and " [Guide for the Care and Use of Laboratory Animals](#)".
- UK authors should conform to the UK legislation under [the Animals \(Scientific Procedures\) Act 1986 Amendment Regulations \(SI 2012/3039\)](#).
- European authors outside the UK should conform to [Directive 2010/63/EU](#).
- Research on animals must adhere to the ethical guidelines of the International Council for Laboratory Animal Science (ICLAS).
- The manuscript must clearly include a declaration of compliance with relevant guidelines (e.g., the revised Animals (Scientific Procedures) Act 1986 in the UK and

Directive 2010/63/EU in Europe) and/or relevant permissions or licenses obtained by the [IUCN Policy Statement on Research Involving Species at Risk of Extinction](#) and the [Convention on the Trade in Endangered Species of Wild Fauna and Flora](#).

#### **Animal Ethics Guidelines for Studies Involving Animal Subjects**

##### **Ethics Approval Exemption:**

If a study is exempted from ethics approval, authors must indicate the reasons for exemption in the ethical statement.

Following is an example of Ethical Statements:

"This study involving animal subjects is exempted from ethics approval for [specific reasons]. The exemption was evaluated and authorized by [Full name of ethics committee], ensuring adherence to ethical standards".

##### **Client-Owned Animals:**

Client-owned animals (non-commercially available animals such as pets or livestock) should be studied exercising best practices in veterinary care. Authors must confirm that the owner(s) (or their legal representatives) have provided written consent for this purpose.

Following is an example of Ethical Statements regarding client-owned animals:

"The animal study was evaluated and authorized by [Full name of the ethics committee]. The owners provided written informed consent for their animals' involvement in this study, ensuring ethical treatment and compliance with standards."

##### **International Standards and 3Rs Principle:**

Studies involving animals must comply with internationally accepted standards and adhere to the 3Rs principles (Replace, Reduce, Refine).

- **Replace:** Replacing animals with alternatives whenever possible.
- **Reduce:** Reducing the number of animals used and
- **Refine:** Refining experimental settings, which can reduce animal damage.

Authors are encouraged to follow the ARRIVE guidelines (Reporting in Vivo Experiments) for reporting experiments involving live animals.

An example of Ethical Statements concerning international standards and the 3Rs Principle is as follows:

"This study adheres to internationally accepted standards for animal research, following the 3Rs principle. The ARRIVE guidelines were employed for reporting experiments involving live animals, promoting ethical research practices."

##### **Euthanasia Protocols:**

Studies on euthanasia, including chloral hydrate, ether, and chloroform overdose, are severely discouraged. Authors should include an in-depth description of any anesthetic, surgical, or euthanasia procedures conducted throughout the study.

If the experimental details explained in the study violate the standard animal research procedure, editors may seek extra documentation, such as approval forms and relevant literature citations.

### **Research Involving Plants**

All experimental research on plants (either cultivated or wild), should comply with international guidelines. The manuscript should include a declaration of compliance of field studies with relevant guidelines and/or relevant permissions or licenses obtained by the [IUCN Policy Statement on Research Involving Species at Risk of Extinction](#) and the [Convention on the Trade in Endangered Species of Wild Fauna and Flora](#).

### **Hazard Study**

Any unusual risks associated with the use of any chemicals, procedures, or equipment used in the work must be explicitly stated by the author in the manuscript, preferably in both the materials and methods section and the declaration section. For more information, visit The World Medical Association ( <https://www.wma.net/what-we-do/public-health/chemicals> )

### **SEX AND GENDER EQUITY IN RESEARCH (SAGER) GUIDELINES**

We strive to promote gender and sex equity in research and adhere to the guidelines of Sex and Gender Equity in Research (SAGER) to ensure inclusivity and rigor of the work. All authors submitting research papers are required to follow the [Sex and Gender Equity in Research \(SAGER\) guidelines](#). These guidelines are intended to encourage the inclusion of sex and gender considerations in research in order to improve the accuracy and relevance of our publications.

Further, the SAGER guidelines for reporting sex and gender information in methodology or study design, data analysis, results, and interpretation of findings are strongly encouraged. Authors of review articles are advised to address the methods used for selecting, locating, extracting, and synthesizing data. Additionally, systematic reviews are also required to follow these guidelines.

### **RESEARCH CONDUCTED IN SPECIAL OR CRITICAL SITUATIONS**

[Bentham Open](#) expects all contributors to respect the values of justice, benevolence, and autonomy when conducting research. We understand that certain situations, such as medical emergencies or humanitarian crises, may differ from non-emergency scenarios. [Bentham Open](#) recommends that research efforts should not hurt human subjects/respondents or the researchers and should be conducted with sufficient scientific rigor as permissible in these situations. Care should be taken to address potential problems faced by persons who may be victims of disasters or involved in a medical emergency. These are vulnerable individuals and their privacy and dignity should be respected. Researchers should note and identify potential issues in their work that may arise because of such situations. Research conducted in emergency circumstances should be to the greatest advantage of survivors involved in the research and with the goal of minimizing any future casualties. For guidance, the essential requirements of research in emergency situations are the preservation of human life, well-being and security, along with the rights to protection, privacy, and confidentiality of subjects.

## UNETHICAL BEHAVIOR

Unethical behavior and misconduct may be pointed out by anyone to the editor and publisher with sufficient evidence. The editor, in consultation with the publisher, must initiate an investigation against any unethical misconduct, complete the procedure till an unbiased decision is reached, and maintain confidentiality throughout the process of the investigation. The author should be given the opportunity to reply to all minor or major accusations.

In case of serious breaches, the author may be informed, where appropriate, by the Editor/Publisher, after reviewing all available information and evidence or after seeking help from experts in that field.

### Conclusion

- Author(s) and reviewers must be informed in case of misinterpretation or mishandling of acceptable International Standards.
- A strict notice should be sent to the author and reviewer to avoid future unethical misconduct.
- An editorial on the reported misconduct should be published, or an official notice of unethical behavior should be posted on the website.
- Official letters about this misconduct should be issued to the heads of departments, funding agencies of the accused author, the reviewer, and the abstracting and Indexing Agencies.
- Where required, retraction and withdrawal of publication may be undertaken from the publisher's journal in discussion with the Head of the Department of the author or reviewer, and other higher authorities should be informed.
- The publisher may impose restrictions on future publications from the accused author in the journals for some period.

### Consent for Publication

If the manuscript has an individual's personal data, such as personal details, audio-video material etc., consent should be obtained from that individual. In the case of children, consent should be obtained from the parent or the legal guardian.

A specific declaration of such approval and consent-to-disclose form must be mentioned in the copyright letter and a stand-alone paragraph at the end of the article, especially in the case of human studies where the inclusion of a statement regarding obtaining the written informed consent from each subject or subject's guardian is a must. The original form should be retained by the guarantor or corresponding author. In addition, editors may request to provide the original forms by fax or email.

## POST-PUBLICATION DISCUSSIONS

**Post-publication discussions** are well-timed and engaging scientific remarks and justifications on research articles published in "**The Open Psychology Journal**". These remarks must be based on the information concurrent with the original study and not on the scientific advancements achieved subsequently.

### Manuscript Preparation, Submission, and Editorial Process:

- Post-publication discussion should commence with a short paragraph that outlines the summary of the article.
- Authors are advised to avoid using inciting tone in the comments and keep the message clear and concise.
- The main text should not exceed 1200 words with up to 15 references and may include one or two figures and/or tables.
- References should be submitted in the ACS or Vancouver style.
- The correspondents are recommended to contact the original authors first prior to submitting their comments to the journal, as this may resolve the issues that may arise due to some misunderstanding.
- The correspondence that has been done with the authors should also be submitted as an attachment with the manuscript.

Any queries therein should be addressed to [info@benthamopen.net](mailto:info@benthamopen.net).

## **RANDOMIZED DRUG CLINICAL TRIAL STUDIES**

Randomized drug clinical trial studies are biomedical or health-related interventional and/or observational research studies conducted in phases on human beings who are randomly allocated to receive or not receive a preventive, therapeutic, or diagnostic intervention that follows a pre-defined protocol. These studies are intended to determine the safety and efficacy of approaches to disease prevention, diagnosis, and treatment.

Authors of randomized controlled trials are encouraged to submit trial protocols along with their manuscripts. All clinical trials must be registered (before recruitment of the first participant) at an appropriate online public trial registry that must be independent of for-profit interest (e.g., [www.clinicaltrials.gov](http://www.clinicaltrials.gov)). If the editor(s) has to consider an unregistered trial, a brief explanation as to why the trial has not been registered is needed.

- All randomized clinical trials must include a flow diagram, and authors should provide a completed randomized trial checklist (see CONSORT Flow Diagram and Checklist at ([www.consort-statement.org](http://www.consort-statement.org))) and a trial protocol. For further details, please visit the complete guidelines at: <http://www.icmje.org/recommendations/browse/publishing-and-editorial-issues/clinical-trial-registration.html>.
- Studies of diagnostic accuracy must be reported according to STARD guidelines ( [www.stard-statement.org](http://www.stard-statement.org)).
- Observational studies (cohort, case-control, or cross-sectional designs) must be reported according to the STROBE statement and should be submitted with their protocols ( [www.strobe-statement.org](http://www.strobe-statement.org)).
- Genetic association studies must be reported according to STREGA guidelines ( [www.equator-network.org/reporting-guidelines/strobe-strega/](http://www.equator-network.org/reporting-guidelines/strobe-strega/)).
- Systematic reviews and meta-analyses must be reported according to PRISMA guidelines ( [www.prisma-statement.org](http://www.prisma-statement.org)).
- To find the reporting guidelines, kindly visit [www.equator-network.org](http://www.equator-network.org).

The following are the important points to remember while submitting clinical trials:

- Each manuscript should clearly state an objective or hypothesis, the design and methods (including the study setting and dates, patients or participants with inclusion and exclusion criteria, or data sources, and how these were selected for the study),



the essential features of any interventions, the main outcome measures, the main results of the study, a comment section placing the results in context with the published literature and addressing study limitations, and the conclusions. Data included in research reports must be original.

- The trial registry name, registration identification number, and URL for the registry should be included at the end of the abstract and also in the space provided on the online manuscript submission form. If the research article reports the results of a controlled health care intervention, the trial registry should be listed, along with the unique identifying number (Please note that there should be no space between the letters and numbers of your trial registration number). Studies designed for other purposes, such as to study pharmacokinetics or major toxicity (e.g., phase 1 trials), are exempted.
- All reports of randomized trials should include a section titled “Randomization and Masking”, within the methods section.
- The manuscript must include a statement identifying the institutional and/or licensing committee that has approved the experiments, including any relevant details.
- The SI system of units and the recommended international non-proprietary name (rINN) for drugs must be used. It is also essential to ensure that the dose, route, and frequency of administration of any drug mentioned are correct.
- It should be ensured that the clinical trials sponsored by pharmaceutical companies follow the guidelines on good publication practice: ( <https://www.ismpp.org/about-us>)

The editors reserve the right to reject manuscripts that do not comply with the above-mentioned requirements. Moreover, the author will be held responsible for false statements or failure to fulfill the above-mentioned requirements.

## REFERENCES

References should be submitted preferably in the ACS or Vancouver style. All references must be complete and accurate. The reference numbers must be finalized and the bibliography must be fully formatted before submission.

The references should be relevant to the study and should refer to the original research sources. Self-citation and self-interest should be avoided by the authors, editors and peer-reviewers.

A few examples of references listed in the ACS and Vancouver Style are as follows:

### ACS Style

In ACS style, all references should be numbered sequentially [in square brackets] in the text and listed in the same numerical order in the reference section. Superscript in the in-text citations and reference section should be avoided.

#### Reference Lists

Different reference formats have different rules for citation. Some common format examples are as follows:

#### Journal Article

The minimum required information for a journal article reference is author, abbreviated journal title, year, publication, volume number, and initial page of cited article, though



complete pagination is possible. Journal abbreviation and volume are *italicized*. Year of publication is **bold**. All authors must be cited and there should be no use of the phrase et al. Journal abbreviations should follow the Index Medicus/MEDLINE.

- [1] Bard, M.; Woods, R.A.; Bartón, D.H.; Corrie, J.E.; Widdowson, D.A. Sterol mutants of *Saccharomyces cerevisiae*: chromatographic analyses. *Lipids*, **1977**, 12(8), 645-654.
- [2] Zhang, W.; Brombosz, S.M.; Mendoza, J.L.; Moore, J.S. A high-yield, one-step synthesis of o-phenylene ethynylene cyclic trimer *via* precipitation-driven alkyne metathesis. *J. Org. Chem.*, **2005**, 70, 10198-10201.

#### Book Reference

- [3] Crabtree, R.H. *The Organometallic Chemistry of the Transition Metals*, 3<sup>rd</sup> ed.; Wiley & Sons: New York, **2001**.

#### Book Chapter Reference

- [4] Wheeler, D.M.S.; Wheeler, M.M. D. Stereoselective Syntheses of Doxorubicin and Related Compounds In: *Studies in Natural Products Chemistry*; Atta-ur-Rahman, Ed.; Elsevier Science B. V: Amsterdam, **1994**; Vol. 14, pp. 3-46.

#### Conference Proceedings

- [5] Jakeman, D.L.; Withers, S.G.E. In: *Carbohydrate Bioengineering: Interdisciplinary Approaches*, Proceedings of the 4<sup>th</sup> Carbohydrate Bioengineering Meeting, Stockholm, Sweden, June 10-13, 2001; Teeri, T.T.; Svensson, B.; Gilbert, H.J.; Feizi, T., Eds.; Royal Society of Chemistry: Cambridge, UK, **2002**; pp. 3-8.

#### URL(WebPage)

- [6] National Library of Medicine. Specialized Information Services: Toxicology and Environmental Health. (Accessed May 23, **2004**).

#### Patent

- [7] Hoch, J.A.; Huang, S. Screening methods for the identification of novel antibiotics. U.S. Patent 6,043,045, March 28, 2000.

#### Thesis

- [8] Mackel, H. *Capturing the Spectra of Silicon Solar Cells*. PhD Thesis, The Australian National University: Canberra, December **2004**.

#### E-citations

- [9] Citations for articles/material published exclusively online or in open access (free-to-view), must contain the accurate Web addresses (URLs) at the end of the reference(s), except those posted on an author's Web site (unless editorially essential), e.g. 'Reference: Available from: URL'.

#### Report presented by Authors

- [10] Smith, J.; Doe, J. *Annual Report on Chemical Research*; National Institute of Chemistry: Washington, DC, 2020; Report No. 12345.

**Guidelines for Citing Retracted References:**

Authors must ensure the accuracy and integrity of the references they cite, including verifying whether any article they intend to cite has been retracted. Citing retracted articles can compromise the credibility of a manuscript and should only be done when absolutely necessary for the context of the discussion.

Authors should consider the following points when citing retracted references:

- Authors must check the status of all cited works before submission. Retracted articles can often be identified in the Retraction Watch database. The version of the record should include a clear retraction notice.
- A disclosure is considered necessary to include in the manuscript if retracted articles are cited for a particular context and authors must explicitly indicate its retraction status in the reference list.
- If citing a retracted article is unavoidable when referencing a retracted article, authors should in that case provide a clear rationale within the manuscript, explaining its relevance and addressing the impact of its retracted status on the discussion
- Add a [Retracted] label before the reference in the bibliography.
- If using citation management software (e.g., EndNote, Zotero), manually update the citation to reflect its retracted status.

**Some important points to remember:**

- The use of non-academic, non-peer-reviewed sources, as well as anonymous or commercial websites, should be limited or avoided whenever possible.
- Authors should refrain from citing content that is not directly relevant to the article's scope or the journal's focus.
- Reference lists should accurately reflect the current state of knowledge in the field, maintain balance, and avoid excessive citations from the same authors, sources, or schools of thought.
- The length of the reference list should be appropriate for the article type, ensuring comprehensive coverage of relevant literature.
- All authors must be cited and there should be no use of the phrase *et al.*
- The date of access should be provided for online citations.
- Punctuation should be properly applied as mentioned in the examples given above.
- Abstracts, unpublished data and personal communications (which can only be included if prior permission has been obtained) should not be given in the references section. The details may however appear in the footnotes.
- The authors are encouraged to use a recent version of EndNote (version 5 and above) or Reference Manager (version 10) when formatting their reference list, as this allows references to be automatically extracted.

**Vancouver Style**

In Vancouver style, all references should be numbered sequentially [in square brackets] in the text and listed in the same numerical order in the reference section. Punctuation should be properly applied as mentioned in the examples given above.

## Reference Lists

Different reference formats have different rules for citation. Some common format examples are given below:

### Journal Article

The required information for a journal article is author, abbreviated journal title, year, publication, volume number, and initial page of cited article, though complete pagination is possible. It is necessary to list all authors if the total number of author is six or less and for more than six authors use three authors and then *et al* (the term "*et al.*" should be in italics). Journal abbreviations should follow the Index Medicus/MEDLINE. Capitalize the first letter of the first word in the title. The rest of the title is in lower-case, with the exception of proper names.

- [1] Al-Habian A, Harikumar PE, Stocker CJ, Langlands K, Selway JL. Histochemical and immunohistochemical evaluation of mouse skin histology: comparison of fixation with neutral buffered formalin and alcoholic formalin. *J Histotechnol*. 2014 Dec;37(4):115-24.
- [2] Guilbert TW, Morgan WJ, Zeiger RS, *et al*. Long-term inhaled corticosteroids in preschool children at high risk for asthma. *N Engl J Med*. 2006 May 11;354(19):1985-97.

### Edited Book

- [3] Blaxter PS, Farnsworth TP. Social health and class inequalities. In: Carter C, Peel JR, Eds. *Equalities and inequalities in health*. 2nd ed. London: Academic Press 1976; pp. 165-78.

### Chapter in a Book

- [4] Phillips SJ, Whisnant JP. Hypertension and stroke. In: Laragh JH, Brenner BM, Eds. *Hypertension: pathophysiology, diagnosis, and management*. 2nd ed. New York: Raven Press 1995; pp. 465-78.

### Patent

- [5] Larsen CE, Trip R, Johnson CR. Methods for procedures related to the electrophysiology of the heart. US Patent 5529067, 1995.

### Conference Proceedings

- [6] Kimura J, Shibasaki H, Eds. Recent advances in clinical neurophysiology. *Proceedings of the 10th International Congress of EMG and Clinical Neurophysiology*; 1995 Oct 15-19; Kyoto, Japan. Amsterdam: Elsevier 1996.

### Thesis and Dissertation

- [7] Borkowski MM. Infant sleep and feeding: a telephone survey of Hispanic Americans. PhD dissertation. Mount Pleasant (MI): Central Michigan [1] Bard, M.; Woods, R.A.; Bartón, D.H.; Corrie, J.E.; Widdowson, D.A. Sterol mutants of *Saccharomyces cerevisiae*: chromatographic analyses. *Lipids*, 1977, 12(8), 645-654.

University 2002.  
**URL(WebPage)**

- [8] Aylin P, Bottle A, Jarman B, Elliott, P. Paediatric cardiac surgical mortality in England after Bristol: descriptive analysis of hospital episode statistics 1991-2002. BMJ [serial on the Internet]. 2004 Oct 9; [cited: 15 October 2004]; 329: [about 10 screens].

#### **Electronic Material**

##### **Journal Article in Electronic Format**

- [9] Frangioni G, Bianchi S, Fuzzi G, Borgioli G. Dynamics of hepatic melanogenesis in newts in recovery phase from hypoxia. Open Zoo J 2009; 2: 1-7. Available from: [benthamopen.com/ABSTRACT/TOZJ-2-1](http://benthamopen.com/ABSTRACT/TOZJ-2-1) [cited: 26<sup>th</sup> Jan 2009]
- [10] Abood S. Quality improvement initiative in nursing homes: the ANA acts in an advisory role. Am J Nurs [serial on the Internet]. June 2002 [cited: 12<sup>th</sup> Aug 2002]; 102(6): [about 3 p.]. Available from: [www.nursingworld.org/ana/](http://www.nursingworld.org/ana/)

##### **Report presented by Authors**

- [11] Smith J, Doe J. Annual report on chemical research. Washington, DC: National Institute of Chemistry; 2020. Report No. 12345.

#### ***Guidelines for Citing Retracted References:***

Authors must ensure the accuracy and integrity of the references they cite, including verifying whether any article they intend to cite has been retracted. Citing retracted articles can compromise the credibility of a manuscript and should only be done when absolutely necessary for the context of the discussion.

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- A disclosure is considered necessary to include in the manuscript if retracted articles are cited for a particular context and authors must explicitly indicate its retraction status in the reference list.
- If citing a retracted article is unavoidable when referencing a retracted article, authors should in that case provide a clear rationale within the manuscript, explaining its relevance and addressing the impact of its retracted status on the discussion
- Add a [Retracted] label before the reference in the bibliography.
- If using citation management software (e.g., EndNote, Zotero), manually update the citation to reflect its retracted status.

#### **Some important points to remember:**

- The use of non-academic, non-peer-reviewed sources, as well as anonymous or commercial websites, should be limited or avoided whenever possible.
- Authors should refrain from citing content that is not directly relevant to the article's scope or the journal's focus.

- Reference lists should accurately reflect the current state of knowledge in the field, maintain balance, and avoid excessive citations from the same authors, sources, or schools of thought.
- The length of the reference list should be appropriate for the article type, ensuring comprehensive coverage of relevant literature.
- The date of access should be provided for online citations.
- Using superscripts should be avoided in the in-text citations and reference section.
- Abstracts, unpublished data and personal communications (which can only be included if prior permission has been obtained) should not be given in the references section. The details may however appear in the footnotes.
- The authors are encouraged to use a recent version of EndNote (version 5 and above) or Reference Manager (version 10) when formatting their reference list, as this allows references to be automatically extracted.

## AVAILABILITY OF DATA AND MATERIALS

The source of data and materials should be mentioned in the manuscript in support of the findings. Sharing research data is integral to its transparency and reproducibility. Data sharing involves the citation and availability of data that support the findings of the research.

[Bentham Open](#) encourages authors to share the source of data and materials in the manuscript, in support of the findings.

### Research Data Policy Types:

Four types of research data policies are mentioned below.

- **Case 1:** Data sharing and data citation
- **Case 2:** Data sharing and its evidence
- **Case 3:** Statement for Data sharing and data availability
- **Case 4:** Data sharing, evidence of data sharing and data for peer-review

### Case 1: Data Sharing and Data Citation

Wherever appropriate and possible, the journal encourages authors to publish data to support their research findings in a public repository. Any datasets mentioned in the article that are available in external repositories should be cited.

How to Cite the Data?

Whether the data was developed by the author(s) or researcher(s), all publicly available data referenced in the preparation of an article should be cited in the text and reference list. The references relating to the data availability should be presented in the following format:

Example: Name of author(s), the title of data set, data repository, document version (e.g., most recent updated version), Digital Object Identifier (DOI), and [Bentham Open](#) reference style should be included in data citations.

### Case 2: Data Sharing and its Evidence

When authors submit a paper to a journal, the authors agree that the data provided in the publication, including the relevant raw data, will be freely available to any researcher who wants to use these for non-commercial reasons without jeopardizing participant anonymity.

### Case 3: Statement for Data Sharing and Data Availability

Data availability declarations are required under [Bentham Open](#) research data policy types.

The statement relating to the data availability should be presented in the following format under a separate section for ‘Availability of Data and Materials’ in the manuscript:

1. *The authors confirm that the data supporting the findings of this study are available within the article and its supplementary materials.*
2. *The data that support the findings of this study are available from the corresponding author, [author initials], on special request.*
3. *The datasets generated or analysed during the current study are not publicly available due to [mention the reason(s)].*
4. *Authors who do not wish to share their data should clearly state that the data will not be shared, and thus mention as ‘Not applicable’.*
5. *The statement relating to the data should be presented in the following format:  
"The data supporting the findings of the article is available in the [repository name] at [URL], reference number [reference number]"*.

### Additional Data Availability Statements

Authors can add or change the statement(s) above to fit their work the best. Depending on the nature of the research, several assertions may need to be merged.

### Case 4: Data Sharing, Evidence of Data Sharing and Data for Peer-Review

All datasets on which the paper's conclusions are based must be made accessible to reviewers and readers, according to the journal's rules. Prior to peer review, authors must either deposit their datasets in publicly accessible repositories or provide them as supplementary materials with their submission. For further details, please visit the complete guidelines at: <http://www.icmje.org/recommendations/browse/publishing-and-editorial-issues/clinical-trial-registration.html>

### Archiving of Datasets

Authors may deposit their datasets openly to Zenodo Repository, in addition to their own or their institutional archives.

[Zenodo](#) is a repository, funded by the European Commission, CERN, and OpenAIRE, which features the Data for Policy community.

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Additionally, Zenodo can be used as a repository to host data and other materials that are referred to in the Data Availability Statement. These may include:

- datasets
- data management plans
- software documentation
- codes
- audio and video files

- proposals
- reports, and
- technical notes

Moreover, authors who wish to cite any relevant materials could use the unique Digital Object Identifier (DOI) that Zenodo assigns to the uploaded content.

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Authors may provide the raw data in connection with a paper for editorial review and should be prepared to provide public access to such data and retain it for a reasonable time after publication.

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The authors are encouraged to use industry-recognized reporting guidelines in their studies, if applicable, to explain that all requirements for reporting have been adopted. Please visit Equator ([www.equator-network.org](http://www.equator-network.org)) to find the most relevant reporting standards.

All authors must strictly follow the reporting guidelines below for preparing the study for publication.

- CONSORT: All randomized clinical trials must include a flow diagram and authors should provide a completed randomized trial checklist [see CONSORT Flow Diagram and Checklist ([www.consort-statement.org](http://www.consort-statement.org))] and a trial protocol. For further details, please visit the complete guidelines at <http://www.icmje.org/recommendations/browse/publishing-and-editorial-issues/clinical-trial-registration.html>
- STARD and TRIPOD: Studies of diagnostic accuracy must be reported according to STARD ( [www.stard-statement.org](http://www.stard-statement.org)) and TRIPOD guidelines ( [www.tripod-statement.org](http://www.tripod-statement.org)).
- STROBE: Observational studies (cohort, case-control, or cross-sectional designs) must be reported according to the STROBE statement, and should be submitted with their protocols ( [www.strobe-statement.org](http://www.strobe-statement.org)).
- CARE: Case reports must be reported according to CARE guidelines ( [www.care-statement.org](http://www.care-statement.org)).
- COREQ: Qualitative research must be reported according to COREQ guidelines ( [academic.oup.com/intqhc/article/19/6/349/1791966](http://academic.oup.com/intqhc/article/19/6/349/1791966)).
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- PRISMA: Systematic reviews and meta-analyses must be reported according to PRISMA guidelines ( [www.prisma-statement.org](http://www.prisma-statement.org)).
- MOOSE: Meta-analyses of observational studies in epidemiology must be reported according to MOOSE guidelines ( [http://www.ijo.in/documents/14MOOSE\\_SS.pdf](http://www.ijo.in/documents/14MOOSE_SS.pdf)).
- EQUATOR: To find the reporting guidelines, please visit ( [www.equator-network.org](http://www.equator-network.org) ).

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The authors are expected to submit good quality figure(s) in PDF, PPT, MS Word, TIFF, or JPEG versions, which, if required, should be improved by themselves or by professional graphic designers of their organization/country. The authors may even consider approaching our contracted service provider [Eureka Science](http://www.eureka-science.com) for graphics enhancement services.

The graphics designing team at Eureka Science can assist in improving the quality of the images at affordable rates. Eureka Science provides special rates of **US \$165** for the improvement of up to five figures, with any additional figures being charged at **US \$30** each.

The quality of graphic enhancement services offered by Eureka Science can be viewed at <http://www.eureka-science.com/images/Binder1.pdf>, along with valuable feedback on their services at <http://www.eureka-science.com/testimonials.php>. Eureka Science can also be contacted at [info@eurekascience.net](mailto:info@eurekascience.net).

**Note: Availing of graphics enhancement services does not guarantee acceptance of the manuscript for publication. The final acceptance/decision on the manuscript is taken by the EiC.**

#### **Guideline for Figures/Illustrations**

Illustrations must be provided according to the following guidelines:

- Illustrations should be embedded in the text file and must be numbered consecutively in the order of their appearance. Each figure should include only a single illustration, which should be cropped to minimize the amount of space occupied by the illustration.
- If a figure is in separate parts, all parts of the figure must be provided in a single composite illustration file.
- Photographs should be provided with a scale bar, if appropriate, as well as high-resolution component files.
- All the numbers, symbols, and letters in figures should be consistent and clear throughout and large enough to remain readable when the size is reduced for publication.
- Each figure must be cited in the text in sequence.

#### **Scaling/Resolution**

Line art image type is normally an image based on lines and text. It does not contain tonal or shaded areas. The preferred file format should be TIFF or EPS, with the color mode being monochrome 1-bit or RGB, in a resolution of 900-1200 dpi.

Halftone image type is a continuous tone photograph containing no text. It should have the preferred file format, TIFF, with color mode being RGB or grayscale, in a resolution of 300 dpi.

Combination image type is an image containing halftone, text, or line art elements. It should have the preferred file format TIFF, with color mode being RGB or grayscale, in a resolution of 500-900 dpi.



## Formats

Illustrations may be submitted in the following file formats:

- **Illustrator**
- **EPS** (preferred format for diagrams)
- **PDF** (also suitable for diagrams)
- **PNG** (preferred format for photos or images)
- **Microsoft Word** (version 5 and above; figures must be positioned on a single page)
- **PowerPoint** (figures must be positioned on a single page)
- **TIFF**
- **JPEG** (conversion should be done using the original file)
- **BMP**
- **CDX** (ChemDraw)
- **TGF** (ISISDraw)

[Bentham Open](#) does not process figures submitted in GIF format.

For TIFF or EPS figures with considerably large file sizes, restricting the file size in online submissions is advisable. Authors may, therefore, convert their files to the JPEG format before submission as this results in significantly reduced file size and uploading time while retaining the acceptable quality. JPEG is a lossy format. However, in order to maintain acceptable image quality, it is recommended that JPEG files be saved at high or maximum quality.

Zipit or Stuffit tools should not be used to compress files prior to submission as the resulting compression through these tools is always negligible.

The authors must refrain from supplying:

1. Graphics embedded in a Word processor document (spreadsheet, presentation).
2. Files optimized for screen use (like GIF, BMP, PICT, and WPG) because of the low resolution.
3. Files with too low resolution.
4. Graphics that are disproportionately large for the content.

### Technical requirements for graphics/figure submissions

The requirements for figures to be submitted are as follows:

Width = 8.5 inches (in-between the required size)

Height = 11 inches (in-between the required size)

Pixels/inches = 300 (minimum dpi)

All figures should be on vector scale (except for half tone and photograph).

### Image Conversion Tools

There are many software packages, most of them being either freeware or shareware, capable of converting to and from different graphics formats, including PNG.

General tools for image conversion include Graphic Converter on the Macintosh, Paint Shop Pro, for Windows, and ImageMagick, which are available on Macintosh, Windows and UNIX platforms.

Bitmap images (e.g. screenshots) should not be converted into EPS as they result in a much larger file size than the equivalent JPEG, TIFF, PNG, or BMP, and poor quality. EPS should only be used for images produced by vector-drawing applications, such as Adobe Illustrator or CorelDraw. Most vector-drawing applications can be saved in or exported in, EPS format. If the images have been originally prepared in an MS Office application, such as Word or PowerPoint, original files should be directly uploaded to the site, instead of being converted to JPEG or another low-quality format.

## Chemical Structures

Chemical structures must be prepared in ChemDraw/CDX and provided as separate files.

### Structure Drawing Preferences

The structure drawing preferences must be according to the ACS style sheet, as follows:

#### Drawing Settings

Chain angle	120°
Bond spacing	18% of the width
Fixed length	14.4 pt (0.500cm, 0.2in)
Bold width	2.0 pt (0.071cm, 0.0278in)
Line width	0.6 pt (0.021cm, 0.0084in)
Margin width	1.6 pt (0.096cm)
Hash spacing	2.5 pt (0.088cm, 0.0347in)

#### Text settings

Font	Times New Roman
Size	10 pt

#### Under the Preference

Units	points
Tolerances	3 pixels

#### Under Page Setup Use

Paper	US letter
Scale	100%

## Tables

- Data tables should be submitted in Microsoft Word table format.
- Each table should include a title/caption that is explanatory in itself with respect to the details discussed in the table. Detailed legends may then follow.
- Table number in bold font, *i.e.*, Table **1**, should follow a title. The title should be in small case with the first letter in caps. A full stop should be placed at the end of the title.
- Tables should be embedded in the text exactly according to their appropriate placement in the submitted manuscript.
- Columns and rows of data should be made visibly distinct by ensuring that the borders of each cell are displayed as black lines.
- Tables should be numbered in Arabic numerals sequentially in order of their citation in the body of the text.
- If a reference is cited in both the table and text, a lettered footnote should be inserted in the table to refer to the numbered reference in the text.
- Tabular data provided as additional files can be submitted as an Excel spreadsheet.

- It is adequate to present data in tables to avoid unnecessary repetition and reduce the length of the text.
- The citation of each table in the text must be ensured.
- Symbols and non-standard abbreviations should be explained at the end of the text.
- All references should be numbered sequentially (in square brackets) in the table and listed in the same numerical order in the reference section.

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Authors must provide a final list of authors at the time of submission, ensuring the correct sequence of authors' names, which will not be added, deleted, or rearranged after the final submission of the manuscript. An asterisk should be provided for the email address of the principal author. However, the complete address, business telephone number, fax number, and e-mail address of the corresponding author must be stated to for the correspondence and galley proofs. [Bentham Open](#) recommends that all contributors regularly update their profiles on SCOPUS/ORCID and other databases.

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Considering the above, we require that:

1. The authors should report any significant use of such tools in their works, such as instruments and software along with text-to-text generative AI consistent with subject standards for methodology.
2. All co-authors should sign a declaration that they take full responsibility for all of its contents, regardless of how the contents were generated. Inappropriate language, plagiarized and biased content, errors, mistakes, incorrect references, or misleading content generated by AI language tools and the relevant results reported in scientific works are a full and shared responsibility of all the authors, including co-authors.
3. AI language tools should not be listed as an author; instead, authors should follow clause (1) above.

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At the time of initial submission, the finalized list of authors in the correct sequence should be provided, which will not be changed once the publication process starts.

In exceptional cases, requests for the addition/deletion of an author may be considered by the publisher subject to a) written approval from all co-authors and b) a strong justification (which may or may not be accepted by the Publisher).

**Here is some advice from COPE on authorship issues. Bentham strives to follow these guidelines.**

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[Advice on how to spot authorship problems](#)

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- Requires major changes
- Rejected with no resubmission

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### **Sample Animated Abstract**

Antimicrobial resistance represents a significant challenge to future healthcare provision. An acronym ESKAPEE has been derived from the names of the organisms recognised as the major threats although there are a number of other organisms, notably *Neisseria gonorrhoeae*, that have become equally challenging to treat in the clinic. These pathogens are characterised by the ability to rapidly develop and/or acquire resistance mechanisms in response to exposure to different antimicrobial agents. A key part of the armoury of these pathogens is a series of efflux pumps, which effectively exclude or reduce the intracellular concentration of a large number of antibiotics, making the pathogens significantly more resistant. These efflux pumps are the topic of considerable interest, both from the perspective of a basic understanding of efflux pump function, and its role in drug resistance, as well as the target for the development of novel adjunct therapies. The necessity to overcome antimicrobial resistance has encouraged investigations into the characterisation of resistance-modifying efflux pump inhibitors to block the mechanisms of drug extrusion, thereby restoring antibacterial susceptibility and returning existing antibiotics to the clinic. A greater understanding of drug recognition and transport by multidrug efflux pumps is needed to develop clinically useful inhibitors, given the breadth of molecules that can be effluxed by these systems. This review discusses different bacterial EPIs originating from both natural sources and chemical synthesis, and examines the challenges in designing successful EPIs that can be useful against multidrug-resistant bacteria.



## Appendix C: Joanna Briggs Institute Critical Appraisal Checklist for analytical Cross-sectional studies (Systematic review)

### CHECKLIST FOR ANALYTICAL CROSS SECTIONAL STUDIES

#### **Critical Appraisal tools for use in JBI Systematic Reviews**

##### **Introduction**

JBIR is an international research organisation based in the Faculty of Health and Medical Sciences at the University of Adelaide, South Australia. JBIR develops and delivers unique evidence-based information, software, education and training designed to improve healthcare practice and health outcomes. With over 70 Collaborating Entities, servicing over 90 countries, JBIR is a recognised global leader in evidence-based healthcare.

##### **JBIR Systematic Reviews**

The core of evidence synthesis is the systematic review of literature of a particular intervention, condition or issue. The systematic review is essentially an analysis of the available literature (that is, evidence) and a judgment of the effectiveness or otherwise of a practice, involving a series of complex steps. JBIR takes a particular view on what counts as evidence and the methods utilised to synthesise those different types of evidence. In line with this broader view of evidence, JBIR has developed theories, methodologies and rigorous processes for the critical appraisal and synthesis of these diverse forms of evidence in order to aid in clinical decision-making in healthcare. There now exists JBIR guidance for conducting reviews of effectiveness research, qualitative research, prevalence/incidence, etiology/risk, economic evaluations, text/opinion, diagnostic test accuracy, mixed-methods, umbrella reviews and scoping reviews. Further information regarding JBIR systematic reviews can be found in the [JBIR Evidence Synthesis Manual](#).

##### **JBIR Critical Appraisal Tools**

All systematic reviews incorporate a process of critique or appraisal of the research evidence. The purpose of this appraisal is to assess the methodological quality of a study and to determine the extent to which a study has addressed the possibility of bias in its design, conduct and analysis. All papers selected for inclusion in the systematic review

(that is – those that meet the inclusion criteria described in the protocol) need to be subjected to rigorous appraisal by two critical appraisers. The results of this appraisal can then be used to inform synthesis and interpretation of the results of the study. JBI Critical appraisal tools have been developed by the JBI and collaborators and approved by the JBI Scientific Committee following extensive peer review. Although designed for use in systematic reviews, JBI critical appraisal tools can also be used when creating Critically Appraised Topics (CAT), in journal clubs and as an educational tool.

## **JBI Critical Appraisal Checklist for analytical cross sectional studies**

Reviewer\_\_\_\_\_

Date\_\_\_\_\_

Author\_\_\_\_\_Year\_\_\_\_\_

Number\_\_\_\_\_

Record

	Yes	No	Unclear	Not applicable
1. Were the criteria for inclusion in the sample clearly defined?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were the study subjects and the setting described in detail?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was the exposure measured in a valid and reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were objective, standard criteria used for measurement of the condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were confounding factors identified?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were strategies to deal with confounding factors stated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were the outcomes measured in a valid and reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal:    Include ☐    Exclude ☐    Seek further info ☐

Comments (Including reason for exclusion)

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### **Explanation of analytical cross-sectional studies critical appraisal**

*How to cite:* Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K, Mu P-F. Chapter 7: Systematic reviews of etiology and risk . In: Aromataris E, Munn Z (Editors). *JBI Manual for Evidence Synthesis*. JBI, 2020. Available from <https://synthesismanual.jbi.global>

## Analytical cross sectional studies Critical Appraisal Tool

Answers: Yes, No, Unclear or Not/Applicable

### 1. Were the criteria for inclusion in the sample clearly defined?

The authors should provide clear inclusion and exclusion criteria that they developed prior to recruitment of the study participants. The inclusion/exclusion criteria should be specified (e.g., risk, stage of disease progression) with sufficient detail and all the necessary information critical to the study.

### 2. Were the study subjects and the setting described in detail?

The study sample should be described in sufficient detail so that other researchers can determine if it is comparable to the population of interest to them. The authors should provide a clear description of the population from which the study participants were selected or recruited, including demographics, location, and time period.

### 3. Was the exposure measured in a valid and reliable way?

The study should clearly describe the method of measurement of exposure. Assessing validity requires that a 'gold standard' is available to which the measure can be compared. The validity of exposure measurement usually relates to whether a current measure is appropriate or whether a measure of past exposure is needed.

Reliability refers to the processes included in an epidemiological study to check repeatability of measurements of the exposures. These usually include intra-observer reliability and inter-observer reliability.

### 4. Were objective, standard criteria used for measurement of the condition?

It is useful to determine if patients were included in the study based on either a specified diagnosis or definition. This is more likely to decrease the risk of bias. Characteristics are another useful approach to matching groups, and studies that did not use specified diagnostic methods or definitions should provide evidence on matching by key characteristics

### 5. Were confounding factors identified?

Confounding has occurred where the estimated intervention exposure effect is biased by the presence of some difference between the comparison groups (apart from the exposure investigated/of interest). Typical confounders include baseline characteristics, prognostic factors, or concomitant exposures (e.g. smoking). A confounder is a difference between the comparison groups and it influences the direction of the study results. A high quality study at the level of cohort design will identify the potential confounders and measure them (where possible). This is difficult for studies where behavioral, attitudinal or lifestyle factors may impact on the results.

### 6. Were strategies to deal with confounding factors stated?

Strategies to deal with effects of confounding factors may be dealt within the study design or in data analysis. By matching or stratifying sampling of participants, effects of confounding factors can be adjusted for. When dealing with adjustment in data analysis, assess the statistics used in the study. Most will be some form of multivariate regression analysis to account for the confounding factors measured.

## **7. Were the outcomes measured in a valid and reliable way?**

Read the methods section of the paper. If for e.g. lung cancer is assessed based on existing definitions or diagnostic criteria, then the answer to this question is likely to be yes. If lung cancer is assessed using observer reported, or self-reported scales, the risk of over- or under-reporting is increased, and objectivity is compromised. Importantly, determine if the measurement tools used were validated instruments as this has a significant impact on outcome assessment validity.

Having established the objectivity of the outcome measurement (e.g. lung cancer) instrument, it's important to establish how the measurement was conducted. Were those involved in collecting data trained or educated in the use of the instrument/s? (e.g. radiographers). If there was more than one data collector, were they similar in terms of level of education, clinical or research experience, or level of responsibility in the piece of research being appraised?

## **8. Was appropriate statistical analysis used?**

As with any consideration of statistical analysis, consideration should be given to whether there was a more appropriate alternate statistical method that could have been used. The methods section should be detailed enough for reviewers to identify which analytical techniques were used (in particular, regression or stratification) and how specific confounders were measured.

For studies utilizing regression analysis, it is useful to identify if the study identified which variables were included and how they related to the outcome. If stratification was the analytical approach used, were the strata of analysis defined by the specified variables? Additionally, it is also important to assess the appropriateness of the analytical strategy in terms of the assumptions associated with the approach as differing methods of analysis are based on differing assumptions about the data and how it will respond.

## Appendix D: Research Advert



### Are you a caregiver to a child/young person with eating-related difficulties?



University of East Anglia

Supporting a child/young person with an eating disorder can be traumatic. Research is essential in understanding how best caregivers can be supported. Researchers at the University of East Anglia are investigating how caring for a child/young person with eating disorders affects caregivers and what influences this.

If you are a caregiver over the age of 18 with a child/young person between the ages of 5 and 25 you may be eligible to take part in our online survey.

To take part, follow the link or scan the QR code



<https://app.onlinesurvey.s.jisc.ac.uk/s/uea/caregiver-eating-disorders-research>



For each participant in our study a £2 donation will be made to an eating disorder charity.

*Do not let your voice go unheard! Fathers, ethnic minorities and those caring for a child or young person experiencing bulimia, binge-eating and OSFED, your participation is valued.*



## Appendix E: Ethics approval (Empirical study)



University of East Anglia  
Norwich Research Park  
Norwich, NR4 7TJ  
Email: [ethicsmonitor@uea.ac.uk](mailto:ethicsmonitor@uea.ac.uk)  
Web: [www.uea.ac.uk](http://www.uea.ac.uk)

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

**Application ID:** ETH2324-1470 (significant amendments)

Dear Rachel,

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

The decision is: **approved**.

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

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

This approval will expire on 1st October 2024.

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

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

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

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

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

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

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

Yours sincerely,

Dr Paul Linsley

**Participant information sheet**

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

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

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

**What is the purpose of the research?**

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

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

**Who is being invited to take part?**

We are interested in recruiting individuals who satisfy all of the criteria below:

You are a parent or guardian caregiver to a child/young person who is currently experiencing eating-related difficulties or has a diagnosed eating disorder

Your child is 5-25yrs

You are 18 or over



You have a substantial caring responsibility for your child (Substantial care = you consider yourself someone who offers practical and/or emotional support in relation to their eating disorder)

You live in the United Kingdom

You have the ability to comfortably read, comprehend and respond to written information presented in English

### **What would taking part involve?**

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

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

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

### **Do I have to take part?**

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

### **Can I stop taking part if I change my mind?**

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

### **What are the possible disadvantages or risks of taking part?**

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

1. *BEAT Eating Disorders*

- Helpline (open 365 days a year from 12pm-12am during weekdays, and 4pm-12am on weekends and bank holidays):
  - 0808 801 0677 (England), 0808 801 0432 (Scotland), - 0808 801 0433 (Wales), 0808 801 0434 (Northern Ireland).
  - <https://www.beateatingdisorders.org.uk> – for resources, and support chat rooms
2. Samaritans are available 24 hours a day to give support to anyone who is struggling on 116 123 or via email [jo@samaritans.org](mailto:jo@samaritans.org). More information is also available on their website <https://www.samaritans.org/>
3. FEAST - A global support and education community for families affected by eating disorders. <https://www.feast-ed.org/>
4. NHS - 111
5. Speak to your GP about accessing support for your own wellbeing
6. If your child has not yet been seen by their GP or local eating disorder service, it is important to contact them to discuss getting support. If they are accessing support and you have concerns, please contact their care providers directly.

**What are the possible benefits of taking part?**

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

**Will this impact my child's care?**

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

**What will happen to the information I provide?**

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

**What will happen to the results?**

The information collected from this survey will be analysed and findings will be written up and submitted as part of two Doctoral theses in Clinical Psychology (UEA). The results of

this study may also be shared with other researchers, published in academic/research journals and/or presented at conferences. All information is collected anonymously and as a result, anything reported will not allow for personal identification of those involved in the research. Results will also be shared via our social media: XXX

### **Who is organizing, funding, and reviewing this study?**

This study is organized and funded by the Doctoral Programme in Clinical Psychology at the UEA. The UEA Faculty of Medicine and Health Sciences Research Ethics Committee has reviewed and approved this study (xxxxxxxxxxxxxxxxxxxxxx).

### **What if I want to get in touch?**

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

#### *Primary researchers:*

Rachel Nabirinde (Trainee Clinical Psychologist)

Email: [r.nabirinde@uea.ac.uk](mailto:r.nabirinde@uea.ac.uk)

Natasha Heal-Cohen (Trainee Clinical Psychologist)

Email: [n.heal-cohen@uea.ac.uk](mailto:n.heal-cohen@uea.ac.uk)

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

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

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

Email: [Aaron.Burgess@uea.ac.uk](mailto:Aaron.Burgess@uea.ac.uk)

Or a member of course staff independent to the study:

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

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

## Appendix G: Consent form (Empirical study)



**Version 2: October 2023**

**Consent form**

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

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

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

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

If you do not agree with any of the above items, then please exit the survey now. You may return at a later date should you wish. If you have any outstanding questions that you would like answered or wish to discuss any element of the study with the researcher,

before participating, then please feel free to contact us by emailing: [n.heal-cohen@uea.ac.uk](mailto:n.heal-cohen@uea.ac.uk), [r.nabirinde@uea.ac.uk](mailto:r.nabirinde@uea.ac.uk)

**Date:**

**Signature:**

## Appendix H: Screening questions and Demographics form (Empirical study)

### **Screening and Demographic and Tool**

**Version 2 - November 2023**

#### **Participant Screening**

Are you a parent or guardian caregiver to a child/young person with eating-related difficulties? Yes/No

Are you over the age of 18? Yes/No

Do you provide substantial care to a child/young person with eating-related difficulties?

(Substantial care = you consider yourself someone who offers practical and/or emotional support in relation to their eating disorder)

Yes/No

#### **Child Screening**

Is the child/young person with eating-related difficulties between the ages of 5 and 25?

Yes/No

Do you suspect, or know that your child has an eating disorder? Yes/No

#### **Participant demographics**

Please tell us a little bit about yourself

Age (drop down)

18,19,20,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35,36,37,38,39,40,41,42,43,44,45,46,47,48,49,50,51,52,53,54,55,56,57,58,59,60,61,62,63,64,65,66,67,68,69,70,71,72,73,74,75,76,77,78,79,80,81,82,83,84,85,86,87,88,89,90,91,92,93,94,95,96,97,98,99, 100, 101, 102, 103,104, 105, 106, 107, 108, 109, 110, 111, 112,113,114,115,116,117,118,119,120

Gender (checklist)

Male

Female

Transgender

Gender neutral

Non-binary

Agender

Pangender

Genderqueer

Two-spirit

Third gender

None of the above

Other

## Ethnicity (checklist)

### **White**

1. Welsh/English/Scottish/Northern Irish/British
2. Irish
3. Gypsy or Irish Traveller
4. Any other White background

### **Mixed/Multiple ethnic groups**

5. White and Black Caribbean
6. White and Black African
7. White and Asian
8. Any other Mixed/Multiple ethnic background

### **Asian/Asian British**

9. Indian
10. Pakistani
11. Bangladeshi
12. Chinese
13. Any other Asian background

### **Black/African/Caribbean/Black British**

14. African
15. Caribbean
16. Any other Black/African/Caribbean background

### **Other ethnic group**

17. Arab
18. Any other ethnic group

## Level of education

Highschool, Diploma, Bachelors, Masters, PhD, other

Your relationship with the child with an eating disorder (mother, father, stepmother, stepfather, grandmother, grandfather, guardian, other)

How often does your child live at home with you? All of the time, Most of the time (e.g. 5 days a week), Some of the time (e.g. holidays, weekends), None of the time

Have you ever experienced an eating disorder yourself? Yes/No

Have you received any support in relation to your child's eating disorder?

Individual therapy

Family-based therapy

Support group

Support from helplines

Self-help resources (books)

Support from friends and/or family

Other (please state)  
No support/None of the above

### **Child demographics**

Age

Gender (checklist)

Duration of eating disorder/behaviors

Does the child/young person have a diagnosis of an eating disorder? Yes/No

If your child has a diagnosis, please select which of the following:

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

If your child does not have a diagnosis or you are not sure, please select which most applies

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

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

Severely underweight  
Restricting food intake  
Excessive exercising  
Vomiting after meals  
Using laxatives or medicines to control their weight  
Missing menstrual periods for three months or more  
Eating large amounts of food in one sitting (Bingeing)  
Eating in secret  
Stealing food/money in order to binge  
Severely overweight  
No behaviors apply/unsure

Which best describes your child's current eating difficulties

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

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

Have not yet approached support, awaiting treatment, treatment ongoing, support has ended, other

Has your child experienced the following medical treatment (please tick all that apply)



Hospitalized in a mental health/eating disorder unit, hospitalized in a general hospital, a feeding tube, none of the above

(if either hospitalized responses are checked) Is your child currently in hospital?

## Appendix I: PTSD Checklist for DSM-5 (PCL-5) (Empirical paper)



**Version date:** 11 April 2018

**Reference:** Weathers, F. W., Litz, B. T., Keane, T. M., Palmieri, P. A., Marx, B. P., & Schnurr, P. P. (2013). *The PTSD Checklist for DSM-5 (PCL-5) – Standard* [Measurement instrument]. Available from <https://www.ptsd.va.gov/>

**URL:** <https://www.ptsd.va.gov/professional/assessment/adult-sr/ptsd-checklist.asp>

**Note:** This is a fillable form. You may complete it electronically.

### PCL-5

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

<b>In the past month, how much were you bothered by:</b>	<b>Not at all</b>	<b>A little bit</b>	<b>Moderately</b>	<b>Quite a bit</b>	<b>Extremely</b>
1. Repeated, disturbing, and unwanted memories of the stressful experience?	0	1	2	3	4
2. Repeated, disturbing dreams of the stressful experience?	0	1	2	3	4
3. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?	0	1	2	3	4
4. Feeling very upset when something reminded you of the stressful experience?	0	1	2	3	4
5. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?	0	1	2	3	4
6. Avoiding memories, thoughts, or feelings related to the stressful experience?	0	1	2	3	4
7. Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)?	0	1	2	3	4
8. Trouble remembering important parts of the stressful experience?	0	1	2	3	4
9. Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?	0	1	2	3	4
10. Blaming yourself or someone else for the stressful experience or what happened after it?	0	1	2	3	4
11. Having strong negative feelings such as fear, horror, anger, guilt, or shame?	0	1	2	3	4
12. Loss of interest in activities that you used to enjoy?	0	1	2	3	4
13. Feeling distant or cut off from other people?	0	1	2	3	4
14. Trouble experiencing positive feelings (for example, being unable to feel	0	1	2	3	4

happiness or have loving feelings for people close to you)?					
15. Irritable behavior, angry outbursts, or acting aggressively?	0	1	2	3	4
16. Taking too many risks or doing things that could cause you harm?	0	1	2	3	4
17. Being “superalert” or watchful or on guard?	0	1	2	3	4
18. Feeling jumpy or easily startled?	0	1	2	3	4
19. Having difficulty concentrating?	0	1	2	3	4
20. Trouble falling or staying asleep?	0	1	2	3	4

PCL-5 (11 April 2018)

National Center for PTSD

Page 1 of 1

## Appendix J: Eating Disorder Mental Health Literacy (Empirical paper)

Please respond to each of the following statements about eating disorders. Try to answer all questions to the best of your knowledge. If you don't know the correct answer please mark "Don't know".

	True 1	False 2	Don't know 3
1. Eating disorders only affect adolescent girls and young adult women. <small>social</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Eating disorders have the highest mortality rate among all mental illnesses. <small>biological</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. If people seek help for an eating disorder early they will recover faster. <small>social</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Rapid weight loss in a short period of time can be a symptom of anorexia nervosa. <small>biological</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. People have to vomit to have bulimia nervosa. <small>biological</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. People with bulimia nervosa can be slightly underweight, normal weight, or overweight. <small>biological</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. A person with an eating disorder might find it difficult to ask for help from family and friends. <small>Social</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. It is common for a person with an eating disorder to also experience another mental illness, such as depression. <small>psychological</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Rapid weight loss or being very underweight can affect your ability to think <small>psychological</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Once someone has an eating disorder, recovery is very unlikely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Not everyone with an eating disorder needs to seek help.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Males can develop anorexia nervosa, but not bulimia nervosa. <small>social</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. People who have had an eating disorder will always worry about their weight, even if they have fully recovered. <small>psychological</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Most people have experienced binge eating at some point in their life. <small>Social</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Eating disorders are simply caused by western cultural values of thinness. <small>social</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Genes do not play a role in the development of eating disorders. <small>biological</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. People with eating disorders can stop their behaviour if they want to. <small>psychological</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Effective treatment for eating disorders is available.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix K: List of measures used by studies included in Meta-Analysis

Measures included in the meta-analysis:

MHLS: Mental health literacy scale (O'Connor, M. & Casey, L. 2015);

MHLA-c: Mental Health Literacy Assessment for College Students (Rabin et al. 2021);

Adapted version of the Epps et al. scale (2010);

Adaptation of 14 items from two subscales of the MHLS;

Vignette identification and character adjustment;

MHKQ: Mental Health Knowledge Questionnaire (Wang et al., 2013);

MAKS: Mental Health Knowledge Schedule (Evans-Lacko et al., 2010);

MHLS-C: Chinese version of the Mental Health Literacy Scale (Wang et al. 2022);

comprehensive 'Questionnaire of Mental Health Work' developed by the Chinese Ministry of Health;

AMHLAQ: Adolescent Mental health literacy Assessment Questionnaire (Zare et al. 2022)

## Appendix L: Additional results

Supplementary results (with focus on PTSS severity)

### *Bivariate correlations between caregiver stressors, ED-MHL, and PTSS Severity*

Due to violations of the assumption of normality in ED-MHL scores and duration of CYP ED, Spearman's rho ( $r_s$ ) was used to examine the associations between PTSS severity, ED-MHL, and the duration of the child's eating-related difficulties. For binary variables (e.g., caregiver ED history, experience with type of hospitalisation, and use of a feeding tube, support received), point-biserial correlations ( $r_{pb}$ ) were calculated. Table presents the full correlation matrix, including both types of correlation coefficients.

A statistically significant positive correlation was observed between ED-MHL scores and support received ( $r_s=0.34$ ,  $p<0.01$ ), suggesting that caregivers who accessed any form of support had higher levels of ED-MHL than those who did not. ED-MHL was also positively

associated with experience of hospitalisation in a mental health or ED unit ( $r_{pb}=0.28$ ,  $p<0.01$ ), general hospital admission ( $r_{pb} = 0.19$ ,  $p<0.05$ ), and feeding tube use ( $r_{pb}=0.33$ ,  $p<0.01$ ). PTSS severity was not significantly correlated with ED-MHL, duration of the eating disorder, support received, or any of the medical treatment options.

Collectively, these findings suggest that greater ED-MHL among caregivers is associated with receiving support and experience with medical treatments. However, ED-MHL does not appear to be directly associated with PTSS severity in this sample.

### **Table**

*Spearman's rho and Point-Biserial Correlations Between Study Variables (N = 123)*

<b>Variable</b>	<b>1</b>	<b>2 (<math>r_s</math>)</b>	<b>3 (<math>r_s</math>)</b>	<b>4 (<math>r_{pb}</math>)</b>	<b>5 (<math>r_{pb}</math>)</b>	<b>6 (<math>r_{pb}</math>)</b>	<b>7 (<math>r_{pb}</math>)</b>	<b>8</b>
1.PTSD severity	-							
2.ED-MHL	-0.16	-						
3.ED duration	0.06	-0.02	-					
4.Caregiver history of ED <sup>a</sup>	-0.01	0.02	0.07	-				
5.Support received	0.04	0.34**	-0.12	-0.08	-			
6.Medical treatment – Mental health hospital or ED unit <sup>a</sup>	0.02	0.28**	0.09	0.01	0.21*	-		
7.Medical treatment – General Hospital	0.13	0.19*	0.03	-0.21*	0.14	0.43**	-	
8.Medical treatment – Feeding tube <sup>a</sup>	-0.08	0.33**	0.04	-0.12	0.17	0.58**	0.47**	-

Note.

Spearman's rho ( $r_s$ ) is reported for associations between continuous variables.

Point-biserial correlations ( $r_{pb}$ ) are reported for relationships involving one dichotomous and one continuous variable.

<sup>a</sup>Binary variables coded as 0 = No, 1 = Yes.

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

### *Regression models*

Prior to conducting the regression analysis, assumptions of linearity, independence of errors, homoscedasticity, residual distribution, and multicollinearity were assessed.

Scatterplots indicated linear relationships between predictors and the outcome variable.

The Durbin-Watson statistic was 2.21, indicating that the assumption of independent errors was met. Visual inspection of the plot of standardised residuals showed that the assumption of homoscedasticity was met. Residuals were approximately normally distributed, as confirmed by visual inspection of the P-P plot. VIF values were all below 2.0, indicating that multicollinearity was not a concern.

### *Multiple and Hierarchical linear regression*

A multiple linear regression was conducted to examine whether a range of caregiver stressors and ED-MHL significantly predicted PTSS severity. In the initial model (Model 1), seven predictors were entered: ED-MHL, ED duration, caregivers' history of ED, support received, and three different types of medical treatment. This model was not statistically significant,  $F(7, 115)=1.38$ ,  $p=.22$ . It only accounted for a small portion of the variance in PTSS severity ( $R^2=0.08$ , *Adjusted*  $R^2=0.02$ ). Among the predictors, only hospitalisation in a

general hospital ( $\beta=.22(t=2.1)$ ,  $p<0.05$ ) significantly predicted PTSS severity (See Model 1, Table 7).

A hierarchical regression using a backward elimination approach was conducted to identify which predictors from the multiple linear regression meaningfully contribute to PTSS severity. The initial model included all seven predictors, then at each step, predictors that did not significantly contribute to the model were removed. Table 2 (Model 2) shows the final model (Step 6) retained only ED-MHL and hospitalisation in a general hospital, explaining 5% of the variance in PTSS severity,  $R^2=0.05$ , *Adjusted R*<sup>2</sup>=0.03,  $F(2, 120)=3.17$ ,  $p=.18$ . ED-MHL was statistically significant in the final model, indicating that when certain caregiver stressors are accounted for, ED-MHL significantly predicts PTSS severity. It is important to note that while ED-MHL and hospitalisation were statistically significant predictors within the final model (Model 2), the overall model was not statistically significant ( $p = .18$ ) and only accounted for 5% of the total variance in PTSS severity. This indicates that the measured demographic and MHL factors account for a relatively small proportion of the variance in caregiver trauma response. The significant individual predictors are interpreted cautiously, suggesting that these factors may still hold clinical significance in a complex, multi-factorial outcome.

**Table 2**

*Hierarchical linear regression using a backwards elimination approach for predictors of PTSS severity*

Predictor	Model 1	Model 2 (Step 6)
	95%CI for B	95%CI for B



	B	LL	UL	$\beta$	B	LL	UL	$\beta$
ED-MHL	-1.36	-2.78	0.06	-.19	-1.29	-2.56	-0.03	-.18*
ED duration	0.21	-0.64	1.06	.05				
Caregiver history of ED	1.25	-7.68	10.18	.03				
Support received	6.44	-5.72	18.61	.10				
Medical treatment – Mental health hospital or ED unit	1.69	-6.01	9.39	.05				
Medical treatment – General Hospital	7.22	0.40	14.04	.22*	5.59	-0.24	11.43	.17
Medical treatment – Feeding tube	-6.10	-14.63	2.42	-.17				
<b>R<sup>2</sup></b>				.08				.05
<b>Adjusted R<sup>2</sup></b>				.02				.03
<b>F</b>				1.38				3.17
<b>p</b>				.22				.04*

Note.

\* p < .05.