Psychological outcomes in parents of children with type 1 diabetes and children admitted to a paediatric intensive care unit (PICU)

Hayley Ryan (Trainee Clinical Psychologist)

Primary Supervisor: Prof. Richard Meiser-Stedman

Secondary Supervisor: Dr Aaron Burgess

Thesis submitted in partial fulfilment of the degree of Doctorate in Clinical Psychology

University of East Anglia

Faculty of Medicine and Health Sciences

Date of Submission: 2nd March 2023

Thesis portfolio word count: 20,901

Candidate Registration Number: 100338036

Contents page

List of tables

List of figures

Thesis portfolio abstract

Aims: The aim of this thesis portfolio was to examine the psychological impact of parenting a child who is chronically and/or severely unwell. Factors that contribute to psychological distress were also explored.

Design: This portfolio contains two main papers and supporting chapters. The first paper, a meta-analysis, reviewed the prevalence of depression in parents of children with Type 1 Diabetes. The second paper, an empirical study, examined the psychological impact of having a child admitted to a paediatric intensive care unit (PICU). In this second paper, factors contributing to psychological distress were explored. The additional chapters include further information to support the two main papers, with an overall discussion and critical review to conclude the portfolio.

Results: The meta-analysis revealed that a significant proportion of parents with a child diagnosed with Type 1 Diabetes met the diagnostic threshold for depression. The empirical paper indicated a high prevalence of parents who met the threshold for anxiety, depression, and low quality of life, following their child's admission to a PICU. Furthermore, maladaptive appraisals and overprotectiveness, but not illness severity, were significantly associated with increased psychological distress in these parents.

Conclusions: Parents of children with a chronic illness and/or are severely unwell are vulnerable to developing anxiety, depression, and experience low quality of life. It is important for clinicians to screen for distress in these parents and offer appropriate psychological interventions. Early identification could enable the reduction of long-term distress, reducing the impact on the child, and thus improving the management of their condition.

Acknowledgements

Firstly, I would like to thank my primary supervisor, Professor Richard Meiser-Stedman. Richard was so incredibly generous with his time, and so responsive to emails, for which I am extremely grateful. He also brought humour to our supervision, which made the experience enjoyable. Richard's knowledge in this field is an inspiration.

I would also like to thank all the families that have taken part in this research project, during such a difficult time in their lives. I hope that this work will improve the experience and outcomes of families with children admitted to a paediatric intensive care unit.

The support from my friends and family has been extraordinary. Thank you in particular to Charlotte and Chris, for their enduring support and friendship throughout this process. I am so grateful to have had you on this journey with me. Thank you also to my wonderful family, in particular my Mum, Dad and Brother, Greg, for always encouraging me and always believing in my capabilities. I am forever grateful.

CHAPTER ONE

Introduction to thesis portfolio

The number of admissions to pediatric intensive care units (PICU) has increased exponentially over the past 20 years (Davis et al., 2018). Recent advances in medical knowledge and technology have led to an increased number of children living with chronic conditions (Kish et al., 2018). The aims of this thesis portfolio are to examine psychological responses in parents of children who are chronically and/or severely unwell. It also explores the factors that contribute to psychological distress in these parents, for example illness severity, and the parents' appraisals and behaviour.

It is widely accepted that parenting has been shown to be both complex and stressful (Crnic & Low, 2002; Deater-Deckard, 2008). Parenting involves coping with everyday stressors, for example, chores, homework, and extracurricular activities, and acute stressors, such as a child choking or an adolescent running away (Mikolajczak et al., 2022). However, having a child with a chronic illness is considered a chronic stressor, due to the additional care, attention and patience that is required (Blanchard, 2006), all of which are time-consuming and expensive (Dodgson et al., 2000). Furthermore, caring for a chronically ill child is associated with worsened parental mental health, in particular anxiety and depression (Cohn et al., 2020). Poor parental mental health has been associated with a number of negative outcomes in children, including lower cognitive and academic performance, withdrawn behaviours and insecure attachment style (Gladstone et al., 2015). In children with chronic health conditions, parental depression has been associated with worsened health outcomes and an increased risk for hospitalization (Barakat et al., 2007; Bartlett et al., 2004; Garrison et al., 2005).

In summary, the number of children living with chronic conditions, and the number of admissions to a PICU are rising. Despite this, research exploring psychological distress in caregivers of these children is limited. This is an important focus of research, considering the

detrimental impact that parental psychological distress can have on family functioning and disease management and outcome.

The meta-analysis presented in this thesis investigates the prevalence of depression in parents of children diagnosed with Type 1 Diabetes (T1D). Management of T1D requires a strict daily regimen of insulin injections, testing blood glucose levels and monitoring dietary intake (Moore et al., 2013). This level of responsibility, paired with the worry associated with the unpredictability of the condition, can have a negative impact on parental mental health (Dodgson et al., 2000; Whittemore et al., 2012; Streisand et al., 2018). In the meta-analysis, prevalence of depression in parents of children with T1D is reported. Furthermore, the prevalence of depression in mothers and fathers is compared. The paper reflects on the importance of early screening for psychological distress in this population in diabetic paediatric clinics and offering appropriate support and interventions to parents.

The empirical paper in this thesis investigated the psychological impact of a child's admission to a PICU on parents' post-admission. Research has shown that psychological distress is higher in parents of children admitted to a PICU, compared to general wards (Rees et al., 2004). The Generalised Anxiety Disorder measure (GAD-7; Spitzer et al., 2006), Patient Health Questionnaire (PHQ-9; Kroenke & Spitzer, 2002), Quality of Life Scale (QOLS; Burckhardt & Anderson, 2003) are administered, to explore levels of anxiety, depression, and quality of life respectively. Second, the paper explored factors associated with poor psychological outcomes in parents following their child's PICU admission. The Parent Trauma Response Questionnaire (PTRQ; Williamson et al., 2018) is used to explore the relationship between parental appraisals and behaviours and anxiety, depression, and quality of life. The paper reflects on the importance

of early screening of psychological distress and focused support in parents within the PICU setting.

In summary, the thesis aimed to: i) raise awareness of the psychological impact on parents caring for a child who is chronically and/or severely unwell, and ii) explore factors that contribute to longer-term psychological distress. This work will equip clinicians to support families, by increasing knowledge about possible prevalence and psychological vulnerability of these populations and emphasising the importance of support early in the process.

Key terms:

Depression. The DSM-5 describes depression as experiencing five or more of the following symptoms during the same 2-week period, with at least one of the symptoms being either depressed mood or loss of interest or pleasure: depressed mood; diminished interest or pleasure in activities; significant weight loss or gain, or decrease or increase in appetite; slowing down of thought or reduction of physical movement; fatigue or loss of energy; feeling worthless or excessive or inappropriate guilt; diminished ability to think or indecisiveness; recurrent thoughts of death, recurrent suicidal ideation without a specific plan, or a suicide attempt or plan for committing suicide (APA, 2013).

Anxiety. The DSM-5 describes anxiety as excessive anxiety and worry, occurring more days than not for at least six months, about a number of events or activities (APA, 2013). One aspect of the diagnosis is that the individual finds it difficult to control this worry. Furthermore, anxiety is described as experiencing three or more of the following symptoms: restlessness; easily fatigued; trouble concentrating; irritability; muscle tension; and sleep disturbance (finding it difficult to fall or stay asleep, or having restless, unsatisfying sleep). The anxiety, worry, or physical symptoms must cause clinically significant distress, or an impairment in social,

occupational, or other important areas of functioning. The disturbance must not be attributable to the physiological effects of a substance, or another medical condition. Finally, the disturbance must not be better explained by another medical disorder (e.g., social phobia, OCD, PTSD).

Quality of Life. Quality of life has been defined as:

> A broad range of human experiences related to one's overall well-being. It implies value based on the subjective functioning in comparison with personal expectations and is defined by subjective experiences, states, and perceptions. Quality of life, by its very natures, is idiosyncratic to the individual, but intuitively meaningful and understandable to most people (Revicki et al., 2000, p. 888).

Furthermore, quality of life goes beyond the individual's health, and is influenced by their perception of their physical, psychological, social, economic, and political environment (Revicki et al., 2000). Quality of life can be assessed by looking at satisfaction in the following domains: material and physical well-being; relationships with other people; social, community and civic activities; personal development and fulfilment; and recreation (Burckhardt & Anderson, 2003).

Paediatric Intensive Care Unit (PICU). The PICU is a section of the hospital that provides children aged 0-16 years with the highest level of medical care for serious and life-threatening conditions. In 2020, 16,400 children were admitted to a PICU across the UK and Republic of Ireland (Paediatric Intensive Care Audit Network, 2021). Notably, this represents a reduction of 19.5% from the number of admissions in 2019, likely attributable to the COVID-19 pandemic resulting in some PICUs temporarily closing paediatric admissions (Paediatric Intensive Care Audit Network, 2021). Reasons for referrals can vary from long-term physical health conditions to road traffic collisions.

Type 1 Diabetes. Diabetes is a chronic, metabolic disease characterised by elevated blood glucose levels, which can lead to serious damage to the heart, blood vessels, eyes, kidneys, and nerves (WHO, 2022). It is estimated that 8.4 million people had T1D in 2021 worldwide, with the figure predicted to rise to 17.4 million by 2040 (Mahase, 2022). T1D is a chronic condition in which the pancreas produces little or no insulin by itself. T1D cannot be prevented and there is currently no known cure, although scientists are exploring immunotherapy treatment as a potential option to prevent and cure the condition. Treatment involves blood glucose control through a combination of diet, physical activity, and medication.

Outline of thesis

This thesis portfolio begins with a meta-analysis of prevalence rates of depression in parents of children diagnosed with T1D. Following this, a bridging chapter summarises the results and considers how the findings relate to the wider research literature around the impact of caring for a child with a chronic and/or severe illness on parents and the wider family. This chapter also introduces the empirical paper that follows in the subsequent chapter. The empirical paper explores the psychological impact of a child's admission to a PICU on parents. The thesis portfolio is concluded with a critical discussion and summary chapter.

CHAPTER TWO

Meta-analysis

This paper has been written for publication to the *Acta Paediatrica* journal. Please see Appendix A for the journal's guidance to authors.

Prevalence of depression in parents of children with Type 1 Diabetes: A systematic review and meta-analysis

Authors:

Hayley Ryan[a]*, Aaron Burgess[a], Alyssa Hewson[a] and Richard Meiser-Stedman[a]

[a]Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, Norfolk, NR4 7TJ, England, United Kingdom.

*Corresponding author: Hayley Ryan, [a]Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, Norfolk, NR4 7TJ, England, United Kingdom.

h.ryan@uea.ac.uk

Word count: 5616 (including references)

Abstract

Aim: This meta-analysis identified the prevalence of depression in parents of children with Type 1 Diabetes.

Methods: The MEDLINE, PsycINFO and CINAHL databases were searched for papers published in English from 1980 to May 2022, yielding 18 studies that met the inclusion criteria (*N* = 2044 participants). The prevalence of parental depression was pooled across the studies.

Results: Two thresholds for depression were considered: moderate depression and above, and mild depression and above. Random-effects meta-analyses estimated prevalence of moderate depression and above in the total sample as 18.4% (95% CI 12.8-24.6%; k= 17, N= 2044), with rates of 17.3% in mothers (95% CI 12.7-22.5%; k= 12, N= 1106) and 9% in fathers (95% CI 4.3-15.1%; k= 6, N= 199). The estimated prevalence of mild depression and above in the total sample was 32.7% (95% CI 20.3-46.6%; k= 8, N= 797), with rates of 29.4% in mothers (95% CI 17.8-42.6%; k= 4 N= 330) and 13.6% in fathers (95% CI 5.2-25.2%; k= 2 N= 44). All results were characterised by high levels of heterogeneity. Risk of publication bias was found to be low.

Conclusion: Approximately 1 in 5 parents of children with Type 1 Diabetes had depression in the moderate plus category, indicating high levels of psychological distress in this population. Generalisability is limited by the number of studies included, and the lack of studies conducted outside of high-income countries. The implications of these results are discussed.

KEYWORDS: Meta-analysis; depression; prevalence; systematic review

Introduction

Type 1 diabetes (T1D) is an autoimmune condition characterised by the body attacking beta cells in the pancreas that produce insulin. This can result in high blood glucose levels, which, if left untreated, can damage the heart, eyes, feet, and kidneys. T1D is a serious and lifelong condition, being one of the most common paediatric chronic illnesses, preceded by asthma and epilepsy.[1] The number of young people under the age of 20 with T1D is estimated to be 1.2 million.[2] Caring for a child with T1D is emotionally challenging and time intensive. Parents are ultimately responsible for the daily management of the condition. This can include checking blood glucose levels, monitoring diet and physical activity, and administering insulin injections.[3] This can have a significant impact on family life, being time consuming and requiring change to family routine, contributing to parental stress and diminished quality of life.[4] Literature has demonstrated elevated rates of depression in parents of children with T1D, with up to 74% reporting symptoms following diagnosis.[5]

Depression in parents of children with T1D is an important focus of research. Depression is one of the most prevalent psychiatric illnesses.[6] In clinical settings, prevalence of depression is higher than the general population.[7] A number of factors may lead to the development of depression in parents of children with T1D. Having a child diagnosed with a chronic condition is associated with loss of perceived control, which is a main risk factor for depression.[8,9] Furthermore, quality of sleep is likely to diminish in these parents, as they struggle to balance their many responsibilities.[10] Sleep deprivation has several negative health consequences, with literature supporting a link between poor sleep and increased levels of stress, anxiety and depression.[11-13] Parents also report considerable levels of worry and preoccupation about their child's health.[14,15] With these factors in mind, it is unsurprising that parents are left with little

time to engage in meaningful activity of their own, consequently increasing their risk of depressed mood.[16,17] Moreover, parents' perception of stress is likely to be elevated, further increasing their risk for depression.[4] Parents of children with T1D report stress around social disruption, emotional strain, and financial strain when a child's condition is associated with unpredictable symptoms,[18] as is the case with diabetes. All of which have been associated with depression.[19-21]

Parent emotional wellbeing and child health are intertwined. Research has revealed a two- to threefold increased risk of depression in children of mothers with depression.[22] Several studies have considered the transactional model of parent-child interaction for T1D, in which children affect parents and parents affect child, suggesting that it represents a 'family condition'. [23-25] Parental psychological distress has shown to have health implications for the parent, the child with T1D and overall family functioning.[26] More specifically, parental psychological distress has shown to be associated with higher family conflict, less adaptability and having a negative effect on the child's mental health and their diabetes management.[4] The magnitude of maternal symptoms of depression has been related to both poor metabolic control and reduced quality of life in children with T1D.[27,28] Notably, depressive symptoms in children and adolescents with T1D has been associated with an increased risk for hospitalisation.[29,30]

Although several studies have explored the prevalence of depression in this population, there are limited literature reviews and meta-analyses pooling the prevalence across studies. Whittemore and colleagues conducted a systematic review to explore the prevalence of psychological distress in parents of children with T1D.[4] The prevalence of depression in parents of children with T1D was found to range from 10% to 74%. However, there was significant heterogeneity in the samples, making it challenging to make comparisons across studies. The

authors also noted limited diversity and small sample sizes in the included studies. More recently, Bassi and colleagues investigated parental stress, anxiety, and depression in paediatric T1D, and how they are associated with self-efficacy in disease management.[3] Although, this was limited to a literature review and did not solely focus on the prevalence of depression in this population. Several meta-analyses have explored health outcomes in parents of children with chronic illness.[9,31,32] Cohn and colleagues revealed that 35% of parents of chronically ill children met cut-offs for clinical depression, compared to 19% in the control group.[32] However, there are limited meta-analyses solely focusing on the psychological impact of having a child with T1D, and none focusing on the prevalence of depression in this group.

Greater understanding of parental psychological distress in response to their child having T1D is needed to guide future research and clinical practice. This knowledge is of significant clinical importance, considering the impact of parental psychological distress on the child's diabetes management, and can be used for the planning of paediatric psychological services. The plan for this meta-analysis was to synthesise the research on depression rates in parents of children with T1D. The paper aimed are to describe the prevalence of depression in this population and present the clinical and research implications.

Method

Selection of studies

Papers from peer-reviewed, English-language journals that were published between 1980 and May 2022 were considered for inclusion. Relevant studies were identified through systemic searches in three electronic databases: MEDLINE, PsycINFO and CINAHL. Animal studies were excluded from the searches. The search was conducted on the 16th May 2022. The Cochrane database and PROSPERO register were searched to ensure no similar reviews were

either in progress or had been published. This review was registered on PROSPERO (ID Number CRD42022317995).

The following search terms and combinations were used: (Parent* OR carer* OR caregiver* OR “care giver” OR mother* OR father* OR Maternal* OR Paternal*) AND (Depress* OR “mood disorder*” OR "low mood" OR "dysthymic disorder") AND Diabet*. The parent terms were created by the research team and MeSH terms were not used as it was felt that these were sufficient. However, to avoid missing anything related to diabetes and depression, the following MeSH terms were also applied to the searches: (MeSH Diabetes Mellitus, Type 1+) AND (MeSH Depression).

Inclusion and exclusion criteria

Screening and selection of studies was conducted by the first author (HR). To ensure relevant papers were included in the meta-analysis, strict inclusion and exclusion criteria were applied. Studies were included if they reported prevalence rates of depression in parents of children aged between 0-18 years with T1D. The term ‘parents’ is used for the child’s primary caregiver and the terms ‘mother’, ‘father’, or ‘other parent descriptor’ are used to describe gender differences. Studies were excluded if: they did not use a validated or reliable measure of depressive symptoms; prevalence rates of depression were not reported; if the children died before parental depression was assessed; if the aim of the study was to investigate the efficacy of treatment or where the sample used were biased (e.g., only recruiting parents or children with depression). Studies were included if they were: cross-sectional design studies; case-controlled studies; and longitudinal studies. Studies were excluded if they were: randomised-controlled trials; treatment or intervention studies; review articles; systematic reviews; meta-analyses; theses and dissertations; book chapters; purely qualitative research; single case reviews; or case

studies. These were excluded as the current review was interested in original, peer-reviewed, and published studies that had solely looked the prevalence of depression in a population of parents of children with T1D. Randomised-controlled trials, treatment or intervention studies were also excluded as it was felt that the sample in these studies were likely to be biased towards higher rates of depression.

Data extracted from each study

The first author (HR) screened all studies and extracted information using a database. Several study variables were examined: author; year of publication; country; setting; inclusion and exclusion criteria; data collection method ; recruitment method; and sample size. The following participant data was extracted: age, gender, and ethnicity of parents; assessment methods and measures; and the number of parents meeting the cut-off for depression. If a study reported depression prevalence at multiple time points, only baseline prevalence was extracted. Data extracted from each study is displayed in Table 1. The extracted data for all studies were reviewed by an independent researcher (AH), to reduce the likelihood of error.[33] Any queries were discussed, until consensus was reached. If consensus could not be reached by the two authors (HR and AH), a final decision was made by the senior researcher (RM-S).

The majority of studies reported levels of depression according to published cut-offs for each measure. For example, no depression, and mild, moderate, and severe depression. In the current study, severity of depression was then divided into two categories: parents who scored in the mild range of depression and above (mild plus); and parents who scored in the moderate range of depression and above (moderate plus) on the measures. Two studies only categorised parents as either below or above the clinical cut-off for depression and were placed into the

'moderate plus' category. One study used a category defined as 'doubtful cases', and these were placed into the 'mild plus' category in the current study.

Risk of bias

The quality of each study was analysed by two researchers (HR and AH). An adapted version of a risk-of-bias tool used in a recent meta-analyses of post-traumatic stress disorder (PTSD) prevalence was used, [34] using common quality assessment questions developed by Munn and colleagues.[35] The risk-of-bias tool included six questions, which assessed quality according to the description of sample characteristics, non-response rates and reasons provided, representativeness, recruitment procedures and reporting of inclusion and exclusion criteria. As prevalence was the only outcome extracted from each study, the type of analyses used were not assessed for quality. A qualitative descriptor of risk-of-bias was applied to each study (Low, Medium, High) and the scoring was adapted to reflect the number of questions assessing quality (9-12 = low risk, 5-8 = medium risk, 0-4 = high risk. All studies were inter-rated by the two researchers (HR and AH). Analysis was then conducted to assess inter-rater reliability, using MAVIS (version 1.1.3). Individual study ratings on each risk-of-bias criteria are detailed in Appendix C.

Statistical analysis

The meta-analyses were conducted using R (version 4.1.3), using the metafor package (version 3.8-1).[36] The prevalence of parents with depression was extracted from each paper. Parents were classed as having depression if they met cut-off on a validated depression measure. To account for likely between-study heterogeneity, a random effects model was used, as it provides a more conservative 95% CI around the estimate of prevalence.

The estimates of prevalence underwent an arcsine square-root (angular) transformation, to ensure that CIs did not fall below zero for samples where the prevalence estimate was low. [37] The results were then back transformed to enable ease of interpretation.

The heterogeneity of studies was assessed by visual inspection of forest plots, in addition to conducting a Cochran's *Q* test.[38] The Cochran's Q test indicates whether heterogeneity is significant between the studies. The I^2 statistic was used to determine the percentage of total variation in sample estimates that is due to between-study heterogeneity.[39] I^2 between 30-60% indicates moderate heterogeneity, 50-90% represents substantial heterogeneity and 75% and above indicates considerable heterogeneity.[40] Prediction intervals (PI) were also reported, enabling clinical interpretation of the heterogeneity.[41] A 95% PI estimates where the true effects are to be expected for 95% of similar studies conducted in the future.[42]

Publication bias was assessed using funnel plots.[43] However, due to the lack of assessment of clinical significance in prevalence studies, the risk-of-bias in levels of acceptance to journals is reduced.[44] Funnel plot asymmetry was tested using Egger's test.[45]

Sensitivity analyses were conducted to assess the impact of risk-of-bias on the pooled prevalence. This was achieved by repeating the meta-analysis, excluding samples where there was a high risk-of-bias. A meta-analytic regression was used to test for any clinically significant differences in the sensitivity analysis.

Moderator analysis was not conducted due to the small number of studies, and the homogeneity of variables, e.g., the type of depression measure used and income status of country.

In clinical research, researchers may choose not to write up and publish studies with uninteresting findings, for example those with smaller or nonstatistically significant effect

sizes.[46] However, this can lead to publication bias. With prevalence research, it is unclear whether researchers would be more likely to publish studies reporting either low or high prevalence rates, and therefore less is known about the risk of publication bias within this research. Nevertheless, publication bias was assessed in the current review for robustness.

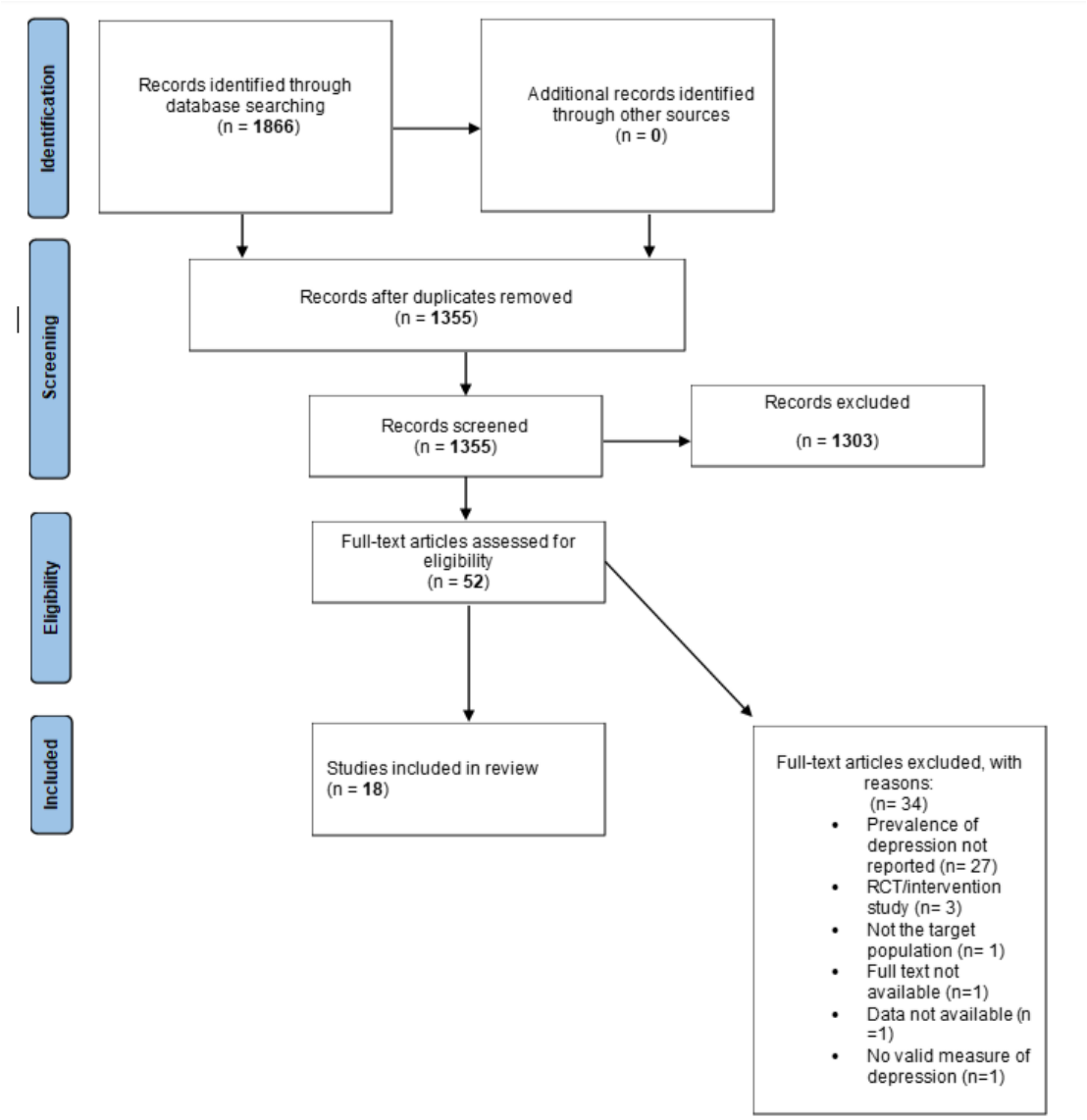


Figure 1. PRISMA flowchart of studies identified, screened, and included in the final meta-analysis

Results

We identified 1,355 papers after duplicates had been removed. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) diagram shows that 52 papers met the eligibility criteria following the initial screen of titles and abstracts (Figure 1). Full text reviews were then conducted on these 52 papers. Following further exclusions, the total number of samples included in this review was 18. All 18 studies reported prevalence rates of depression in parents of children diagnosed with T1D. Five studies included only female participants. One study did not report the percentage of female participants. Of the remaining twelve studies, the average percentage of female participants was 74.6%. The average child age was 11.45 across the seventeen studies that reported child age. Studies mostly originated from high-income countries (k = 15).

Characteristics of the studies

The characteristics of the included studies can be found in Table 1. Participants ranged in age from 20-61. The estimated mean age across all studies was 40.4. Seven studies were not included in this overall mean age calculation as they either did not report mean age or they reported it according to gender or severity of depression, rather than the total sample. A range of inclusion and exclusion criteria were applied across the studies. Participants were frequently excluded if their child had another serious mental or physical comorbidity, and if the diagnosis of T1D was less than six months. To assess depression prevalence in their samples, six studies used the Centre for Epidemiologic Studies Depression Scale (CES-D) [47]; three studies used the Beck's Depression Inventory (BDI) [48]; three studies used the Patient Health Questionnaire (PHQ-9) [49];

four studies used the Hospital Anxiety and Depression Scale (HADS) [50]; and two studies used the Hamilton Depression Rating Scale (HDRS).[51]

Risk-of bias assessment

Fourteen studies were deemed to be at medium risk-of-bias and four were deemed to be at low risk-of-bias. No studies were deemed to be at high risk-of-bias. The proportion of studies rated as low, moderate, and high risk across the six quality assessment items can be seen in Appendix C. Inter-rater reliability was assessed for all ratings on all studies (n = 18) by the two raters (HR, AH). They achieved an intra-class correlation of 0.68 for risk-of-bias, indicating a good correlation on all items [interclass correlation = 0.68, 95% confidence intervals (CI) 33.5-86.6].[52] This suggests that the quality assessment tool was robust, with good inter-rater reliability.

Depression prevalence

The pooled prevalence of depression estimates and heterogeneity statistics for all studies can be seen in Table 2. A total of 18 studies reported prevalence rates, which resulted in a pooled prevalence of parental depression following their child's diagnosis of T1D.

Six meta-analyses were conducted: total participants scoring in the moderate depression and above range (moderate plus); total number of mothers scoring in the moderate depression and above range; total number of fathers scoring in the moderate depression and above range; total participants scoring in the mild depression and above range (mild plus); total number of mothers scoring in the mild depression and above range; total number of fathers scoring in the mild depression and above range.

<u>Moderate plus depression</u>

The overall pooled prevalence was 18.4% (95% CI 12.8-24.6%) of the parents from the studies (k=17) who had a child diagnosed with T1D developed depression in the moderate and above range. For mothers, the pooled prevalence was 17.3% (95% CI 12.7-22.5%; k= 12). The degree of heterogeneity for these two meta-analyses was considerably high. For fathers, the pooled prevalence was 9% (95% CI 4.3-15.1%; k= 6), with a low degree of heterogeneity.

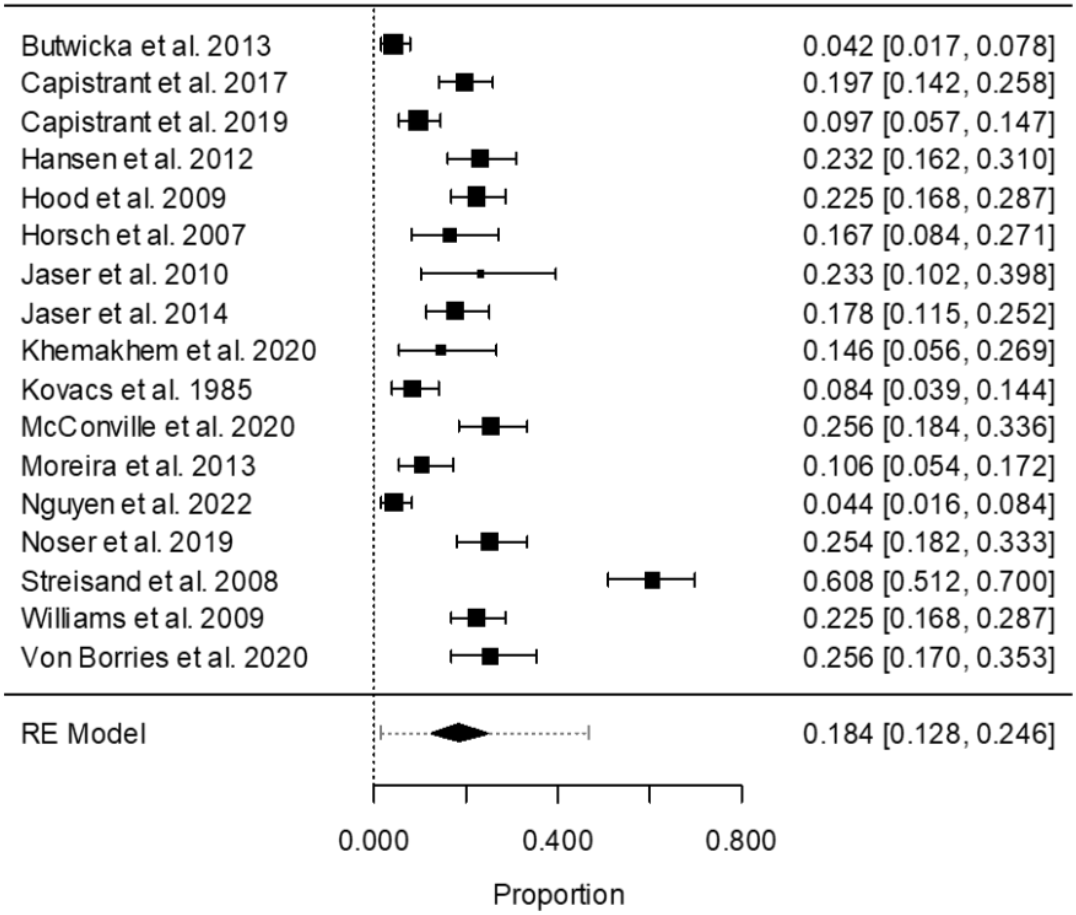


Figure 2. Forest plot for prevalence of moderate depression and above (moderate plus) in the total sample

Mild plus depression

This overall pooled prevalence was 32.7% (95% CI 20.3-46.6%) of the parents from the studies (k=8) who had a child diagnosed with T1D developed depression in the mild and above range. For mothers, the pooled prevalence was 29.4% (95% CI 17.8-42.6%; k= 4). The degree of

heterogeneity for these two meta-analyses was considerably high. For fathers, the pooled prevalence was 13.6% (95% CI 5.2-25.2%; k= 2), with a low degree of heterogeneity.

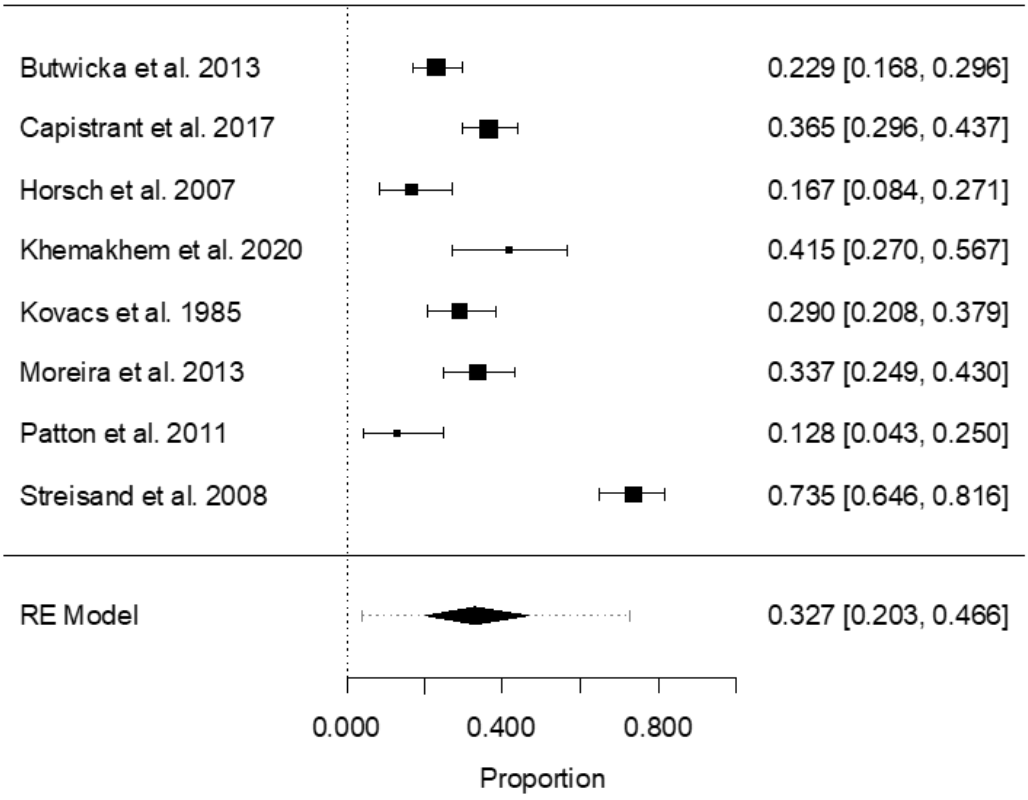


Figure 3. Forest plot for prevalence of mild depression and above (mild plus) in the total sample

Sensitivity analysis of prevalence

On visual inspection of the forest plot, the study of Streisand et al. appeared to be an outlier.[5] The two meta-analyses estimating prevalence of mild (mild plus) and moderate (moderate plus) depression and above in the total sample were run again, excluding this study, to analyse the impact of this study on the overall pooled prevalence of depression. Streisand and colleagues did not report depression prevalence for mothers and fathers separately.[5] Therefore, sensitivity analysis was only conducted for the total sample. For moderate plus, the prevalence of

depression reduced to 16.2% (95% CI 12.2-20.5%); for mild plus, the prevalence of depression reduced to 27.4% (95% CI 20.4-35).

Publication bias

Publication bias was only reported for categories with 10 studies or more:[53] moderate plus – total sample; and moderate plus – mothers only.

For the moderate plus threshold including all studies, visual inspection of the funnel plot suggested that the distribution of studies was symmetrical (k=17). This was confirmed by Egger's test, which was non-significant (p = 0.67). The trim-and-fill analysis did not highlight null or weaker studies as missing, indicating little to no publication bias.

For the moderate plus threshold including only data for mothers, visual inspection of the funnel plot suggested that the distribution of studies was symmetrical (k=14). This was confirmed by Egger's test, which was non-significant (p = 0.41). The trim-and-fill analysis highlighted a lack of studies on the left side of the funnel plot, indicating a small degree of potential publication bias; including two additional estimated studies, which reduced the pooled prevalence to 15.5% (95% CI 11.2, 20.3). However, this should be interpreted with caution due to the small number of studies.[53]

Table 1
Characteristics of the 18 studies included in the meta-analysis

Sample	Location	Age		n	Proportion female (%)	Depression measure	Risk of bias (/12)
		Range	*Mean (SD)*				
Butwicka 2013	Poland	NR	39.6 (5.1)	166	100	HDRS	Medium (7)
Capistrant 2017	India	NR	40.6 (6.8)	178	50	PHQ-9	Medium (8)
Capistrant 2019	India	NR	1. 41.56 (6.78), 2. 41.30 (6.47)*	165	1. 68.8%; 2. 48.3%*	PHQ-9	Medium (8)
Hansen 2012	USA	NR	1. 41.4 (5.5) 2. 44.1 (5.6)**	125	66	HADS	Medium (7)
Hood 2009	USA	NR	NR	187	84	CES-D	Low (9)
Horsch 2007	UK	NR	40.2 (5.9)	60	100	HADS	Medium (6)
Jaser 2010	USA	30-57	43.5 (6.7)	30	100	CES-D	Medium (8)
Jaser 2014	USA	28-58	44.2 (5.8)	118	100	CES-D	Medium (8)
Khemakhem 2020	Tunisia	NR	NR	41	85	HADS	Medium (7)

Kovacs 1985	USA	NR	1. 37.5 (6.2) 2. 40.8 (6.9)**	107	64.5%	BDI	Medium (8)
McConville 2020	USA	NR	36.6 (6.4)	125	87.5	CES-D	Medium (8)
Moreira 2013	Portugal	25-65	42 (6)	104	94	HADS	Medium (5)
Nguyen 2022	Netherlands	34-59	46 (4.6)	137	89	PHQ-9	Medium (6)
Noser 2019	USA	NR	36.6 (6.4)	126	88	CES-D	Low (9)
Patton 2011	USA	NR	35.1 (6.4)	39	NR	BDI-II	Low (9)
Streisand 2008	USA	20-61	40.2 (7.2)	102	61	CES-D	Medium (7)
Williams 2009	USA	NR	NR	187	82	CES-D	Low (9)
von Borries 2020	Chile	NR	1. 42.5 (7.53) 2. 44.5 (9.52)***	86	100	BDI	Medium (7)

*1 = moderate/severe depression, 2 = no/mild depression
**1 = mothers, 2 = fathers
***1 = with depression, 2 = no depression

Table 2
Pooled point prevalence of depression for all samples (k = 18)

Meta-analysis subgroup	k	n	Pooled prevalence (%)	95% CI	Q	I^2	95% PI
Moderate plus							
Total	17	2044	18.4%	12.8, 24.6	191.15***	91.7%	1.8, 46.6
Total (less outlier)	16	1942	16.2%	12.2, 20.5	100.46***	84.0%	4.0, 34.3
Mothers	12	1106	17.3%	12.7, 22.5	59.27***	78.0%	5.0, 35.0
Fathers	6	199	9%	4.3, 15.1	8.05	35.4%	1.9, 20.4
Mild plus							
Total	8	797	32.7%	20.3, 46.6	100.78***	93.7%	3.9, 72.6
Total (less outlier)	7	695	27.4%	20.4, 35.0	23.26***	77.3%	11.6, 46.8
Mothers	4	330	29.4%	17.8, 42.6	14.3	82.1%	8.2, 57.0
Fathers	2	44	13.6%	5.2, 25.2	0.05	0%	5.2, 25.2

k, number of studies; *n*, number of participants; CI, confidence interval; PI, prediction interval.
***$p < 0.0001$

Discussion

This meta-analysis investigated the prevalence of depression in parents of children with T1D. The prevalence was 18.4% for moderate depression and above, and 32.7% for mild depression and above, across a total sample of 2044 parents from 18 studies. This suggests that a significant majority of parents of children with T1D will develop depression, with approximately 1 in 5 developing moderate depression and above. However, there was significant heterogeneity across studies (I^2=91.7% in the moderate plus category and 93.7% in the mild plus category). Sensitivity analysis showed little change in the prevalence of depression when an outlier was removed from the meta-analysis.

Comparison to prevalence of depression in parents of children with other chronic health conditions and healthy children

The World Health Organisation (WHO) estimate that approximately 5% of adults are affected by depression worldwide.[54] The prevalence of depression is higher in women compared to men, with a global prevalence of 5.5% and 3.2% respectively in 2010.[55] Between 6% and 17% of women experience depression in their lifetime, with elevated rates in mothers.[56] Several studies have addressed the relationship between parenthood and depression, suggesting that parents may have lower psychological wellbeing when compared with those without children.[57] Furthermore, it is important to consider the prevalence of depression in parents of healthy children, in order to make comparisons to the results of the current study. Cohn and colleagues compared rates of depression in parents of children with and without chronic illness, defined as those suffering from a physical, developmental, behavioural, or emotional condition lasting at least three months. Parents of affected children had higher rates of depression (35%) compared to parents of healthy children (19%). This highlights that the prevalence rate of mild and above depression found in the current study is considerably higher than rates in parents of healthy children. Moreover, the prevalence of depression of children with chronic illness found in the Cohn and colleagues' study (35%) is comparable to the prevalence of mild depression and above found in parents of children with T1D in the current study (32.7%). However, limited studies in recent years report on prevalence of depression in parents of healthy children and adolescents, and further research is needed to support this claim. Moreover, it appears little is known about the relationship between parenting and depression. Despite these gaps in the literature, our findings support previous studies demonstrating that parents of children with T1D have elevated rates of depression,[4,5,23] particularly in mothers.[59]

Gender differences in prevalence of depression

The current review found a higher prevalence of depression in mothers, compared to fathers. This finding is consistent with the wider literature on gender differences in the rates of depression in the general population.[55,56,60] In this literature, several reasons for these differences have been considered. These include women reporting higher levels of depressed mood than men, biological vulnerabilities, and gender-related environmental experiences.[61] Furthermore, in a qualitative study, it was found that the men's experience lay outside the standard diagnostic criteria for depression.[62] For example, men were more likely to withdraw socially, abuse substances and use risk-taking behaviours.[63] It is widely recognised that men are less likely to report depression or seek help, with potential barriers including feelings of weakness or vulnerability, fear, denial, and personal beliefs.[63] This may explain the higher rates of depression found in mothers in the current study. However, the literature calls for further research to explore gender differences in depression prevalence.

Clinical implications and suggestions for future research

This meta-analysis suggests that depression is common in parents of children with T1D, and therefore should be routinely assessed for in clinical settings. Moreover, depression was found to be more common in mothers than fathers. Diabetes centres should routinely screen for depression in parents of children with T1D. It is recommended that this screening is conducted as early as possible following a child's diagnosis. Interventions should then also be offered to support these parents. According to recent guidelines from the National Institute for Health and Care Excellence (NICE), this could involve anything from guided self-help to individual cognitive behavioural therapy (CBT).[64] This could prevent severe depression developing in these parents and reduce the risk of poor diabetes management for the child. Future research could also

explore the outcomes of such interventions, to establish their efficacy in improving symptoms of both mild and moderate depression. It is important to consider the appropriate time to offer psychological intervention to parents following their child's diagnosis of T1D. It has been recognised that parents experience a psychosocial transition following their child's diagnosis of T1D, leading to a period of behavioural and emotional readjustment.[65] Moreover, parents may experience a sense of loss of their healthy child, leading to a grief reaction similar to that associated with bereavement.[65] There is a risk of intervening too soon after the diagnosis and pathologizing what could be a normal reaction and a necessary readjustment process to a life-changing event. In one study, mothers valued the support of experienced parent mentors shortly after diagnosis, suggesting that more informal support early on could be beneficial.[66] Further research is needed to explore these processes in parents following their child's diagnosis of T1D and consider the optimum time to assess depression in these parents and the level of psychological intervention to offer considering time since diagnosis.

Studies did not report whether parents had a history of depression. Therefore, it is unclear whether parents had depression before their child's diagnosis, or whether they developed it following the child's diagnosis. Future research could explicitly explore this. Furthermore, research could consider prevalence of depression in parents before their child's diagnosis, and how this is associated with the child's diabetes management. Research is needed to explore differences in prevalence of depression in parents of children with T1D, compared to those with healthy children. As previously discussed, parenting has been associated with lower psychological wellbeing. Therefore, it is unclear to what extent the high levels of depression found in the population of parents in the current study is a result of the child having T1D, or the demands of parenting in general. Finally, although ideas have been explored in the introduction

section of this study, little is known about the processes involved in the development of depression in this population. For example, systemic factors, disease management, traumatic memories, or psychological appraisals e.g., rumination.

Strengths and limitations

This study is strengthened by minimal publication bias, and by being the first meta-analysis, to our knowledge, to report the prevalence of depression in parents of children with T1D. However, several limitations should be considered. Although some level of heterogeneity is expected in a meta-analysis, the level of heterogeneity in the current study was considerable, making it challenging to make comparisons across studies. Heterogeneity may exist due to differences in measures, culture, age of children, study design, measures and cut-offs used, and whether measures were administered online or face-to-face. Furthermore, all studies were considered non-representative, with limited diversity in race and ethnicity, and recruitment restricted to a particular geographical locality. Although the overall prevalence of depression was found to be high in the moderate plus category, the range of depression scores was wide, ranging from 17.9% to 46.6%, making it challenging to make inferences from these results. The majority of participants in the included studies were mothers. With a limited sample size, less is known about the prevalence of depression in fathers of children with T1D. Finally, all studies included in this review used self-report measures of depression, which are at risk of response bias.

Conclusion

To our knowledge, this study is the first to meta-analyse data on the prevalence of depression in parents of children with T1D. The estimated prevalence of moderate depression and above (moderate plus) was 18.4% (95% CI 12.8-24.6%) in the total sample; 17.3% (95% CI 12.7-22.5%) in mothers; and 9% (95% CI 4.3-15.1%) in fathers. The estimated prevalence of

mild depression and above (mild plus) was 32.7% (95% CI 20.3-46.6%) in the total sample; 29.4% (95% CI 17.8-42.6%) in mothers; and 13.6% (95% CI 5.2-25.2%) in fathers. These results suggest that a significant majority of parents of children with T1D meet diagnostic criteria for depression, which highlights the psychological impact of having a child diagnosed with T1D. However, all results were characterized by high levels of heterogeneity. Further research is required to investigate the prevalence of depression in parents of children with T1D.

Declaration of interest: None

Funding: This research was supported by the University of East Anglia and was written as part of a doctoral thesis for the Doctoral Programme in Clinical Psychology.

References

1. Miller, G. F., Coffield, E., Leroy, Z., & Wallin, R. Prevalence and costs of five chronic conditions in children. *The Journal of School Nursing*. 2016; 32(5), 357–364.
2. International Diabetes Federation Diabetes around the world in 2021. 2021. Accessed February 20, 2023. https://diabetesatlas.org/atlas.
3. Tully, C., Wang, C. H., Sinisterra, M., Clary, L., Hilliard, M. E., Monaghan, M., Wang, J., & Streisand, R. Diabetes-specific functioning in parents of young children with recently diagnosed type 1 diabetes. *Health Psychology*. 2022; 41(6), 423-432
4. Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. Psychological experience of parents of children with type 1 diabetes: A systematic mixed-studies review. *The Diabetes Educator*. 2012; 38(4), 562–579.
5. Streisand, R., Mackey, E. R., Elliot, B. M., Mednick, L., Slaughter, I. M., Turek, J., & Austin, A. Parental anxiety and depression associated with caring for a child newly

diagnosed with type 1 diabetes: Opportunities for education and counseling. *Patient Education and Counseling*. 2008; 73(2), 333–338.

6. Burke, L. The impact of maternal depression on familial relationships. *International Review of Psychiatry*. 2003; 15(3), 243–255.
7. Kessing, L. V. Epidemiology of subtypes of depression. *Acta Psychiatrica Scandinavica*. 2007; 115, 85–89.
8. Carpentier, M. Y., Mullins, L. L., Chaney, J. M., & Wagner, J. L. The relationship of illness uncertainty and attributional style to long-term psychological distress in parents of children with type 1 diabetes mellitus. *Children's Health Care*. 2006; 35(2), 141-154.
9. Pinquart, M. Featured Article: Depressive Symptoms in Parents of Children with Chronic Health Conditions: A Meta-Analysis. *Journal of Pediatric Psychology*. 2019; 44(2), 139–149.
10. Feeley, C. A., Sereika, S. M., Chasens, E. R., Siminerio, L., Charron-Prochownik, D., Muzumdar, R. H., & Viswanathan, P. Sleep in parental caregivers and children with type 1 diabetes. *The Journal of School Nursing*. 2021; 37(4), 259–269.
11. Chu, J., & Richdale, A. L. Sleep quality and psychological wellbeing in mothers of children with developmental disabilities. *Research in Developmental Disabilities*. 2009; 30(6), 1512–1522.
12. Estrada, C. L., Danielson, K. K., Drum, M. L., & Lipton, R. B. Insufficient sleep in young patients with diabetes and their families. *Biological Research for Nursing*. 2012; 14(1), 48–54.
13. Feeley, C. A., Turner-Henson, A., Christian, B. J., Avis, K. T., Heaton, K., Lozano, D., & Su, X. Sleep quality, stress, caregiver burden, and quality of life in maternal caregivers of

young children with bronchopulmonary dysplasia. *Journal of Pediatric Nursing*. 2014; 29(1), 29–38.

14. Kovacs, M., Finkelstein, R., Feinberg, T. L., Crouse-Novak, M., Paulauskas, S., & Pollock, M. Initial psychologic responses of parents to the diagnosis of insulin-dependent diabetes mellitus in their children. *Diabetes Care*. 1985; 8(6), 568–575.
15. Lowes, L., Lyne, P., & Gregory, J. W. Childhood diabetes: Parents' experience of home management and the first year following diagnosis. *Diabetic Medicine*. 2004; 21(6), 531–538.
16. Zettle, R. ACT for depression: A clinician's guide to using acceptance and commitment therapy in treating depression. *New Harbinger Publications;* 2007.
17. Pearce, M., Garcia, L., Abbas, A., Strain, T., Schuch, F. B., Golubic, R., Kelly, P., Khan, S., Utukuri, M., & Laird, Y. Association Between Physical Activity and Risk of Depression: A Systematic Review and Meta-analysis. *JAMA Psychiatry*. 2022; 79(6), 550-559.
18. Dodgson, J. E., Garwick, A., Blozis, S. A., Patterson, J. M., Bennett, F. C., & Blum, R. W. Uncertainty in childhood chronic conditions and family distress in families of young children. *Journal of Family Nursing*. 2000; 6(3), 252–266.
19. Cohen, S., Murphy, M. L. M., & Prather, A. A. Ten Surprising Facts About Stressful Life Events and Disease Risk. *Annual Review of Psychology*. 2019; 70, 577–597.
20. Guan, N., Guariglia, A., Moore, P., Xu, F., & Al-Janabi, H. Financial stress and depression in adults: A systematic review. *PLoS ONE*. 2022; 17(2), 1-20.
21. Rosenquist, J. N., Fowler, J. H., & Christakis, N. A. Social network determinants of depression. *Molecular Psychiatry*. 2011; 16(3).

22. Weissman, M. M., Pilowsky, D. J., Wickramaratne, P. J., Talati, A., Wisniewski, S. R., Fava, M., ... & Rush, A. J. Remissions in maternal depression and child psychopathology: a STAR* D-child report. *Jama.* 2006; 295(12), 1389-1398.

23. Bassi, G., Mancinelli, E., Di Riso, D., & Salcuni, S. Parental stress, anxiety and depression symptoms associated with self-efficacy in paediatric type 1 diabetes: A literature review. *International Journal of Environmental Research and Public Health*. 2021; 18(1), 152-172.

24. Helgeson, V. S., Becker, D., Escobar, O., & Siminerio, L. Families with children with diabetes: Implications of parent stress for parent and child health. *Journal of Pediatric Psychology*. 2012; 37(4), 467–478.

25. Zysberg, L., & Lang, T. Supporting parents of children with type 1 diabetes mellitus: A literature review. *Patient Intelligence*. 2015; 17, 21-31.

26. Mitchell, S. J., Hilliard, M. E., Mednick, L., Henderson, C., Cogen, F. R., & Streisand, R. Stress among fathers of young children with type 1 diabetes. *Families, Systems, & Health*. 2009; 27(4), 314-324.

27. Jaser, S. S., Whittemore, R., Ambrosino, J. M., Lindemann, E., & Grey, M. Mediators of depressive symptoms in children with type 1 diabetes and their mothers. *Journal of Pediatric Psychology*. 2008; 33(5), 509–519.

28. Driscoll, K. A., Johnson, S. B., Barker, D., Quittner, A. L., Deeb, L. C., Geller, D. E., Gondor, M., & Silverstein, J. H. Risk factors associated with depressive symptoms in caregivers of children with type 1 diabetes or cystic fibrosis. *Journal of Pediatric Psychology*. 2010; 35(8), 814–822.

29. Garrison, M. M., Katon, W. J., & Richardson, L. P. The impact of psychiatric comorbidities on readmissions for diabetes in youth. *Diabetes Care*. 2005; 28(9), 2150-2154.
30. Stewart, S. M., Rao, U., Emslie, G. J., Klein, D., & White, P. C. Depressive symptoms predict hospitalization for adolescents with type 1 diabetes mellitus. *Pediatrics.* 2005; 115(5), 1315-1319.
31. Miodrag, N., Burke, M., Tanner-Smith, E., & Hodapp, R. M. Adverse health in parents of children with disabilities and chronic health conditions: A meta-analysis using the Parenting Stress Index's Health Sub-domain. *Journal of Intellectual Disability Research*. 2015; 59(3), 257–271.
32. Cohn, L. N., Pechlivanoglou, P., Lee, Y., Mahant, S., Orkin, J., Marson, A., & Cohen, E. Health outcomes of parents of children with chronic illness: A systematic review and meta-analysis. *The Journal of Pediatrics*. 2020; 218, 166–177.
33. Buscemi, N., Hartling, L., Vandermeer, B., Tjosvold, L., & Klassen, T. P. Single data extraction generated more errors than double data extraction in systematic reviews. *Journal of Clinical Epidemiology*. 2006; 59(7), 697–703.
34. Burgess, A., Wilcoxon, L., Rushworth, I., & Meiser-Stedman, R. Meta-analysis found high rates of post-traumatic stress disorder and associated risk factors in parents following paediatric medical events. *Acta Paediatrica*. 2021; 110(12), 3227–3236.
35. Munn, Z., Moola, S., Riitano, D., & Lisy, K. The development of a critical appraisal tool for use in systematic reviews addressing questions of prevalence. *International Journal of Health Policy and Management*. 2014; 3(3), 123.

36. Viechtbauer, W. Conducting meta-analyses in R with the metafor package. *Journal of Statistical Software*. 2010; 36(3), 1–48.

37. Barendregt, J. J., Doi, S. A., Lee, Y. Y., Norman, R. E., & Vos, T. Meta-analysis of prevalence. *J Epidemiol Community Health*, 2015; *67*(11): 974–978.

38. Cochran, W. The combination of estimates from different experiments. *Biometrics*. 1954; 10.

39. Higgins, J. P., & Thompson, S. G. Quantifying heterogeneity in a meta-analysis. *Statistics in Medicine*. 2002; 21(11), 1539–1558.

40. Higgins, J. P., & Green, S. *Identifying and measuring heterogeneity; Cochrane Handbook for Systematic Reviews of Interventions* (Version 5.1). The Cochrane Edition; 2011.

41. IntHout, J., Ioannidis, J. P., Rovers, M. M., & Goeman, J. J. Plea for routinely presenting prediction intervals in meta-analysis. *BMJ open. 2016; 6*(7), e010247.

42. Higgins, J. P., Thompson, S. G., & Spiegelhalter, D. J. A re-evaluation of random-effects meta-analysis. *Journal of the Royal Statistical Society: Series A (Statistics in Society)*. 2009; 172(1), 137-159.

43. Higgins, J., & Altman, D. Assessing Risk of Bias in Included Studies. 2008; 187–241.

44. Brewin, C. R., Andrews, B., & Valentine, J. D. Meta-analysis of risk factors for posttraumatic stress disorder in trauma-exposed adults. *Journal of Consulting and Clinical Psychology*. 2000; 68(5), 748.

45. Egger, M., Smith, G. D., Schneider, M., & Minder, C. Bias in meta-analysis detected by a simple, graphical test. *BMJ*. 1997; 315(7109), 629-634.

46. Cooper, H. M., Hedges, L. V., & Valentine, J. C. (Eds.). *The handbook of research synthesis and meta-analysis* (2nd ed). Russell Sage Foundation; 2009.

47. Radloff, L. S. The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*. 1977; 1(3), 385–401.

48. Beck, A. T., Steer, R. A., & Brown, G. Beck depression inventory–II. *Psychological Assessment*. 1996.

49. Kroenke, K., & Spitzer, R. L. The PHQ-9: A new depression diagnostic and severity measure. *Psychiatric annals*. 2002; 32(9), 509–515.

50. Zigmond, A. S., & Snaith, R. P. The hospital anxiety and depression scale. Acta Psychiatr Scand. *PubMed.* 1983; 67(6), 361–370.

51. Hamilton, M. A rating scale for depression. *Journal of Neurology, Neurosurgery, and Psychiatry*. 1960; 23(1), 56-62.

52. Cicchetti, D. V. Guidelines, criteria, and rules of thumb for evaluating normed and standardized assessment instruments in psychology. *Psychological Assessment*. 1994; 6(4), 284-290.

53. Higgins, J. P. T., & Green, S. Recommendations on testing for funnel plot asymmetry. *Cochrane Handbook for Systematic Reviews of Interventions, version 5.0;* 2011.

54. World Health Organisation. Depression. 2021. Accessed January 20, 2023. https://www.who.int/news-room/fact-sheets/detail/depression.

55. Albert P. Why is depression more prevalent in women? *Journal of Psychiatry & Neuroscience.* 2015; 40(4): 219-221.

56. Goodman, S. H. Depression in mothers. *Annual review of clinical psychology*. 2007; 3(1), 107-135.

57. Pace, G. T., & Shafer, K. Parenting and depression: Differences across parental roles. *Journal of Family Issues*. 2015; 36(8), 1001–1021.

58. Gallagher, S., & Hannigan, A. Depression and chronic health conditions in parents of children with and without developmental disabilities: The growing up in Ireland cohort study. *Research in developmental disabilities.* 2014; 35(2), 448-454.

59. Kokkonen, J., Taanla, A., & Kokkonen, E. R. Diabetes in adolescence: The effect of family and psychologic factors on metabolic control. *Nordic Journal of Psychiatry*. 1997; 51(3), 165-172.

60. Piccinelli, M., & Wilkinson, G. Gender differences in depression: Critical review. *The British Journal of Psychiatry*. 2000; 177(6), 486-492.

61. Kessler, R.C. Epidemiology of women and depression. *Journal of affective disorders*. 2003; 74(1), 5-13.

62. Brownhill, S., Wilhelm, K., Barclay, L., & Schmied, V. 'Big build': hidden depression in men. *Australian & New Zealand Journal of Psychiatry.* 2005; 39(10), 921-931.

63. Wilhelm, K.A. Men and depression. *Australian family physician.* 2001; 30(1), 102-105.

64. Kendrick, T., Pilling, S., Mavranezouli, I., Megnin-Viggars, O., Ruane, C., Eadon, H., & Kapur, N. Management of depression in adults: summary of updated NICE guidance. *BMJ*. 2022; 378-387.

65. Lowes, L., Gregory, J.W. and Lyne, P., 2005. Newly diagnosed childhood diabetes: a psychosocial transition for parents?. *Journal of advanced nursing.* 2005; 50(3), 253-261.

66. Sullivan-Bolyai, S., Bova, C., Leung, K., Trudeau, A., Lee, M. and Gruppuso, P. Social support to empower parents (STEP). *The Diabetes Educator.* 2010; 36(1), 88-97.

CHAPTER THREE

Bridging chapter

Results from meta-analysis

The meta-analysis reported in Chapter two identified that a high number of parents of children with T1D met the diagnostic criteria for depression. This supports previous research that found high rates of depression in this population (Streisand et al., 2008). However, to our knowledge, this review was the first to meta-analyse data on the prevalence of depression in parents of children with T1D, adding new insights into psychological outcomes for these parents. Ideas as to why parents of children with T1D may develop depression were explored. These included the loss of control when a child is diagnosed with a chronic condition, sleep deprivation, considerable levels of worry and preoccupation, parents' perception of stress, social disruption, emotional and financial strain and the unpredictability of T1D. The review discussed prevalence of depression in parents of healthy children, compared to those with T1D. Clinical implications were considered, advising that parents of children with T1D are routinely assessed for depression, using validated measures, such as the PHQ-9 (NICE, 2011). It was recognised that psychological distress in parents could lead to worsened mental and physical outcomes in children, further supporting the need to screen for distress in these parents. Strengths and limitations of the review were acknowledged, and suggestions were given for future research directions.

Effects of a child's illness on parental wellbeing and wider family

Observing a loved one in a life-threatening state is an extremely distressing event. In a recent study exploring paediatric intensive care unit (PICU) admissions in the UK, the most common reason for an admission under 28 days was cardiovascular illness, followed by respiratory, gastrointestinal, neurology, trauma and orthopaedic, musculoskeletal, and endocrine/metabolic, including T1D (Kanthimathinathan et al., 2020). In a PICU environment,

illness trajectory can swing dramatically between both deterioration and recovery (Shudy et al., 2006). Caring for a child with a life-threatening illness can lead to anticipatory grief, where the individual experiences the grief process before a loss actually occurs (Kustanti et al., 2022; Reynolds & Botha, 2006). When anticipatory grief occurs, parents experience a lengthy period of uncertainty, where death or permanent damage to their child is a possibility (Al-Gamal & Long, 2010; Wong & Chan, 2006). Unsurprisingly, this can be a source of significant parental distress.

Critical illness in childhood is not only a source of distress for the child, but for the entire family (Fuhrman & Zimmerman, 2006). If the child survives and is discharged from a PICU, long-term management of their condition is often required. More than 70% of children admitted to a PICU report functional health problems six months post PICU admission (Jones et al., 2006). One study reported that 45% of children admitted to a PICU had pre-existing special health care needs, with 3% already being technology dependent (Dosa et al., 2001). Furthermore, in the remaining previously healthy children, it is likely that many will have special health care needs and/or be technology dependent following discharge. The impact on siblings and marital relationships is thought to be substantial and detrimental, with family reactions including anguish, helplessness, and aggravation (Latour et al., 2011). When families are faced with the management of a chronic illness, they are confronted with the likelihood of making major changes to their usual routine to accommodate the illness demands, paired with an uncertain future (Knafl & Gilliss, 2002). Uncertainty is a common experience of chronic illness, due to inconsistent symptom onset, the potential for recurrence or exacerbation and an unknown future (Mishel, 1999). Intolerance of uncertainty has been associated with lower levels of psychological wellbeing (Gecgin & Sahranc, 2017), often causing feelings of stress, avoidance, and resistance (George & Lowe, 2019). In summary, diagnosis of a chronic illness is a significant source of

distress for families, supporting the need to explore prevalence and factors that may contribute to such distress. Unfortunately, research exploring psychological distress in parents following their child's admission to a PICU is limited.

Empirical paper

"I know a PICU is usually quite sterile but human feelings are not sterile and they really do count" (Mother; Latour et al., 2011, p. 320).

Parents of children admitted to a PICU are typically either responding to the crisis of their child's sudden illness or the gravity of a planned major surgery, with an interruption of normal familial activities and a shift in parental responsibilities (Seideman et al., 1997). These parents often experience high levels of psychological distress (Stremler et al., 2017).

There is abundant research to suggest that parental distress is associated with adverse family outcomes, including worsened mental health in children (Amrock & Weitzman, 2014) and poorer long-term adjustment to the child's illness (Rabineau et al., 2008). This supports the need to understand the prevalence of psychological distress in these parents. Knowledge of a high prevalence of distress in this population would support the need to screen for distress and offer psychological intervention, to reduce parental strain.

The empirical paper reported in this thesis portfolio describes data from parents of children admitted to a PICU. The findings discussed in the empirical paper illustrate factors contributing to psychological distress in parents up to two years after their child's PICU admission, including parental appraisals and behaviours. Implications for clinical practice are presented, including potential interventions that could be offered according to NICE guidance. Limitations of the empirical paper are discussed, and suggestions for future research directions are given.

CHAPTER FOUR

Empirical paper

This paper has been written for publication to the Journal of Pediatric Psychology. Please see Appendix F for the journal's guidance to authors.

Psychological outcomes and quality of life in parents of children admitted to a PICU and ventilated.

Authors:

Hayley Ryan[a*], Fransesca Woolgar[b], Lucy Wilcoxon[c], Nazima Pathan[d], Gillian Colville[c] Esther Daubney[d], Deborah White[e], and Richard Meiser-Stedman[a]

[*a]Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, Norfolk, NR4 7TJ, England, United Kingdom

[B]To be confirmed

[C]To be confirmed

[d]Department of Paediatrics, Addenbrookes Hospital, Hills Road, Cambridge, CB2 0QQ, England, United Kingdom

[e]Department of Paediatric Psychology, St George's Hospital, Blackshaw Rd, London SW17 0QT

*Corresponding Hayley Ryan, [a]Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, Norfolk, NR4 7TJ, England, United Kingdom. h.ryan@uea.ac.uk.

Word count 4964/5000 (excluding title page, abstract, figures/tables, and references)

Abstract

Purpose: This study aims to explore parental psychological outcomes following a paediatric intensive care unit (PICU) admission. Due to advances in medical and surgical care, there has been a substantial reduction in patient mortality. Simultaneously, the number of survivors from PICUs living with long-term disability is increasing, with major emotional implications. However, literature on prevalence rates of psychological distress and quality of life in parents following their child's PICU admission is limited. Furthermore, little is known about quality of life and correlates of poor psychological outcomes in this population.

Design and Methods: A total of 74 parents, of 58 children who were admitted to a PICU, completed outcome measures assessing anxiety, depression, quality of life and parenting cognitions and behaviours.

Results: 31.1% of parents met the cut-off for both anxiety and depression, and 57.5% met the cut-off for low quality of life. Maladaptive parental appraisals and overprotectiveness, but not child illness severity, were significantly associated with increased scores on the GAD-7 and PHQ-9.

Conclusion: This study suggests that psychological distress and low quality of life is common in parents of children admitted to a PICU. Parental appraisals of the event also play a role in psychological distress. The importance of early screening in this population is discussed. Identification of distress can enable a preventative approach to reduce long-term difficulties in parents and the wider family.

Introduction:

The number of paediatric intensive care unit (PICU) admissions has increased exponentially over the past 20 years (Davis et al., 2018), with a recent recognition of the impact on parents (Colville & Gracey, 2006). Adverse psychological reactions are being increasingly recognised in a significant proportion of both adults and children (Colville et al., 2008). In response to a PICU admission, parents report experiencing fatigue, low energy, malaise, headache, irritability, and interrupted sleep and meal patterns (Abela et al., 2020). The number of parents with a new mental health diagnosis in the six months following their child's PICU discharge has nearly doubled in recent years (Logan et al., 2020). Literature exploring psychological outcomes in critically ill hospitalised children has indicated that 24% of parents meet the threshold for severe anxiety, and 51% for major depression (Stremler et al., 2017). High levels of distress in parents can persist for months following hospital discharge (Board & Ryan-Wenger, 2002; Colville et al., 2009; Rees et al., 2004), with the potential for significant familial disruption (O'Meara et al., 2022). The UK government have published guidelines highlighting the need for more research into the experiences of patients and carers impacted by a critical care admission (Department of Health, 2000).

Having a child admitted to the PICU is an extremely difficult event, with parents experiencing fear, vulnerability, and helplessness (Terp & Sjöström-Strand, 2017). Potential stressors unique to the PICU may include a fast-paced environment, the presence of technologically advanced equipment, noises from monitors and alarms and the prospect of rapid and negative changes in the child's medical state (Mortensen et al., 2015). In the PICU environment, parents are separated from their child and forced to entrust strangers with their care, which can fracture the previously defined parenting role (Heuer, 1993). Indeed, seminal

studies have shown that it is the impact on the parental role that causes parents the most distress (Carter & Miles, 1989; Miles & Mathes, 1991). In these challenging circumstances, proximity and access to regular information have been identified as primary needs for parents, reducing parental stress related to their child's hospitalisation (Smith et al., 2007; Linton et al., 2008).

It is important to consider potential factors associated with psychological distress in parents following a PICU admission. For example, the way in which a traumatic event is appraised and interpreted by the individual may help to explain the development and maintenance of psychological distress. Maladaptive appraisals include permanent change or damage to the child, preoccupation with the child's vulnerability, and parental self-blame (Williamson et al., 2018). Pre-event elevated levels of depression paired with a ruminative style has been associated with higher prevalence of post-event depression (Nolen-Hoeksema & Morrow, 1991). Rumination has been compared to other avoidant behaviours, for example social withdrawal, as it functions to avoid active engagement with the environment and problem-solving (Moulds et al., 2007). Thus, behavioural and cognitive avoidance are considered potential problematic responses to a traumatic event (Williamson et al., 2018). Avoidant coping strategies may reduce distress in the short term but contribute to the maintenance of anxiety in the long term (Moulds et al., 2007). However, the literature on the potential factors associated with psychological distress in parents following a PICU admission is scarce. Understanding the psychological factors that may be involved in driving poor mental health post-trauma is necessary and could allow for a preventative approach by identifying families with maladaptive appraisals and coping behaviours and providing them with targeted support.

Significant associations between parent and child distress scores following admission to a PICU highlight the importance of considering both the parent and child's experiences (Rees et

al., 2004; Morris et al., 2012). Family functioning is an important predictor of outcomes for children following trauma (Hiller et al., 2016; Testa et al., 2006), with parenting style having a small but significant impact on a child's mental health (Williamson et al., 2017; Williamson et al., 2018). It is recognised that parenting styles may be trauma specific, influenced by the parents' own appraisals and maladaptive interpretations of the event (Williamson et al., 2018). The literature has shown that parental avoidance and overprotection are associated with poor child psychological adjustment (Bokszczanin, 2008; Ehlers et al., 2003; Henry et al., 2004), as these result in the child perceiving themselves as vulnerable or damaged by the event (Meiser-Stedman et al., 2009). This further supports the need to look at how parents respond following their child's PICU admission and the factors that drive psychological distress.

Diagnoses of a formal mental health disorder is not the only indicator of distress. In 1946, the World Health Organisation (WHO) defined health as not only the absence of disease or infirmity, but the presence of physical, mental and social wellbeing (International Health Conference, 1946). Since this time, quality of life (QOL) measures are increasingly being used as assessment measures in clinical research (Testa & Simonson, 1996). Key QOL domains include interpersonal relations, social inclusion, personal development, physical wellbeing, self-determination, material well-being, emotional well-being, and rights (Schalock, 2004). Previous studies examining health related QOL are limited to small sample sizes and specific diagnoses, impacting their generalisability (Hordijk et al., 2020). Moreover, the literature largely focuses on parent-reported child QOL, which can be subjective and must be interpreted with caution. Further exploration of QOL in parents following a PICU admission would allow for a richer insight into its impact.

Not all parents will develop mental health difficulties or experience significant distress post-discharge. In fact, some may experience post-traumatic growth, including improved relationships with family and friends, new perspectives on what is important in life and greater recognition of their ability to cope in difficult circumstances (Colville et al., 2009). Therefore, developing an understanding of the factors associated with adverse reactions is of upmost importance. The literature has identified a range of factors that could contribute to an individual having poorer psychological outcomes following a hospital admission. For example, gender, course of illness, illness severity and duration of sedation have been associated with poorer psychological outcomes in ICU survivors (Faessler et al., 2016; Mahmood et al., 2012; Wade et al., 2012). However, these are scarcely studied within the PICU.

Knowledge around the prevalence of psychological distress and the factors associated with poor psychological outcomes would enable early identification of vulnerable individuals and prevention of long-term distress and inform the development of tailored intervention packages. The National Institute of Health and Care Excellence (NICE) guidelines advise that clinicians stay alert to possible depressive and anxiety symptoms, offering guidance on the identification, assessment, monitoring and treatment of these conditions (NICE, 2011). The World Health Organisation (WHO) recognise that even once a mental health disorder has developed, it is still possible to reduce its severity, course and duration by taking preventative measures throughout the course of the disorder (WHO, 2002). In addition to considering potential interventions for these parents, it is also important to consider approaches that could prevent or minimise psychological distress. These may include anticipatory guidance during and after PICU treatment, protocols to inform and prepare parents for a PICU discharge and follow-up clinics (Bronner et al., 2008). In a survey, two thirds of parents reported that they would have

valued a follow-up appointment to discuss their child's admission (Colville, Cream, & Gracey, 2003), supporting the importance of follow-up appointments for parents following their child's PICU admission.

In summary, the PICU has been recognised as a particularly stressful environment when compared to general wards. Despite this understanding, research exploring psychological distress in parents following a PICU admission is limited. This study hopes to fill these gaps and pave the way for future research in this area. It is hoped that the results of this study will identify risk factors to enable the identification of vulnerable families and the implementation of early intervention and preventative measures to reduce long-term distress.

Research Questions

1. What is the prevalence of clinically significant anxiety, depression and low quality of life in parents following their child's admission to a PICU?
2. Which demographic, illness severity and psychological factors are associated with poor parental outcomes following a PICU admission?

Materials and Method:

Design.

This cross-sectional study focused on the psychological adjustment of parents following their child's admission to a PICU. This study investigates the psychological responses of parents up to two years post admission. The term parent is used to represent the child's primary caregiver.

Participants.

Parents were included if they met the following criteria: they were the primary caregiver for a child aged 0-16 years; the child was admitted to a PICU within the last two years; reasons for admission were either an acute trauma (e.g., motor vehicle collision) or medical emergency (e.g.,

acute respiratory illness, meningitis); and the child was ventilated for a minimum of 48 hours (to enable investigation of illness severity and to exclude less severe cases, for example children who were admitted to PICU for monitoring following a planned or elective operation).

Parents were excluded if their child passed away during admission, there were safeguarding concerns, or they were not fluent in the English language.

Procedure.

Initially, recruitment was aimed at parents of children who had been admitted to the PICU at Addenbrookes Hospital, Cambridge University Hospitals NHS Foundation Trust, where their admission was due to an acute trauma (e.g., a motor vehicle collision) or medical emergency (e.g., acute respiratory illness, meningitis). Research nurses at Addenbrooke's Hospital approached eligible families whilst their children were admitted to the PICU and provided them with information sheets about the study. Participants were asked to complete a questionnaire survey relating to their mental health 3 months post-admission, to which 53 participants responded and completed the measures. A further 6 participants, who had not completed the measures at 3 months, completed the measures 12 months post-admission. This method of recruitment yielded a total of 59 participants.

Given concerns over recruitment rate at this site, further recruitment was conducted via social media. The same inclusion and exclusion criteria were applied. For the social media sample, advertisements were posted on relevant social media websites and networking groups with information about the research study. For this social media sample, information regarding time since the child's PICU admission was not collected and was therefore unknown. This method of recruitment yielded 15 additional participants, bringing the total number of participants to 74.

Measures.

Demographic information

The following demographic information was collected in the hospital-recruited and social media samples: parent gender; child gender; age of child (date of birth); date of admission (month and year): length of admission (hours and days); and length of ventilation in the PICU (days). Further information on parent age and ethnicity was available in the hospital-recruited sample.

Generalised anxiety disorder (GAD-7; Spitzer et al., 2006; see Appendix G)

The GAD-7 is a brief 7-item self-report screening tool and severity measure for GAD. It asks, 'over the last two weeks, how often have you been bothered by any of the following problems?' Respondents are then asked to select responses ranging from 0 ("not at all" to 3 "nearly every day"). The GAD-7 has been validated as an efficient tool for screening for GAD and assessing its severity in clinical practice and research (Spitzer et al., 2006). Scores of 10 or greater were used as the cut-off for anxiety in the current study (Spitzer et al., 2006).

Patient health questionnaire (PHQ-9; Kroenke & Spitzer, 2002; see Appendix H)

The PHQ-9 is a brief 9-item self-report measure of depression. It asks, 'over the last two weeks, how often have you been bothered by any of the following problems?' Respondents are then asked to select responses ranging from 0 ("not at all") to 3 ("nearly every day"). The PHQ-9 has good construct and criterion validity, making it a useful tool to screen for and assess the severity of depression (Kroenke & Spitzer, 2002). Scores of 10 or greater were used as the cut-off for depression in the current study (Kroenke & Spitzer, 2002).

Quality of life scale (QOLS; Burckhardt & Anderson, 2003; see Appendix I)

The QOLS consists of 16 items, measuring five domains of QOL: material and physical wellbeing; relationships with others; social, community and civic activities; personal development and fulfilment; recreation; and independence. The QOLS has been validated for measuring QOL across patient groups and cultures (Burckhardt & Anderson, 2003). Scores on the QOLS range from 16 to 112, with the average total for healthy populations standing at 90.

Parent trauma response questionnaire (PTRQ; Williamson et al., 2018; see Appendix J)

The PTRQ is a 30-item self-report assessment of parenting cognitions and coping following child trauma. Items were adapted to reflect the distinct experiences of parents of children in a PICU. The Appraisals Subscale assesses the parent's cognitions regarding permanent damage to the child or family, rumination about the child's vulnerability and parental self-blame. The Behaviours Subscale assesses the parent's cognitions regarding behavioural avoidance, cognitive avoidance and overprotection. Respondents are asked to indicate how much they agree with a series of statements, ranging from 'don't agree at all' to 'agree completely.' The PTRQ is considered a valid and reliable assessment of parenting cognitions and coping following child trauma (Williamson et al., 2018).

Ethical considerations

This project was granted ethical approval from the East of England – Cambridge South Research Ethics Committee (reference 18/EE/0035; IRAS ID 230001; Appendix N). All participants provided informed consent and were reminded of their right to withdraw from the study at any point (Appendix L).

Data analyses

The data were analysed using the Statistical Package for Social Sciences (SPSS; version 25) and screened for errors and missing values. Descriptive statistics were used to summarise sample characteristics. Histograms and P-Plots were used to assess for normality of distributions. Analysis of skewness and kurtosis statistics revealed that the data did not follow a normal distribution. Therefore, non-parametric tests were used.

Distribution of scores on the GAD-7, PHQ-9 and QOLS were all left-skewed, with a platykurtic distribution. Therefore, non-parametric tests were used in the analysis.

For research question one, chi-square tests were used to determine group differences on the GAD-7, PHQ-9 and QOLS. The total percentage of parents who met the cut-off was calculated for the GAD-7 and PHQ-9, which was defined as a score of 10 or above (Kroenke & Spitzer, 2002; Spitzer et al., 2006). The percentage of parents who met the cut-off for low QOL on the QOLS was also determined, by calculating one standard deviation lower than a score of 90 for QOL in normal populations, thus approximating the mean given for groups with chronic health conditions (Burckhardt & Anderson, 2003). The cut-off for low QOL was defined as scores below 85. For research question two, a Spearman's correlational analysis was used to examine associations between scores on the GAD-7, PHQ-9 and QOLS and illness severity and scores on the PTRQ appraisal and behaviour subscales.

Results

Sample characteristics

Parent demographics

Data from 74 parents were included in the current study, with 59 parents recruited from Addenbrookes Hospital and 15 via social media. 64.9% of participants were mothers and 35.1%

were fathers. Limited demographic information was available for the social media sample (n=15). Parent age and ethnicity was only available for the hospital-recruited sample (n=59). For these parents, age brackets were as follows: 25-29 (n=8, 13.6%); 30-34 (n=21, 35.6%); 35-39 (n=16, 27.1%); 40-44 (n=7, 11.9%); 45-49 (n=6, 10.2%); 50+ (n=1, 1.7%). The majority of parents were white British (88.1%).

Child demographics

The 74 parents recruited to the study provided care to 58 children. In some cases, both parents of one child completed the questionnaires, as they identified as joint primary caregivers, resulting in a higher number of parents than children. Their age ranged from 0 to 14 years and 8 months (177 months), with a mean age of 39.9 months (SD=56.1). 50% of the children were male (mean age= 27.9 months). The mean age of the females was 51.9 months. For 16 children, both parents participated in the study. For these children, two data points were available for each scale (one from each parent), so their information is repeated in further sample analyses.

The average length of ventilation was 134.6 hours (SD=89.3) with a range of 12 to 424 hours. Length of admission ranged from 3 to 116 days, with a mean length of admission of 10.5 days (SD=18.3).

In the hospital-recruited sample, parents completed questionnaires either 3 months or 12 months following their children admission to a PICU. In the social media-recruited sample, parents completed questionnaires up to two years following their child's admission, although the exact time since admission in the social media-recruited sample was unknown.

Further information on the reason for admission to the PICU was available for the hospital-recruited sample. Reasons included respiratory infections, neurological, surgical, oncology, sepsis and trauma.

Internal consistency

Internal consistency was measured for the GAD-7, PHQ-9, QOLS and the six individual sub-scales of the PTRQ, using Cronbach's Alpha (see Appendix K). The internal consistency for the majority of measures and sub-scales was found to be greater than .8, indicating a good level of reliability across the board (Field, 2009). **Comparison of the two recruitment pathways**

An independent t-test revealed no significant differences between length of ventilation, $t(69) = -.02$, $p = .985$, or length of stay, $t(72) = .54$, $p = .593$, between the hospital-recruited and social media-recruited samples.

An independent t-test revealed no significant differences between the source of recruitment (hospital vs. social media) and scores on the GAD-7, $t(72) = -1.31$, $p = .193$, PHQ-9, $t(71) = .22$, $p = .829$, and QOLS, $t(71) = .42$, $p = .677$. Due to the lack of differences between the two samples, it was considered appropriate to merge the two samples for the main analyses.

Further analyses were conducted to explore any differences in scores on the measures and time since trauma. An independent t-test revealed no significant differences between measures completed at 3 months and 12 months post-admission in the hospital recruited sample. Furthermore, an independent t-test revealed no significant differences between measures completed at 3 months in the hospital recruited sample and the social media-recruited sample. In the following sections, results are reported for each primary research question.

Question 1: What is the prevalence of clinically significant parental anxiety and depression, and low quality of life following their child's admission to a PICU?

Scores on all measures for mothers, fathers and the total sample can be seen in Table 2.

Anxiety.

Seventy-four parents completed the GAD-7 (M = 7.56, SD = 5.55). In total, 23 of 74 (31.1%) parents met the cut-off for anxiety. A chi-square test of independence was performed to examine the relationship between parent sex and meeting the cut-off on the GAD-7. This test showed that there was no significant association between these variables, X^2 (1, N = 74) = 2.63, p = .11.

Depression.

Due to missing data, only seventy-three parents completed the PHQ-9 (M = 7.15, SD = 5.65). In total, 23 of 73 (31.1%) parents met the cut-off for depression. A chi-square test of independence was performed to examine the relation between parent sex and meeting the cut-off on the PHQ-9. This test showed that there was no significant association between these variables, X^2 (1, N = 73) = .28, p = .64.

Quality of life.

Due to missing data, only seventy-three parents completed the QOLS (M = 78.02, SD = 16.69). In total, 42 of 73 (57.5%) met the cut-off for low QOL. A chi-square test of independence was performed to examine the relation between parent sex and meeting the cut-off for low QOL on the QOLS. This test showed that there was no significant association between these variables, X^2 (1, N = 73) = .477, p = .49.

A Spearman's correlational analysis revealed large negative correlations, indicating a significant relationship, between QOL score and meeting the cut-off for both anxiety, r_s = -.51, p = <0.01 and depression, r_s = -.49, p = <0.01. Figure 1 presents the overlap between clinically significant anxiety, depression and low QOL. Almost all parents meeting the cut-off for anxiety or depression also endorsed lower quality of life. Of all parents endorsing a lower quality of life, 59.5% (25 of 42) also endorsed anxiety or depression.

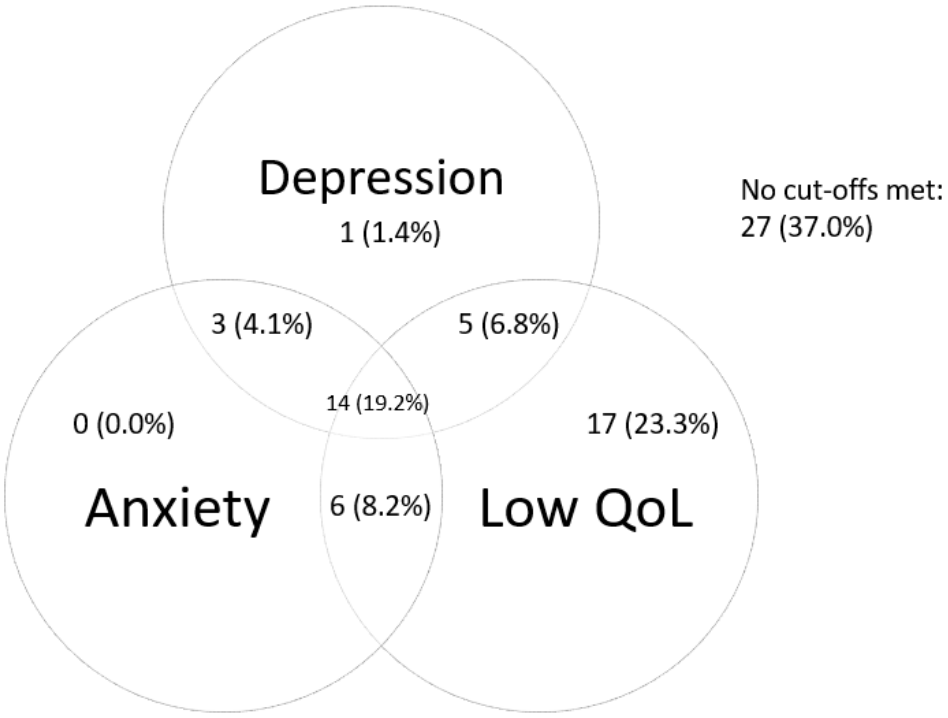


Figure 1
Venn diagram showing the relationship between anxiety, depression and quality of life.

Table 1
Proportion of parents meeting cut-off on the outcome measures

	Total sample *n=74**	Mothers *n=48*	Fathers *n=26*
Anxiety (GAD-7) Cut-off, n (%)	23 (31.1)	18 (37.5)	5 (19.2)
Depression (PHQ-9) Cut off, n (%)	23 (31.1)	16 (33.3)	7 (26.9)
Quality of life (QOLS) Cut-off, n (%)	42 (57.5)	29 (60.4)	13 (50)

*Due to missing data, only 73 participants completed the PHQ-9 and QOLS.

Question 2: Which demographic, illness severity and psychological factors are associated with poor parental outcomes following a PICU admission?

The correlation matrix for relationships between variables is presented in Table 2. A Spearman's correlational analysis revealed no significant relationship between our three outcome measures and parent sex, child sex, length of ventilation or length of stay. This suggests that illness severity was not related to psychological outcomes in these parents.

Significant associations were found between scores on the GAD-7 and PHQ-9 and all parent appraisals (permanent damage, rumination and parent self-blame). Endorsement of permanent damage and rumination appraisal were also associated with poorer quality of life. No significant associations were found between all three outcome measures and parent behavioural and cognitive avoidance. The behaviour 'overprotection' was found to be significantly associated with scores on the GAD-7 and PHQ-9, but not scores on the QOLS.

Table 2
Spearman's correlational matrices for continuous independent variables

	Anxiety *(GAD-7)*	Depression *(PHQ-9)*	Quality of life *(QOLS)*
Parent demographics			
Sex (Female = 1, Male= 2)	-.23	-.10	.10
Child demographics			
Sex (Female= 1, Male= 2)	.12	.07	-.03
Child illness severity			
Length of ventilation	-.02	-.02	.04
Length of stay	-.12	-.14	.18
Parent appraisals			
Permanent damage	.51**	.56**	-.41**
Rumination	.62**	.57**	-.34**
Parent self-blame	.39**	.35**	-.16
Parent behaviours			
Behavioural avoidance	.14	.17	-.10
Cognitive avoidance	.14	.06	.03
Overprotection	.34**	.27*	-.10

** p<.001
*** p<.0001

Discussion

This study investigated the psychological impact on parents of having a child admitted to a PICU. Overall, a high proportion of parents developed clinical levels of anxiety and depression (31.1%) following their child's admission to a PICU. This is compared to approximately 5% scoring 10 or above on the GAD-7 (Lowe et al., 2008) and 6.5% scoring 10 or above on the PHQ-9 (Shin et al., 2020) in normative samples. No participant had clinical levels of anxiety without depression. Only one participant had clinical levels of depression without the presence of anxiety. Sixteen participants (19.2%) met the cut-off for anxiety and depression and low quality

of life. In total, over half of parents met the cut-off for low QOL (57.5%). Significant negative correlations were found between scores on the QOLS and meeting the cut-off for both anxiety and depression, i.e., worsening anxiety and depression were strongly associated with poorer QOL. However, this association does not prove causation. The average score on the QOL in the current sample was approximately 78, which is lower than the national average of 90 and comparable to the average scores of adults with severe chronic health conditions (e.g. an average score of 70 in patients with fibromyalgia, 82 in patients with psoriasis and 83 in those with rheumatoid arthritis; Burckhardt & Anderson, 2003).

The findings of this study suggest that parents with a child admitted to a PICU are vulnerable to adverse psychological reactions, and that such reactions are unrelated to illness severity. This is supported by a recent systematic review reporting no clear relationship between severity of illness and length of hospitalisation with parent and family outcomes (Yagiela et al., 2019). Parents with children admitted to a PICU for several days appear just as likely to develop depression, anxiety and experience low QOL, as those with children admitted for several weeks or months. This is an important finding. Historically, PICU staff may have assumed that those parents with children admitted to a PICU for longer periods would need the most support. However, these findings highlight that the majority of parents will need psychological support regardless of the length of their child's admission.

Psychological factors appear to be closely involved with poor parent mental health. Specifically, parents with maladaptive appraisals and who endorse overprotective behaviours are more vulnerable to adverse psychological reactions. These findings are supported by previous research (Bokszczanin, 2008; Ehlers et al., 2003; Henry et al., 2004). Parental overprotectiveness has been interpreted as a reaction to the threat of further illness (Bokszczanin, 2008), which in

this context could refer to the threat of further illness and hospital admissions. It has been characterised as a tendency for infantilisation, excessive physical and social contact with the child, extreme fear associated with fulfilling parental functions, unwarranted control, intrusiveness and frequently impeding the child's independence (Holmbeck et al., 2002). Parents may feel overprotective of their child due to a sense of losing control and feeling helpless whilst their child was admitted to the PICU (Terp & Sjöström-Strand (2017). Overprotective behaviours are also associated with poorer psychological adjustment in children (Bokszczanin, 2008; Ehlers et al., 2003; Henry et al., 2004; Meiser-Stedman et al., 2009), further highlighting the importance of understanding more about this behaviour and how it can be prevented. This also promotes the need for proximity and access to regular information from hospital staff, to reduce parental stress, loss of control and helplessness, and perhaps reduce the potential for the development of overprotective behaviours (Smith et al., 2007; Linton et al., 2008).

The current study did not find an association between behavioural and cognitive avoidance and psychological distress. Literature exploring the role of avoidance coping has yielded mixed findings. One study highlighted an association between higher avoidance coping and posttraumatic growth (London et al., 2017), perhaps explaining the lack of association with psychological distress within this study. However, on the contrary, another study found that lower avoidance coping was associated with higher growth (Brooks et al., 2019). Interestingly, avoidance coping has also been considered maladaptive in the long term (Hagenaars et al., 2011), which perhaps was not captured in the current study as parents were largely recruited three months post-admission. This supports the need for research exploring the longer-term impact of PICU admission on parents. Although the behavioural and cognitive avoidance subscales have good internal consistency, they consist of only three items each, potentially

impacting their validity. Further research could use additional measures, paired with clinical interview, to explore the association between avoidance and psychological distress.

Implications for clinical practice

The findings of this study highlight the importance of screening for anxiety and depression in parents within the PICU setting, as prevalence of anxiety and depression in parents of children admitted to a PICU is high. NICE guidelines advise a stepped-care approach, where the least intrusive, most effective intervention is offered first (NICE, 2011). Paediatric nurses could also look out for certain appraisals and behaviours that may suggest parents are more vulnerable to adverse psychological reactions, for example expression of fear of permanent damage to the child and family, rumination, self-blame and/or overprotective tendencies. Early screening and intervention can enable a preventative approach, reducing long-term distress (O'Donnell et al., 2012). As literature has shown an association between parent and child distress (Rees et al., 2004; Morris et al., 2012), this could also alleviate long-term distress in children.

Cognitive Behavioural Therapy (CBT) is widely recognised as an effective intervention for the treatment of anxiety and depression (Gautam et al., 2020). CBT and mindfulness interventions could alleviate rumination and worry in parents of children with chronic diseases (Querstret & Cropley, 2013). Psychoeducation could also work to reduce uncertainty in these parents, improving their adaptation and QOL, whilst indirectly improving the child's health and wellbeing (Rodrigues et al., 2022). Educational interventions are also low-cost (Phadnis & Kar, 2017). Group interventions may also be effective by enabling parents to share worries, enhance problem resolution and develop group identity (Rodrigues et al., 2022). Moreover, attending a group may also provide respite and reduce isolation for parents who spend the majority of their time caring for their child (Lopez-Larrosa, 2013). Furthermore, psychoeducation can increase

hope in parents, as they begin to understand and cope with a diagnosis and its implications (Conway et al., 2017). QOL was found to be significantly related to clinically significant anxiety and depression in the current study, underscoring the importance of taking parent mental health seriously. Therefore, it is possible that interventions for anxiety and depression could improve QOL in these parents. Literature has shown that adverse parental psychological reactions can negatively impact the child and management of their condition, increasing the risk of further hospital admissions (Garrison et al., 2005; Stewart et al., 2005). The management of psychological distress in parents is therefore of significant importance and could serve to reduce further cost to health services.

The time at which to both screen for distress and deliver psychological intervention to these parents requires some consideration. Psychological distress experienced by parents shortly after their child's admission to a PICU may be a normal reaction to a difficult event. In many cases, these difficulties are short-lived and diminish over time, without the need for psychological intervention (Giummarra et al., 2018). By intervening too soon, clinicians may run the risk of pathologising a normal reaction and adjustment process following a difficult event. However, this is not to say that support should not be offered at this stage. In the PTSD literature, it is identified that immediate support and practical help, together with follow-up to identify those with persistent difficulties who may benefit from more in-depth psychological intervention, is likely to be the most appropriate course of action following a difficult event (Mayou et al., 2000). Research clarifying those requiring intervention in the aftermath of trauma versus who will recover spontaneously could further enhance research on early intervention (Kearns et al., 2012).

The current study supports the need for well-funded psychological services within the PICU setting, for example the employment of a psychology workforce, including Clinical and Assistant Psychologists, and the newly established Clinical Associate Psychologist (CAP) role, to offer psychological interventions with an aim to reduce psychological distress. Additionally, the psychology team could provide training for PICU nursing staff, to enable them to deliver low-intensity psychological interventions, for example psychoeducation.

Limitations and future research directions

The current study used a cross-sectional design, which comes with several limitations. For example, potential non-response bias, as those who consented to take part may differ from those who did not (Sedgwik, 2014). Furthermore, only an association, rather than causation, can be inferred from a cross-sectional study. For example, it is unknown whether having anxiety, depression, or low QOL preceded having a child admitted to a PICU. It can only be inferred that these were associated with certain appraisals and behaviours that may have developed following the PICU admission. Future research could look at the longer-term impact of having a child admitted to a PICU, by asking parents to complete measures at various time points following admission. This would also enable the exploration of factors that contribute to long term psychological distress in these parents.

Several demographic variables were not collected in the current study. The participants in the current study completed the measures after some time had passed following their child's admission to a PICU, however the exact time since trauma was unknown in the social media-recruited sample and must be considered as a potential confounding variable. Time since trauma would be useful to establish, to explore outcomes at these various time points post-admission. Moreover, the health outcomes of the children were unknown, only that the child had survived

their PICU admission. Future research could collect this information to understand how the severity of the child's illness in the longer term is related to psychological distress. Despite this limitation, this research highlights that parents of children admitted to a PICU are a vulnerable group that clinicians need to closely monitor. Furthermore, future research could also recruit parents of children who were admitted to a PICU but did not require ventilation, to explore any differences in psychological distress between the two groups.

The current study intended to collect data on PTSD in parents following their child's admission to a PICU. However, due to an IT issue, the measure of PTSD was not properly administered. Future research could explore the prevalence of clinically significant PTSD in these parents, along with an exploration of the association between PTSD and the demographic, illness severity and psychological factors explored in this study.

Data used in the current study were from two separate recruitment streams. Recruitment of parents in the PICU setting for research is notoriously difficult, due to it being an extremely stressful time. One benefit of using a second recruitment stream from social media is that the sample size was increased, however, it is important to consider differences between the two groups when looking at the study findings. For example, the hospital-recruited sample largely completed the measures 3 months post-admission, whereas the social media sample completed the measures up to two years post-admission.

Further limitations include the use of self-report measures with a risk of response bias (Sigmon et al., 2005), and a predominantly White British sample, limiting generalisability of the study findings to the wider population.

Conclusion

The current study found a large proportion of parents whose children were admitted to a PICU met the clinical cut-off for anxiety and depression and low QOL. Certain appraisals and behaviours are associated with increased psychological distress, specifically fear of permanent damage to the child and family, rumination, self-blame and/or overprotective behaviours. Further research is needed to explore the longer-term impact of having a child admitted to a PICU. These findings indicate a need to screen for, identify and treat psychological distress in parents early on. Having a child admitted to a PICU is an extremely challenging experience for parents. Reducing psychological suffering in this population is of paramount importance for the parent and wider family.

Declaration of interest: None

Funding: This research was supported by the University of East Anglia and was written as part of a doctoral thesis for the Doctoral Programme in Clinical Psychology.

References

Abela, K. M., Wardell, D., Rozmus, C., & LoBiondo-Wood, G. (2020). Impact of pediatric critical illness and injury on families: an updated systematic review. *Journal of pediatric nursing, 51*, 21-31.

Board, R., & Ryan-Wenger, N. (2002). Long-term effects of pediatric intensive care unit hospitalization on families with young children. *Heart & Lung*, *31*(1), 53-66.

Bokszczanin, A. (2008). Parental support, family conflict, and overprotectiveness: Predicting PTSD symptom levels of adolescents 28 months after a natural disaster. *Anxiety, Stress, & Coping*, *21*(4), 325-335.

Bronner, M. B., Knoester, H., Bos, A. P., Last, B. F., & Grootenhuis, M. A. (2008). Follow-up after paediatric intensive care treatment: parental posttraumatic stress. *Acta paediatrica, 97*(2), 181-186.

Brooks, M., Graham-Kevan, N., Robinson, S., & Lowe, M. (2019). Trauma characteristics and posttraumatic growth: The mediating role of avoidance coping, intrusive thoughts, and social support. *Psychological Trauma: Theory, Research, Practice, and Policy, 11*(2), 232.

Burckhardt, C. S., & Anderson, K. L. (2003). The Quality of Life Scale (QOLS): reliability, validity, and utilization. *Health and quality of life outcomes, 1*(1), 1-7.

Carter, M., & Miles, M. (1989). The parental stressor scale: pediatric intensive care unit. *Maternal-child nursing journal, 18*(3), 187-198.

Colville, G. A., Cream, P., & Gracey, D. (2003). Parents' views on follow up after paediatric intensive care. *British Journal of Anaesthesia, 90*(4), 548.

Colville, G., Kerry, S., & Pierce, C. (2008). Children's factual and delusional memories of intensive care. *American Journal of Respiratory and Critical Care Medicine, 177*(9), 976-982.

Colville, G., Darkins, J., Hesketh, J., Bennett, V., Alcock, J., & Noyes, J. (2009). The impact on parents of a child's admission to intensive care: integration of qualitative findings from a cross-sectional study. *Intensive and Critical Care Nursing, 25*(2), 72-79.

Conway, M. F., Pantaleao, A., & Popp, J. M. (2017). Parents' experience of hope when their child has cancer: Perceived meaning and the influence of health care professionals. *Journal of Pediatric Oncology Nursing, 34*(6), 427-434.

Davis, P., Stutchfield, C., Evans, T. A., & Draper, E. (2018). Increasing admissions to paediatric intensive care units in England and Wales: more than just rising a birth rate. *Archives of disease in childhood, 103*(4), 341-345.

Department of Health. (2000). Comprehensive critical care: a review of adult critical care services. The Stationary Office.

Ehlers, A., Mayou, R. A., & Bryant, B. (2003). Cognitive predictors of posttraumatic stress disorder in children: Results of a prospective longitudinal study. *Behaviour research and Therapy, 41*(1), 1-10.

Faessler, L., Kutz, A., Haubitz, S., Mueller, B., Perrig-Chiello, P., & Schuetz, P. (2016). Psychological distress in medical patients 30 days following an emergency department admission: results from a prospective, observational study. *BMC emergency medicine, 16*(1), 1-8.

Garrison, M. M., Katon, W. J., & Richardson, L. P. (2005). The impact of psychiatric comorbidities on readmissions for diabetes in youth. *Diabetes Care, 28*(9), 2150-2154.

Gautam, M., Tripathi, A., Deshmukh, D., & Gaur, M. (2020). Cognitive behavioral therapy for depression. *Indian journal of psychiatry, 62*(2), 223-229.

Giummarra, M. J., Lennox, A., Dali, G., Costa, B., & Gabbe, B. J. (2018). Early psychological interventions for posttraumatic stress, depression and anxiety after traumatic injury: A systematic review and meta-analysis. *Clinical psychology review, 62,* 11-36.

Hagenaars, M. A., Fisch, I., & van Minnen, A. (2011). The effect of trauma onset and frequency on PTSD-associated symptoms. *Journal of affective disorders, 132*(1-2), 192-199.

Henry, D. B., Tolan, P. H., & Gorman-Smith, D. (2004). Have there been lasting effects associated with the September 11, 2001, terrorist attacks among inner-city parents and children?. *Professional Psychology: Research and Practice, 35*(5), 542.

Heuer, L. (1993). Parental stressors in a pediatric intensive care unit. *Pediatric Nursing, 19*(2), 128-131.

Hiller, R. M., Halligan, S. L., Ariyanayagam, R., Dalgleish, T., Smith, P., Yule, W., ... & Meiser-Stedman, R. (2016). Predictors of posttraumatic stress symptom trajectories in parents of children exposed to motor vehicle collisions. *Journal of Pediatric Psychology, 41*(1), 108-116.

Holmbeck, G. N., Johnson, S. Z., Wills, K. E., McKernon, W., Rose, B., Erklin, S., & Kemper, T. (2002). Observed and perceived parental overprotection in relation to psychosocial adjustment in preadolescents with a physical disability: the mediational role of behavioral autonomy. *Journal of consulting and clinical psychology, 70*(1), 96-110.

Hordijk, J., Verbruggen, S., Vanhorebeek, I., Van den Berghe, G., Utens, E., Joosten, K., & Dulfer, K. (2020). Health-related quality of life of children and their parents 6 months after children's critical illness. *Quality of Life Research, 29*(1), 179-189.

Kearns, M. C., Ressler, K. J., Zatzick, D., & Rothbaum, B. O. (2012). Early interventions for PTSD: a review. *Depression and anxiety, 29*(10), 833-842.

Kroenke, K., & Spitzer, R. L. (2002). The PHQ-9: a new depression diagnostic and severity measure. *Psychiatric Annals, 32*(9), 509-515.

Linton, S., Grant, C., & Pellegrini, J. (2008). Supporting families through discharge from PICU to the ward: the development and evaluation of a discharge information brochure for families. *Intensive and Critical Care Nursing, 24*(6), 329-337.

Logan, G. E., Sahrmann, J. M., Gu, H., & Hartman, M. E. (2020). Parental Mental Health Care After Their Child's Pediatric Intensive Care Hospitalization. *Pediatric Critical Care Medicine, 21*(11), 941-948.

London, M. J., Mercer, M. C., & Lilly, M. M. (2017). Considering the impact of early trauma on coping and pathology to predict posttraumatic growth among 9-1-1 Telecommunicators. *Journal of interpersonal violence, 35*(21-22), 4709-4731.

López-Larrosa, S. (2013). Quality of life, treatment adherence, and locus of control: Multiple family groups for chronic medical illnesses. *Family process, 52*(4), 685-696.

Löwe, B., Decker, O., Müller, S., Brähler, E., Schellberg, D., Herzog, W., & Herzberg, P. Y. (2008). Validation and standardization of the Generalized Anxiety Disorder Screener (GAD-7) in the general population. *Medical care,* 266-274.

Mahmood, K., Eldeirawi, K., & Wahidi, M. M. (2012). Association of gender with outcomes in critically ill patients. *Critical Care, 16*(3), 1-9

Mayou, R. A., Ehlers, A., & Hobbs, M. (2000). Psychological debriefing for road traffic accident victims: Three-year follow-up of a randomised controlled trial. *The British Journal of Psychiatry, 176*(6), 589-593.

Meiser-Stedman, R., Dalgleish, T., Glucksman, E., Yule, W., & Smith, P. (2009). Maladaptive cognitive appraisals mediate the evolution of posttraumatic stress reactions: A 6-month follow-up of child and adolescent assault and motor vehicle accident survivors. *Journal of abnormal psychology, 118*(4), 778.

Miles, M. S., & Mathes, M. (1991). Preparation of parents for the ICU experience: what are we missing?. *Children's health care, 20*(3), 132-137.

Morris, A., Gabert-Quillen, C., & Delahanty, D. (2012). The association between parent PTSD/depression symptoms and child PTSD symptoms: A meta-analysis. *Journal of pediatric psychology, 37*(10), 1076-1088.

Mortensen, J., Simonsen, B. O., Eriksen, S. B., Skovby, P., Dall, R., & Elklit, A. (2015). Family-centred care and traumatic symptoms in parents of children admitted to PICU. *Scandinavian journal of caring sciences, 29*(3), 495-500.

Moulds, M. L., Kandris, E., Starr, S., & Wong, A. C. (2007). The relationship between rumination, avoidance and depression in a non-clinical sample. *Behaviour research and therapy, 45*(2), 251-261.

National Institute for Health and Care Excellence (2011). *Common mental health problems: identification and pathways to care.* Retrieved from https://www.nice.org.uk/guidance/CG123/chapter/Recommendations#steps-2-and-3-treatment-and-referral-for-treatment

Nolen-Hoeksema, S., & Morrow, J. (1991). A prospective study of depression and posttraumatic stress symptoms after a natural disaster: the 1989 Loma Prieta Earthquake. *Journal of personality and social psychology, 61*(1), 115.

O'donnell, M. L., Lau, W., Tipping, S., Holmes, A. C., Ellen, S., Judson, R., ... & Forbes, D. (2012). Stepped early psychological intervention for posttraumatic stress disorder, other anxiety disorders, and depression following serious injury. *Journal of traumatic stress, 25*(2), 125-133.

O'Meara, A., Akande, M., Yagiela, L., Hummel, K., Whyte-Nesfield, M., Michelson, K. N., ... & Hartman, M. E. (2022). Family outcomes after the pediatric intensive care unit: a scoping review. *Journal of Intensive Care Medicine, 37*(9), 1179-1198.

Phadnis, S., & Kar, A. (2017). The impact of a haemophilia education intervention on the knowledge and health related quality of life of parents of Indian children with haemophilia. *Haemophilia, 23*(1), 82-88.

Querstret, D., & Cropley, M. (2013). Assessing treatments used to reduce rumination and/or worry: A systematic review. *Clinical psychology review, 33*(8), 996-1009.

Rees, G., Gledhill, J., Garralda, M. E., & Nadel, S. (2004). Psychiatric outcome following paediatric intensive care unit (PICU) admission: a cohort study. *Intensive care medicine, 30*(8), 1607-1614.

Rodrigues, M. G., Rodrigues, J. D., Pereira, A. T., Azevedo, L. F., Rodrigues, P. P., Areias, J. C., & Areias, M. E. (2022). Impact in the quality of life of parents of children with chronic diseases using psychoeducational interventions–A systematic review with meta-analysis. *Patient Education and Counseling, 105*(4), 869-880.

Sedgwik, P. (2014). Cross sectional studies: advantages and disadvantages. *BMJ.*

Schalock, R. L. (2004). The concept of quality of life: what we know and do not know. *Journal of intellectual disability research, 48*(3), 203-216.

Shin, C., Ko, Y. H., An, H., Yoon, H. K., & Han, C. (2020). Normative data and psychometric properties of the Patient Health Questionnaire-9 in a nationally representative Korean population. *BMC psychiatry, 20*(1), 1-10.

Sigmon, S. T., Pells, J. J., Boulard, N. E., Whitcomb-Smith, S., Edenfield, T. M., Hermann, B. A., ... & Kubik, E. (2005). Gender differences in self-reports of depression: The response bias hypothesis revisited. *Sex Roles, 53*(5), 401-411.

Smith, A. B., Hefley, G. C., & Anand, K. (2007). Parent bed spaces in the PICU: effect on parental stress. *Pediatric nursing, 33*(3), 215-221.

Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of internal medicine, 166*(10), 1092-1097.

Stewart, S. M., Rao, U., Emslie, G. J., Klein, D., & White, P. C. (2005). Depressive symptoms predict hospitalization for adolescents with type 1 diabetes mellitus. *Pediatrics, 115*(5), 1315-1319.

Stremler, R., Haddad, S., Pullenayegum, E., & Parshuram, C. (2017). Psychological outcomes in parents of critically ill hospitalized children. *Journal of Pediatric Nursing, 34,* 36-43.

Terp, K., & Sjöström-Strand, A. (2017). Parents' experiences and the effect on the family two years after their child was admitted to a PICU—An interview study. *Intensive and Critical Care Nursing, 43,* 143-148.

Testa, J. A., Malec, J. F., Moessner, A. M., & Brown, A. W. (2006). Predicting family functioning after TBI: impact of neurobehavioral factors. *The Journal of head trauma rehabilitation, 21*(3), 236-247.

Testa, M. A., & Simonson, D.C. (1996). Assessment of quality-of-life outcomes. *New England journal of medicine, 334*(13), 835-840.

Wade, D. M., Howell, D. C., Weinman, J. A., Hardy, R. J., Mythen, M. G., Brewin, C. R., ... & Raine, R. A. (2012). Investigating risk factors for psychological morbidity three months after intensive care: a prospective cohort study. *Critical care, 16*(5), 1-16.

Williamson, V., Creswell, C., Fearon, P., Hiller, R. M., Walker, J., & Halligan, S. L. (2017). The role of parenting behaviors in childhood post-traumatic stress disorder: A meta-analytic review. *Clinical psychology review, 53,* 1-13.

Williamson, V., Hiller, R. M., Meiser-Stedman, R., Creswell, C., Dalgleish, T., Fearon, P., Goodall, B., McKinnon, A., Smith, P., & Wright, I. (2018). The parent trauma response questionnaire (PTRQ): development and preliminary validation. *European journal of psychotraumatology, 9*(1), 1478583.

World Health Organization. (1946). International health conference. *New York, 19.*

World Health Organisation. (2002). Prevention and promotion in mental health. World Health Organisation. Retrieved June 18, 2021, from - https://www.who.int/mental_health/media/en/545.pdf.

Yagiela, L. M., Carlton, E. F., Meert, K. L., Odetola, F. O., & Cousino, M. K. (2019). Parent medical traumatic stress and associated family outcomes after pediatric critical illness: A systematic review. *Pediatric Critical Care Medicine, 20*(8), 759-768.

CHAPTER FIVE

Discussion and Critical Evaluation

Overview of chapter

The purpose of this final chapter is to summarise the findings from the meta-analysis and empirical paper, provide a critical evaluation of the research conducted and consider the clinical implications and future research directions. In addition, reflections on the thesis process will be presented. The chapter will end with an overall conclusion of the thesis portfolio.

Meta-analysis findings

A meta-analysis was conducted to investigate the prevalence of depression in parents of children with Type 1 Diabetes (T1D). The meta-analysis only included studies that utilised a standardised measure of depression. A total of 18 studies were included, providing a total pooled sample of 2044 parents. Random-effects meta-analyses estimated prevalence of moderate depression and above in the total sample as 18.4%, with rates of 17.3% in mothers and 9% in fathers. The estimated prevalence of mild depression and above in the total sample was 32.7%, with rates of 29.4% in mothers and 13.6% in fathers. These findings indicate high levels of psychological distress in parents of children with T1D.

Empirical paper findings

The empirical study aimed to explore the prevalence of clinically significant anxiety, depression and low quality of life (QOL) in parents of children admitted to Paediatric Intensive Care Unit (PICU). Furthermore, factors associated with poor parental outcomes following a PICU admission were explored. The Generalised Anxiety Disorder Scale (GAD-7; Spitzer et al., 2006), Patient Health Questionnaire (PHQ-9; Kroenke & Spitzer, 2002), Quality of Life Scale (QOLS; Burckhardt & Anderson, 2003) were used to screen for anxiety, depression and QOL. The Parent Trauma Response Questionnaire (PTRQ; Williamson et al., 2018) was administered

to explore whether parental appraisals and coping behaviours were associated with psychological distress in parents following their child's PICU admission.

A total of 74 parents of 58 children were recruited, 59 were recruited from Addenbrookes Hospital, Cambridge University Hospitals NHS Foundation Trust and a further 15 participants were recruited via social media. A large proportion of parents met the cut-off for anxiety (31.1%), depression (31.1%) and low QOL (57.5%). A high number of parents had clinically significant anxiety, depression and low QOL (21.9%). These findings suggest that parents of children admitted to a PICU are likely to experience psychological distress in the form of clinically significant anxiety and depression, with a negative impact on their quality of life. Demographic variables, such as parent and child sex, were not associated with scores on the GAD-7, PHQ-9 and QOLS. This was an interesting finding as it suggests that child illness severity is not related to parent outcomes, advocating that PICU staff should be alert to psychological distress in parents regardless of the severity of their child's illness.

The empirical study also evaluated the factors associated with psychological distress in parents following their child's PICU admission. The findings revealed that parents with maladaptive appraisals and overprotective behaviours were also more vulnerable to adverse psychological reactions. In contrast, the study showed no association between behavioural and cognitive avoidance and psychological distress. Various hypotheses were explored, including a potential link between higher avoidant coping and posttraumatic growth (London et al., 2017). However, it was highlighted that avoidance coping may be maladaptive in the long-term, which was perhaps not captured in the empirical study, thus indicating the need to explore the longer-term impact of a PICU admission on parents.

Critical evaluation

A high level of heterogeneity was found across studies included in the meta-analysis. Although high levels of heterogeneity are common in meta-analyses, it is important to consider this when interpreting the findings (Engels et al., 2000). Furthermore, the meta-analysis was limited to 18 studies, with a total sample of 2044 parents. Although this meta-analysis provided a pooled prevalence estimate of depression in this population, the sample size is limited and must be taken into account when interpreting the study findings.

In the empirical study, parents were only included if their child had been ventilated for a minimum of 48 hours, which enabled the researchers to consider the impact of illness severity on parental psychological outcomes. However, collecting data from parents whose children did not require ventilation would have allowed for a comparison of the two groups. This additional data could be obtained in the future to enable this investigation.

The meta-analysis and empirical paper relied on parents completing self-report measures, which carry a risk of response bias (Sigmon et al., 2005). The majority of parents who completed measures in the empirical study were recruited two months after their child's PICU admission. These parents are likely to have been experiencing acute stress and may have over-reported their distress or perception of QOL. Further, in both the meta-analysis and empirical paper, prevalence rates only reflect a single time point. However, it is likely that psychological distress fluctuates over time following diagnosis of a chronic health condition or an admission to a PICU. It is important to consider these limitations when interpreting the data.

Clinical implications

The findings from both the meta-analysis and empirical paper have important clinical implications. The meta-analysis highlighted that a significant number of parents of children with

T1D will develop depression. This is an important finding for clinicians working with children with T1D and their families. Numerous psychological interventions could be offered to parents of children with T1D. Group interventions incorporating CBT and Acceptance Commitment Therapy (ACT) strategies have proven to reduce distress in parents of children with T1D, with a focus on identifying unhelpful thoughts and feelings attributed to caring for a child with T1D, behavioural activation and mindfulness strategies (Patton et al., 2022). Patton and colleagues aimed to reduce diabetes stress, depressive symptoms and hypoglycaemia fear in parents, by incorporating diabetes management into these therapeutic groups, including 'diabetes survival' skills, information regarding sick-day care and long-term complications, and managing guilt and burnout. Group interventions may also reduce isolation in parents of children with T1D, as they meet other parents in similar circumstances to their own (Rodrigues et al., 2022). Family therapy interventions may also be effective in enhancing family dynamics, decreasing conflict and improving health outcomes in children with T1D (Feldman et al., 2018; Harris et al., 2009; McBroom & Enriquez, 2009). This could in turn may alleviate psychological distress in parents, although this is an area of research that requires further exploration as the existing research base largely focuses on the outcomes of children with T1D.

The empirical paper highlighted that a substantial number of parents whose children have recently been admitted to a PICU will experience anxiety, depression and low QOL. Cognitive behavioural therapy interventions are likely to be the most effective treatment for anxiety and depression (Gautam et al., 2020). In particular, mindfulness-based and CBT interventions have shown to be effective in reducing rumination and worry (Querstret & Cropley, 2013). Furthermore, behavioural activation is effective in reducing depressive symptoms, anxiety and increasing activation (Ekers et al., 2014). As the current study found a significant association

between anxiety, depression and QOL, it is possible that the treatment of anxiety and depression could indirectly improve QOL, although further research is needed to explore this. Parents also appear to develop negative appraisals surrounding their child's PICU admission. Psychological interventions could be targeted at addressing these and forming new, more adaptive appraisals. For example, CBT interventions could involve highlighting the child's ability to recover from severe illness, reforming appraisals that the child is permanently damaged. Treatments in which individuals are encouraged to change their thinking styles or disengage from the emotional response to rumination, through mindfulness techniques, have shown to be effective (Querstret & Cropley, 2013).

A model for paediatric medical traumatic stress could be useful to consider useful interventions for more generalised psychological distress, such as anxiety and depression (Kazak et al., 2006). This could include physicians providing anticipatory guidance to parents and children, involving parents in hospital care and facilitating awareness and communication about the ongoing impact of the illness on the family and how beliefs about the illness can affect the family (Kazak et al., 2006). The empirical paper findings support the need for routine screening of depression and anxiety in parents within the PICU setting. Moreover, the requirement for well-funded psychological support is indicated. Reducing psychological distress in parents could improve the management of the child's condition, reducing further cost to health services.

Future research

The meta-analysis highlighted the need to investigate whether depression developed in parents in response to their child's diagnosis of T1D, or whether it pre-existed it. Research could then explore how pre-existing depression in parents of children with T1D is associated with the management of the child's condition. Furthermore, additional research could consider the

processes involved in the development of depression in these parents, to inform targeted psychological intervention.

The empirical paper looked at parental psychological outcomes at a single time point following a PICU admission. Future research could consider the longer-term impact of having a child admitted to a PICU, by evaluating psychological outcomes at various time points. Additional research could also evaluate the association between psychological distress and time since trauma, as this information was not collected in the current study. This could provide useful information about when parental follow-up would be most helpful for parents following their child's PICU admission. Longer-term data could also enable further understanding of the role of maladaptive appraisals and coping behaviours in the development of poor psychological outcomes at various time points. This information could inform early intervention to reduce future psychological distress. For example, if future research highlighted that participants are likely to develop particular maladaptive appraisals or coping behaviours in the longer term following a PICU admission, earlier interventions could include work to minimise the risk of these developing. Furthermore, future research could investigate whether interventions to reduce anxiety and depression in parents improves their QOL, which would further support the drive to improve psychological distress in this population. In the empirical study, only parents of children who were ventilated for a minimum of 48 hours were included. Future research could also recruit parents of children who were admitted to a PICU but did not require ventilation, to explore any differences in distress, appraisals and behaviours between the two groups.

Reflections

For my empirical paper, I had aimed to recruit more participants via social media, to further increase the sample size. However, there were several barriers to recruitment. Although these

barriers were not formally explored, one hypothesis is that parents of children with a chronic illness are required to devote a great deal of their time and energy to their child and perhaps they did not have the time to participate in the current study. A further hypothesis is that participating in the current study could bring up difficult memories that the parents do not wish to revisit. Despite challenges with recruitment, the total number of participants included in the study was sufficient to draw meaningful conclusions.

I completed the final write-up of this portfolio whilst on placement within a palliative care department based in a hospital. This was my first time working psychologically within a health setting, and it helped me to understand and conceptualise the impact that illness can have on an individual and their family. Completing this thesis portfolio was challenging at times due to the high workload on placement. I found it useful to create a Gantt chart to plan and prioritise my thesis work within the time frame. Once I had established a plan, I then found placement days were a form of respite from thesis work. This process has developed my skills in organising my time efficiently in the face of multiple demands, a skill that I plan to take with me into my career as a Clinical Psychologist.

The process of putting together this thesis portfolio has enhanced my skills as a scientist practitioner. I have further developed my skills in conducting a systematic review and meta-analysis, applying for ethical approval, recruitment, data collection and data analysis using advanced statistical software. I look forward to learning more about the process of applying to academic journals for publication in the upcoming months. I also look forward to taking these skills with me into my career, where I aim to continue to build on my research skills.

Overall conclusion

The aim of this thesis portfolio was to explore psychological outcomes in parents of children with T1D and children admitted to a PICU. The findings indicate that a significant proportion of these parents will experience psychological distress, manifesting as clinically significant anxiety, depression and/or QOL. Furthermore, parents of children admitted to a PICU may adopt maladaptive appraisals and coping behaviours, some of which are associated with psychological distress. Several limitations of the current research have been presented, with suggestions for future research. The importance of screening for distress in these parents and offering interventions to reduce distress are both demonstrated by the papers within this portfolio. Reducing distress in this population is of utmost importance and can also serve to reduce distress in children living with chronic health conditions.

References for additional chapters

Al-Gamal, E., & Long, T. (2010). Anticipatory grieving among parents living with a child with cancer. *Journal of advanced nursing, 66*(9), 1980-1990.

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders. Fifth Edition. *American Psychiatric Association*, *21*(21), 591–643.

Amrock, S. M., & Weitzman, M. (2014). Parental psychological distress and children's mental health: results of a national survey. *Academic pediatrics, 14*(4), 375-381.

Barakat, L. P., Patterson, C. A., Weinberger, B. S., Simon, K., Gonzalez, E. R., & Dampier, C. (2007). A prospective study of the role of coping and family functioning in health outcomes for adolescents with sickle cell disease. *Journal of pediatric hematology/oncology, 29*(11), 752-760.

Bartlett, S. J., Krishnan, J. A., Riekert, K. A., Butz, A. M., Malveaux, F. J., & Rand, C. S. (2004). Maternal depressive symptoms and adherence to therapy in inner-city children with asthma. *Pediatrics, 113*(2), 229-237.

Blanchard, L. T., Gurka, M. J., & Blackman, J. A. (2006). Emotional, developmental, and behavioral health of American children and their families: a report from the 2003 National Survey of Children's Health. *Pediatrics, 117*(6), e1202-e1212.

Burckhardt, C. S., & Anderson, K. L. (2003). The Quality of Life Scale (QOLS): reliability, validity, and utilization. *Health and quality of life outcomes, 1*(1), 1-7.

Cohn, L. N., Pechlivanoglou, P., Lee, Y., Mahant, S., Orkin, J., Marson, A., & Cohen, E. (2020). Health outcomes of parents of children with chronic illness: a systematic review and meta-analysis. *The Journal of pediatrics, 218,* 166-177.

Crnic, K., & Low, C. Everyday stresses and parenting. In: Bornstein, M. H. ed. *Practical issues in parenting, Volume 5.* Lawrence Erlbaum Associates Publishers; 2002:243-267.

Davis, P., Stutchfield, C., Evans, T. A., & Draper, E. (2018). Increasing admissions to paediatric intensive care units in England and Wales: more than just rising a birth rate. *Archives of disease in childhood, 103*(4), 341-345.

Deater-Deckard, K. (2008). Parenting stress. Yale University Press.

Dodgson, J. E., Garwick, A., Blozis, S. A., Patterson, J. M., Bennett, F. C., & Blum, R. W. (2000). Uncertainty in childhood chronic conditions and family distress in families of young children. *Journal of Family Nursing*, *6*(3), 252–266.

Dosa, N. P., Boeing, N. M., Ms, N. P., & Kanter, R. K. (2001). Excess risk of severe acute illness in children with chronic health conditions. *Pediatrics, 107*(3), 499-504.

Ekers, D., Webster, L., Van Straten, A., Cuijpers, P., Richards, D., & Gilbody, S. (2014). Behavioural activation for depression; an update of meta-analysis of effectiveness and sub group analysis. PloS one, 9(6), e100100.

Engels, E. A., Schmid, C. H., Terrin, N., Olkin, I., & Lau, J. (2000). Heterogeneity and statistical significance in meta-analysis: an empirical study of 125 meta-analyses. *Statistics in medicine*, *19*(13), 1707-1728.

Feldman, M. A., Anderson, L. M., Shapiro, J. B., Jedraszko, A. M., Evans, M., Weil, L. E., ... & Weissberg-Benchell, J. (2018). Family-based interventions targeting improvements in health and family outcomes of children and adolescents with type 1 diabetes: a systematic review. *Current Diabetes Reports, 18,* 1-12.

Fuhrman, B. P., & Zimmerman, J. J. (2006). Pediatric critical care. Philadelphia: Mosby-Elsevier.

Garrison, M. M., Katon, W. J., & Richardson, L. P. (2005). The impact of psychiatric comorbidities on readmissions for diabetes in youth. *Diabetes Care, 28*(9), 2150-2154.

Gautam, M., Tripathi, A., Deshmukh, D., & Gaur, M. (2020). Cognitive behavioral therapy for depression. *Indian journal of psychiatry, 62*(Suppl 2), S223.

Gecgin, F. M., & Sahranc, Ü. (2017). The relationships between intolerance of uncertainty and psychological well-being. *Sakarya University Journal of Education, 7*(4), 739-756.

George, R. E., & Lowe, W. A. (2019). Well-being and uncertainty in health care practice. *The Clinical Teacher, 16*(4), 298-305.

Gladstone, T. R., Beardslee, W. R., & Diehl, A. (2015). The impact of parental depression on children. *Parental psychiatric disorder: Distressed parents and their families,* 117-126.

Harris, M. A., Freeman, K. A., & Beers, M. (2009). Family therapy for adolescents with poorly controlled diabetes: initial test of clinical significance. *Journal of pediatric psychology, 34*(10), 1097-1107

Jones, S., Rantell, K., Stevens, K., Colwell, B., Ratcliffe, J. R., Holland, P., ... & United Kingdom Pediatric Intensive Care Outcome Study Group. (2006). Outcome at 6 months after admission for pediatric intensive care: a report of a national study of pediatric intensive care units in the United Kingdom. *Pediatrics, 118*(5), 2101-2108

Kanthimathinathan, H. K., Plunkett, A., Scholefield, B. R., Pearson, G. A., & Morris, K. P. (2020). Trends in long-stay admissions to a UK paediatric intensive care unit. *Archives of Disease in Childhood, 105*(6), 558-562.

Kazak, A. E., Kassam-Adams, N., Schneider, S., Zelikovsky, N., Alderfer, M. A., & Rourke, M. (2006). An integrative model of pediatric medical traumatic stress. *Journal of pediatric psychology, 31*(4), 343-355.

Kish, A. M., Newcombe, P. A., & Haslam, D. M. (2018). Working and caring for a child with chronic illness: a review of current literature. *Child: care, health and development, 44*(3), 343-354.

Knafl, K. A., & Gilliss, C. L. (2002). Families and chronic illness: A synthesis of current research. *Journal of Family Nursing, 8*(3), 178-198.

Kroenke, K., & Spitzer, R. L. (2002). The PHQ-9: a new depression diagnostic and severity measure. *Psychiatric Annals, 32*(9).

Kustanti, C. Y., Chu, H., Kang, X. L., Pien, L. C., Chen, R., Tsai, H. T., & Chou, K. R. (2022). Anticipatory grief prevalence among caregivers of persons with a life-threatening illness: A meta-analysis. *BMJ Supportive & Palliative Care, 0,* 1-10.

Latour, J. M., van Goudoever, J. B., Schuurman, B. E., Albers, M. J., van Dam, N. A., Dullaart, E., ... & Hazelzet, J. A. (2011). A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units. I*ntensive care medicine, 37,* 319-325

London, M. J., Mercer, M. C., & Lilly, M. M. (2017). Considering the impact of early trauma on coping and pathology to predict posttraumatic growth among 9-1-1 Telecommunicators. *Journal of interpersonal violence, 35*(21-22), 4709-4731.

Mahase, E. (2022, September 22). Type 1 diabetes: Global prevalence is set to double by 2040, study estimates. *The BMJ.* Retrieved from Type 1 diabetes: Global prevalence is set to double by 2040, study estimates (bmj.com)

McBroom, L. A., & Enriquez, M. (2009). Review of family-centered interventions to enhance the health outcomes of children with type 1 diabetes. *The Diabetes Educator, 35*(3), 428-438.

Mikolajczak, M., Raes, M. E., Avalosse, H., & Roskam, I. (2022). Exhausted parents: Sociodemographic, child-related, parent-related, parenting and family-functioning correlates of parental burnout. In *Key Topics in Parenting and Behavior* (pp. 57-69). Springer, Cham.

Mishel, M. H. (1999). Uncertainty in chronic illness. *Annual review of nursing research, 17*, 269-294

Moore, S. M., Hackworth, N. J., Hamilton, V. E., Northam, E. P., & Cameron, F. J. (2013). Adolescents with type 1 diabetes: parental perceptions of child health and family functioning and their relationship to adolescent metabolic control. *Health and quality of life outcomes, 11*(1), 1-8.

National Institute for Health and Care Excellence (2011). *Common mental health problems: identification and pathways to care.* Retrieved from https://www.nice.org.uk/guidance/CG123/chapter/Recommendations#steps-2-and-3-treatment-and-referral-for-treatment

Paediatric Intensive Care Audit Network. (2021) *Annual Report.* Retrieved from https://www.picanet.org.uk/wp-content/uploads/sites/25/2022/04/PICANet-2021-Annual-Report_v1.1-22Apr2022.pdf

Patton, S. R., Monzon, A. D., Marker, A. M., & Clements, M. A. (2022). A nonrandomized pilot of a group, video-based telehealth intervention to reduce diabetes distress in parents of youth with type 1 diabetes mellitus. *Canadian Journal of Diabetes, 46*(3), 262-268.

Querstret, D., & Cropley, M. (2013). Assessing treatments used to reduce rumination and/or worry: A systematic review. *Clinical psychology review, 33*(8), 996-1009.

Rabineau, K. M., Mabe, P. A., & Vega, R. A. (2008). Parenting stress in pediatric oncology populations. *Journal of Pediatric Hematology/Oncology, 30*(5), 358-365.

Rees, G., Gledhill, J., Garralda, M. E., & Nadel, S. (2004). Psychiatric outcome following paediatric intensive care unit (PICU) admission: a cohort study. *Intensive care medicine, 30*(8), 1607-1614.

Revicki, D. A., Osoba, D., Fairclough, D., Barofsky, I., Berzon, R., Leidy, N. K., & Rothman, M. (2000). Recommendations on health-related quality of life research to support labeling and promotional claims in the United States. *Quality of Life Research, 9*(8), 887-900.

Reynolds, L., & Botha, D. (2006). Anticipatory grief: Its nature, impact, and reasons for contradictory findings. *Counselling, Psychotherapy, and Health, 2*(2), 15-26.

Rodrigues, M. G., Rodrigues, J. D., Pereira, A. T., Azevedo, L. F., Rodrigues, P. P., Areias, J. C., & Areias, M. E. (2022). Impact in the quality of life of parents of children with chronic diseases using psychoeducational interventions–A systematic review with meta-analysis. *Patient Education and Counseling, 105*(4), 869-880.

Seideman, R. Y., Watson, M. A., Corff, K. E., Odle, P., Haase, J., & Bowerman, J. L. (1997). Parent stress and coping in NICU and PICU. *Journal of pediatric nursing, 12*(3), 169-177.

Shudy, M., De Almeida, M. L., Ly, S., Landon, C., Groft, S., Jenkins, T. L., & Nicholson, C. E. (2006). Impact of pediatric critical illness and injury on families: a systematic literature review. *Pediatrics, 118*(Supplement_3), S203-S218.

Sigmon, S. T., Pells, J. J., Boulard, N. E., Whitcomb-Smith, S., Edenfield, T. M., Hermann, B. A., ... & Kubik, E. (2005). Gender differences in self-reports of depression: The response bias hypothesis revisited. *Sex Roles, 53*(5), 401-411.

Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of internal medicine, 166*(10), 1092-1097.

Streisand, R., Mackey, E. R., Elliot, B. M., Mednick, L., Slaughter, I. M., Turek, J., & Austin, A. (2008). Parental anxiety and depression associated with caring for a child newly diagnosed with type 1 diabetes: Opportunities for education and counseling. *Patient Education and Counseling, 73*(2), 333–338.

Stremler, R., Haddad, S., Pullenayegum, E., & Parshuram, C. (2017). Psychological outcomes in parents of critically ill hospitalized children. *Journal of Pediatric Nursing, 34*, 36-43.

Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. (2012). Psychological experience of parents of children with type 1 diabetes: A systematic mixed-studies review. *The Diabetes Educator, 38*(4), 562–579.

Williamson, V., Hiller, R. M., Meiser-Stedman, R., Creswell, C., Dalgleish, T., Fearon, P., Goodall, B., McKinnon, A., Smith, P., & Wright, I. (2018). The parent trauma response questionnaire (PTRQ): development and preliminary validation. *European journal of psychotraumatology, 9*(1), 1478583.

Wong, M. Y. F., & Chan, S. W. C. (2006). The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing, 15*(6), 710-717.

World Health Organisation. (2022). Diabetes. World Health Organisation. Retrieved from https://www.who.int/health-topics/diabetes#tab=tab_1.

Appendices:

Appendix A: Author Guidelines for meta-analysis

Author Guidelines
Revised October 2021

PREPARING FOR SUBMISSION

Please read the submission checklist which summarizes the main points for manuscripts submitted to Acta Paediatrica. Please ensure your manuscript follows the recommended number of pages, references, etc., for the various types of the articles accepted in Acta Paediatrica, shown below:

Type of article	No. of references	Abstract	Key Notes	Max no. of printed pages	Headings	Keywords
Original Article	30	Yes, *200 words*	Yes	4 (= 12 ms pages*) approx. 3250 words #	Yes	Yes
Mini Commentary concerning articles published in the journal	5	No	No	1/2 printed page, or max. 500 words #	No	No
Brief Report	5	No	No	2 printed pages, or max. 1000 words and one figure or table #	No	No
Editorial	10	No	No	2 pages, or max. 1500 words	No	No
Clinical Overview	30	Yes,*100 words*	No	3 (= 9 ms pages*) approx. 2400 words	No	Yes
Commentary EBNEO commentary included	9	No	No	1/2 page, or max. 500 words	No	No
Perspective	5	No	No	2 (= 6 ms pages*) approx. 1550 words #	Yes	No

Essay	5	No	No	2 (= 6 ms pages*) approx. 1550 words #	Yes	No
Reader's Forum Letter concerning articles published in the journal	3	No	No	1/2 printed page, or max. 500 words #	Yes	No
Review Article	60	Yes, *200 words*	Yes	8 (= 24 ms pages*) approx. 6650 words #	Yes	Yes
Mini Review	30	Yes, *200 words*	Yes	4 (= 12 ms pages*) approx. 3250 words #	Yes	Yes
A Different View	10	No	No	2 (= 6 ms pages*) approx.1550 words #	Yes	No

* Ordinary double-spaced manuscript pages - tables, illustrations and references included (i.e., the more space tables and illustrations require, the shorter the text).
# Tables and illustrations not included

Submitted manuscripts should be arranged according to the rules stated in 'Uniform requirements for manuscripts submitted to biomedical journals' Ann Intern Med 1997;126:36-47, or JAMA 1997;277:927-34. The full document is available at www.icmje.org

Acta Paediatrica employs a plagiarism detection system. By submitting your manuscript to this journal, you accept that your manuscript may be screened for plagiarism against previously published works.

When submitting a paper, the author should make a full statement to the editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work. Publication of abstracts is not considered to be duplicate publication. Submit approval of the paper for publication, signed by all authors, to the Editorial Office, and state clearly in the paper that the study has been approved by an institutional ethics committee. An author must have made significant contributions to the design, execution analysis and writing of the study, and he or she must share responsibility for what is published. We ask authors to specify their individual contribution, if appropriate, we publish this information (Author statements). *Example:*
Dr A had primary responsibility for protocol development, patient screening, enrolment, outcome assessment, preliminary data analysis and writing the manuscript.
Drs B and C participated in the development of the protocol and analytical framework for the study and contributed to the writing of the manuscript.

Dr D contributed in the same ways as B and C and was responsible for patient screening.
Dr E supervised the design and execution of the study, performed the final data analyses and contributed to the writing of the manuscript.
Be as concise as possible. Regular Articles may not exceed four published pages (including illustrations, tables and references). Exceeding this limit will incur a page charge for each exceeding page. Short Communications may not exceed two published pages. Clinical Observations will no longer be published.

Acta Paediatrica does not publish case reports. Authors of case reports are encouraged to submit to the journal *Clinical Case Reports* (www.clinicalcasesjournal.com), which aims to directly improve health outcomes by identifying and disseminating examples of best clinical practice. *Clinical Case Reports* is an open access journal, and article publication fees apply.

Reports on randomised trials must conform to Consort guidelines and should be submitted with their protocols.

Conflict of interest and funding
Authors are responsible for recognising and disclosing financial and other conflicts of interest that might bias their work. They should acknowledge in the manuscript all financial support for the work and other financial or personal connections to the work. If reported research has been supported by pharmaceutical or other industries, this should be stated.

Statistic validity
If statistical data are provided the authors may be requested to submit an official statement issued by a certified statistician (with a proper affiliation) regarding the validity of the methods used.

Publication Ethics
Acta Paediatrica is a member of the Committee on Publication Ethics (COPE).

Ethics and consent
When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation and with the Helsinki Declaration of 1975, as revised in 1983. Do not use patients' names, initials, or hospital numbers, especially in illustrative material. Papers including animal experiments or clinical trials must have been approved by the institutional ethics committee.
Identifying information should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) has given written informed consent for publication (A Patient Consent Certificate should be completed and sent to the journal). Informed consent for this purpose requires that the patient be shown the manuscript to be published.

Encourages Data Sharing
Acta Paediatrica encourages authors to share the data and other artefacts supporting the results

in the paper by archiving it in an appropriate public repository. Authors should include a data accessibility statement, including a link to the repository they have used, in order that this statement can be published alongside their paper**.**

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

Page Charges
If your article exceeds the free pages limit, a page charge of GBP 60 will be applied for each additional page. Please confirm in your Author's response letter that you would be prepared to stand such a cost should you be unable to shorten your paper.

Original Article: 4 free pages
Brief Report: 2 free pages
Clinical Overview: 3 free pages
Review Article: 8 Free pages
Mini Review: 4 free pages
A Different View: 2 free pages
Invited review: No charge
Invited mini-review: No charge
EBNEO commentary: No charge
Editorial: No charge
Letter to the editor: No charge
Perspective: No charge
Mini Commentary: No charge
Commentary: No charge
Essay: No charge
Reader's Forum: No charge
Book review: No charge
All Open access articles: No charge for exceeding pages for any open access article

COPYRIGHT
If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement
If the Open Access option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:

CTA Terms and Conditions http://authorservices.wiley.com/bauthor/faqs_copyright.asp

For authors choosing Open Access
If the Open Access option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

Creative Commons Attribution Non-Commercial License OAA

Creative Commons Attribution Non-Commercial -NoDerivs License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services https://authorservices.wiley.com/author-resources/Journal-Authors/licensing-and-open-access/licensing/licensing-info-faqs.html and visit http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html.

If you select the Open Access option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit: http://www.wiley.com/go/funderstatement.

For RCUK and Wellcome Trust authors click on the link below to preview the terms and conditions of this license:

Creative Commons Attribution License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services
http://authorservices.wiley.com/bauthor/faqs_copyright.asp and visit
http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html.

Open Access
Open Access is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With Open Access, the author, the author's funding agency, or the author's institution pays a fee (APC) to ensure that the article is made available to non-subscribers upon publication via Wiley InterScience, as well as deposited in the funding agency's preferred archive.
For more information on this journal's APCs, please see the Open Access page.
Any authors wishing to send their paper Open Access will be required to complete the payment form available from our website at: https://authorservices.wiley.com/bauthor/Open Access_order.asp
Prior to acceptance there is no requirement to inform an Editorial Office that you intend to publish your paper Open Access if you do not wish to. All Open Access articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

Accepted Articles

Acta Paediatrica now offers Accepted Articles for all articles within a short time of acceptance. Further to acceptance in *Acta Paediatrica*, the manuscripts of articles (excluding Quest for Diagnosis) are immediately made publicly available online. 'Accepted Articles' have been peer-reviewed and accepted for formal publication, but have not been subject to copyediting, composition or proof correction. The service has been designed to ensure the earliest possible circulation of research papers after acceptance. Accepted Articles appear in PDF format only and are given a Digital Object Identifier (DOI), which allows them to be cited and tracked. The DOI remains unique to a given article in perpetuity and can continue to be used to cite and access the article further to Early View publication (see below). More information about DOIs can be found online here.

Neither the Acta Paediatrica Foundation nor Wiley-Blackwell can be held responsible for errors or consequences arising from the use of information contained in Accepted Articles; nor do the views and opinions expressed necessarily reflect those of the Acta Paediatrica Foundation or Wiley-Blackwell.

SUBMISSION

Electronic Manuscripts

All submissions should be made online at *Acta Paediatrica*'s Manuscript Central site to facilitate rapid accessibility of your work to the readers. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre. The submitting author will be required to suggest the names/email addresses of two reviewers and add the names, affiliations and email addresses of the co-authors. The accompanying letter should be entered in a separate field. The manuscript text, tables and figures should preferably be uploaded as separate files.

ORCID

As part of the journal's commitment to supporting authors at every step of the publishing process, *Acta Paediatrica* requires the submitting author (only) to provide an ORCID iD when submitting a manuscript. This takes around 2 minutes to complete. Please see Wiley's resources on ORCID here.

Manuscript Layout

Please use these simple guidelines when preparing your electronic manuscript.

(i) Key elements consistently throughout. (ii) Do not break words at the ends of lines. Use a hyphen only to hyphenate compound words. (iii) Use one space only at the ends of sentences. (iv) Do not use underlining; use the italics feature instead. (v) Leave the right-hand margin unjustified. (vi) Use a double hyphen to indicate a dash. (vii) Do not use the lower case 'ell' for 1 (one) or the upper-case O for 0 (zero). (viii) When indenting paragraphs or separating columns in tables, use the TAB key, not the spacebar.

Double-space the entire manuscript. Prepare the manuscript with each of the following parts starting on a new page: (1) The title, with authors' names and affiliations (as a rule the number of authors should be limited to six. The names of others who contributed to the article in varying degree should be mentioned under the heading 'Acknowledgements'), the address of the corresponding author and a short running title; (2) the abstract ending with one or two sentences

of conclusion, summarizing the message of the article including keywords; (3) the text; (4) the references; (5) tables; (6) figure legends.

Language
Manuscripts must be in English. Authors from non-English speaking countries are requested to have their text thoroughly checked by a competent person whose native language is English. Manuscripts may be rejected on the grounds of poor English. Revision of the language is the responsibility of the author.

Article Preparation Support
Wiley Editing Services offers expert help with English Language Editing, as well as translation, manuscript formatting, figure illustration, figure formatting, and graphical abstract design – so you can submit your manuscript with confidence.
Also, check out our resources for Preparing Your Article for general guidance about writing and preparing your manuscript.

Notes/Footnotes
Incorporate notes/footnotes in the text, within parentheses, rather than in their usual place at the foot of the page.

Abbreviations
Do not use abbreviations in the title or Abstract, and in the text use only standard abbreviations, i.e. those listed in the latest editions of any recognized medical dictionary (e.g. Dorland's, Butterworth's). The full term for which an abbreviation stands should precede its first use in the text unless it is a standard unit of measurement. Use the SI system of notation. Redefine abbreviations used in the figure legends.

Illustrations
In manuscripts that contain photographs of patients, we require a certificate by the author that consent to publish such a photograph has been given by the patient, a child's parent or a caretaker.

All figures should be cited in the text in numerical order. Figure legends must be typed on a separate page at the end of the manuscript. When submitting artwork electronically, please read the information on the Wiley-Blackwell website at
http://authorservices.wiley.com/prep_illust.asp. Vector graphics (e.g. line artwork) should be saved in Encapsulated Postscript Format (EPS), and bitmap files (e.g. photographs) in Tagged Image File Format (TIFF). Line art must be scanned at a minimum of 800 dpi, photographs at a minimum of 300 dpi.

For queries, please contact Production Editor Florencio Curammeng,
fpcurammen@wiley.com

Tables
Number tables with Arabic numerals.

Title Page
Example of a title page showing content and spacing. Leave 7-8 cm at top of page.
Mechanics of breathing in the newborn (title)
L Andersson and K Pettersson (authors)
Department of Paediatrics, University Hospital, Lund, Sweden
Short title: Neonatal breathing
Corresponding author: K. Pettersson, Department of Paediatrics, University Hospital, S-221 85 Lund, Sweden. Tel +00 0 000 00 00. Fax +00 0 000 00 00.

Abstract
The abstract of a regular article should not exceed 200 words for regular articles and should be structured with the following headings: Aim, Methods, Results and Conclusion. Where appropriate, use Design, Setting, Subjects, Interventions and Main outcome measures. The abstract should be followed by a maximum of five keywords, listed alphabetically. Type as illustrated below:
ABSTRACT
Huppke P, Roth C, Christen HJ, Brockmann K, Hanefeld F. Endocrinological study on growth retardation in Rett syndrome. *Acta Paediatrica* 2001;90:1257-61. Stockholm. ISSN 0803-5253

Aim: To determine whether primary or secondary growth hormone … (text) **Methods**: In 38 patients with Rett syndrome... **Results**: … **Conclusion**: ... Keywords: Endocrinology, growth hormone, growth retardation …
Please note that clear, descriptive and search-optimized titles and abstracts are important considerations to the journal. Guidelines available here.

Key Notes
In Regular Articles and Review Articles, after the Abstract, please sum up your article in three short sentences of max. 70 words in total, with the aim of creating an easy digestible take home message for the reader.

Text Pages
Leave a left-hand margin of about 4 cm. Number the pages in the top right-hand corner, beginning with the title page. Headings (left-hand margin): Patients and Methods, Results, Discussion, Acknowledgements, References.

References
This journal uses AMA reference style. **AMA Manual of Style**.
Reference Citations in Text
- Superscript reference numbers are placed after periods and commas and before colons and semicolons.
- Reference numbers should be in sequence.
- Use a hyphen to join the first and last numbers of a closed series.
- Use commas without spaces to separate other parts of a multiple citation.

Reference List

Journal article with 1-6 authors	Hu P, Reuben DB. Effects of managed care on the length of time that elderly patients spend with physicians during ambulatory visits. *Med Care*. 2002;40(7):606-613.
Journal article with more than 6 authors	Geller AC, Venna S, Prout M, et al. Should the skin cancer examination be taught in medical school? *Arch Dermatol*. 2002;138(9):1201-1203.
Electronic journal article	Gage BF, Fihn SD, White RH. Management and dosing of warfarin therapy. *Am J Med*. 2000;109(6):481-488. **https://doi:10.1016/S0002-9343(00)00545-3**.

For more information please see: AMA Manual of Style.

Proofs

The corresponding author will be sent a web link via e-mail directing them to the Acrobat PDF (portable document format) file of the proof. Please return proofs following the instructions in the email within 72 hours of receipt, or you will risk delaying the publication of your article.

Early View

Acta Paediatrica is covered by the Early View service. Early View articles are complete full-text articles published online in advance of their publication in a monthly issue. Articles are therefore available as soon as they are ready, rather than having to wait for the next scheduled issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles mean that they do not yet have volume, issue or page numbers, so Early View articles cannot be cited in the traditional way. They are therefore given a Digital Object Identifier (DOI), which allows the article to be cited and tracked before it is allocated to an issue. After issue publication, the DOI remains valid and can continued to be used to cite and access the article. More information about DOIs can be found at http://www.doi.org/faq.html

Wiley's Author Name Change Policy

In cases where authors wish to change their name following publication, Wiley will update and republish the paper and redeliver the updated metadata to indexing services. Our editorial and production teams will use discretion in recognizing that name changes may be of a sensitive and private nature for various reasons including (but not limited to) alignment with gender identity, or as a result of marriage, divorce, or religious conversion. Accordingly, to protect the author's privacy, we will not publish a correction notice to the paper, and we will not notify co-authors of the change. Authors should contact the journal's Editorial Office with their name change request.

Author Services

Online production tracking is available for your article through Wiley-Blackwell's Author Services. Author Services enables authors to track their article - once it has been accepted - through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of

production so they don't need to contact the production editor to check on progress. Visit http://authorservices.wiley.com/bauthor/author.asp for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.
Our helpful guide will make your paper more discoverable with **Search Engine Optimization.**

Article Promotion Support
Wiley Editing Services offers professional video, design, and writing services to create shareable video abstracts, infographics, conference posters, lay summaries, and research news stories for your research – so you can help your research get the attention it deserves.

Offprints
Free access to the final PDF offprint of your article will be available via author services only. Please therefore sign up for author services if you would like to access your article PDF offprint and enjoy the many benefits the service offers.

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

Appendix B: Quality checklist for meta-analysis

Checklist to assess each study's quality.

Score 0, 1 or 2 for each question on each study.

Assessed by: _____

Population

1. Were participants and setting well described?

(2) Information regarding the characteristics (age, gender, ethnicity) of the sample are well described with the setting well reported (health setting, country, geography)

(1) Some information regarding participants characteristics are reported, with limited information on the setting

(0) Sample characteristics and setting information are not reported in any detail

2. Was participation rate of those eligible at least 50%?

(2) More than 50% of those eligible to participate took part

(1) Less than 50% of those eligible to participate took part

(0) The number of eligible potential participants was not reported

3. Were reasons for non-response described?

(2) Reasons for non-response were described with the number of those participants not responding reported

(1) Reasons were described for non-responders, but no numbers provided OR Numbers of non-responders are reported but with no reasons

(0) Non-response rates were not reported in the study

4. Was the study's population a close representation of the national population in relation to relevant variables, e.g., age, sex, occupation?

(2) The study's target population (the group of people or entities to which the results of the study will be generalised) was a close representation of the national population

(0) The study's target population was clearly not representative of the national population (e.g., the study was conducted in one province or village) OR the population was not described in enough detail to determine representation

5. Were participants recruited in an appropriate way?

(2) Consecutive or random sampling was used to recruit potential participants

(1) Recruitment was conducted through methods other than consecutive or random sampling e.g., self-selection via advert, convenience or opportunity sampling

(0) Recruitment procedures were not reported in the study

Were inclusion and exclusion criteria explicit and appropriate?

(2) Inclusion and exclusion criteria were reported in detail

(1) Some information regarding inclusion and exclusion was provided, but not in detail

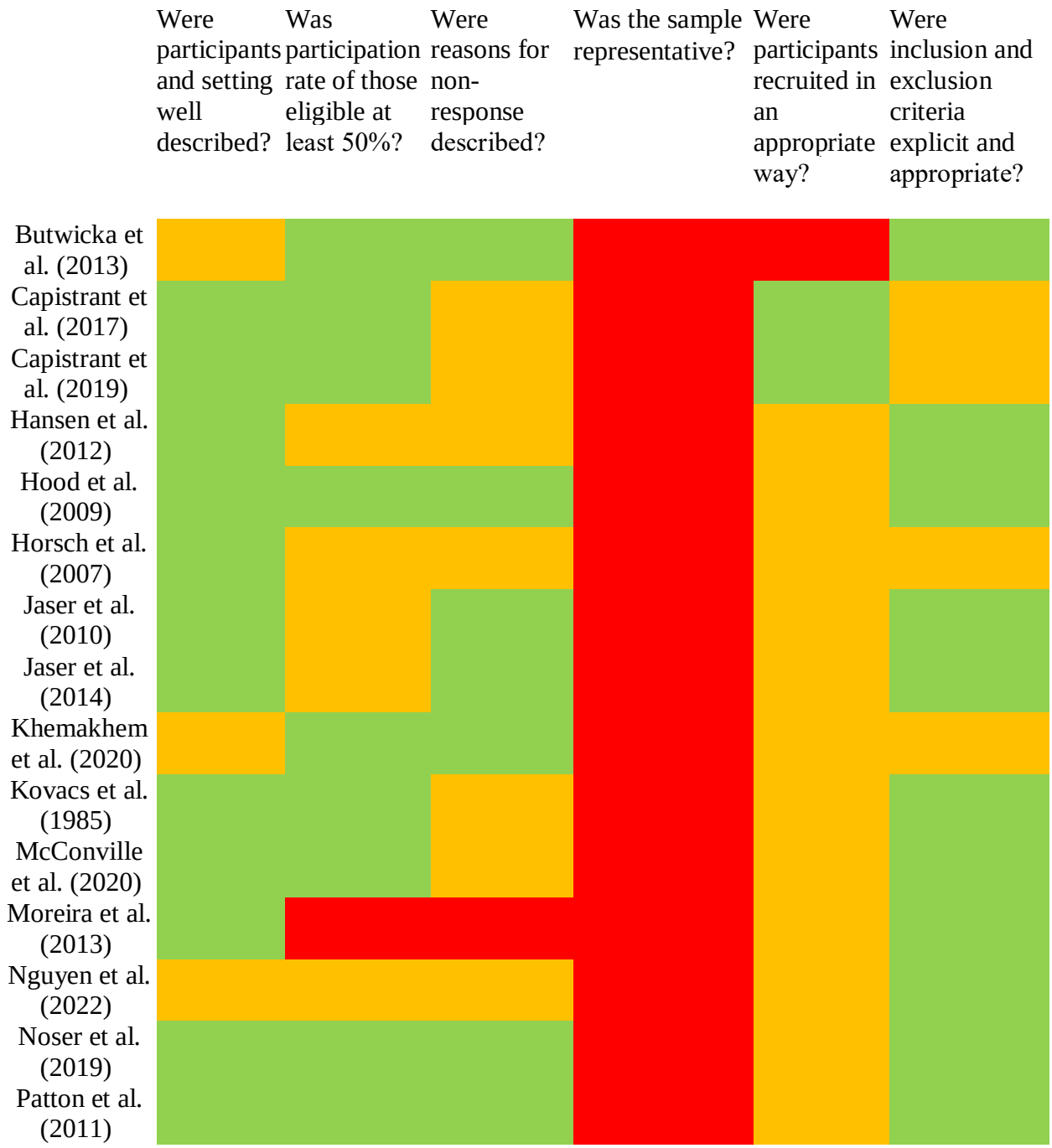
(0) Inclusion and exclusion criteria were not reported

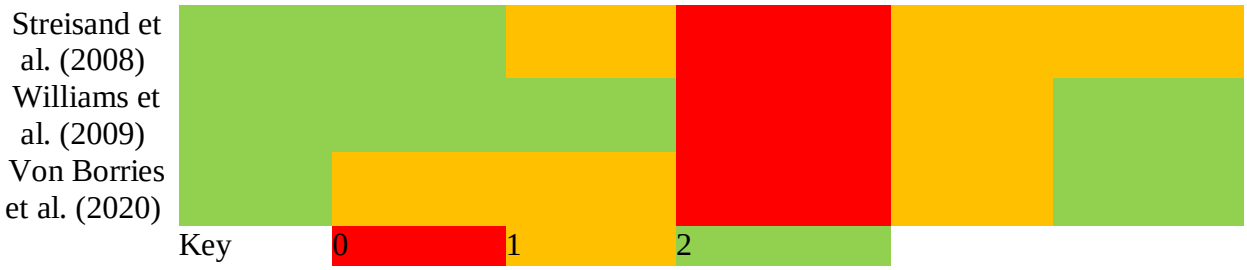
Appendix C: Quality check outcome for each study

Individual study outcome of risk of bias assessment

Table 1

Risk of bias assessment outcomes by criteria




Streisand et al. (2008)
Williams et al. (2009)
Von Borries et al. (2020)
Key
0
1
2

Appendix D: Reference list of studies included in the meta-analysis

Butwicka, A., Zalepa, A., Fendler, W., Szadkowska, A., & Mlynarski, W. Maternal depressive symptoms predict acute hospitalization among children with type 1 diabetes. *Pediatric Diabetes.* 2013; 14(4), 288-294.

Capistrant, B. D., Friedemann-Sánchez, G., Novak, L. K., Zuijdwijk, C., Ogle, G. D., & Pendsey, S. Mental health and well-being among type 1 diabetes caregivers in India: Evidence from the IDREAM study. *Diabetes Research and Clinical Practice.* 2017; 134, 168–177.

Capistrant, B. D., Friedemann-Sánchez, G., & Pendsey, S. Diabetes stigma, parent depressive symptoms and Type-1 diabetes glycemic control in India. *Social Work in Health Care.* 2019; 58(10), 919-935.

Hansen, J. A., Weissbrod, C., Schwartz, D. D., & Taylor, W. P. Paternal involvement in pediatric Type 1 diabetes: fathers' and mothers' psychological functioning and disease management. *Families, Systems, & Health.* 2012; 30(1), 47.

Hood, K. K. The influence of caregiver depressive symptoms on proxy report of youth depressive symptoms: A test of the depression-distortion hypothesis in pediatric type 1 diabetes. *Journal of Pediatric Psychology.* 2009; 34(3), 294-303.

Horsch, A., McManus, F., Kennedy, P., & Edge, J. Anxiety, depressive, and posttraumatic stress symptoms in mothers of children with type 1 diabetes. *Journal of traumatic stress.* 2007; 20(5), 881-891.

Jaser, S. S., & Grey, M. A pilot study of observed parenting and adjustment in adolescents with type 1 diabetes and their mothers. *Journal of pediatric psychology.* 2010; 35(7), 738-747.

Jaser, S. S., Linsky, R., & Grey, M. Coping and psychological distress in mothers of adolescents with type 1 diabetes. *Maternal and child health journal.* 2014; 18(1), 101-108.

Khemakhem, R., Dridi, Y., Hamza, M., Hamouda, A. B., Khlayfia, Z., Ouerda, H., ... & Maherzi, A. How do parents of children with type 1 diabetes mellitus cope and how does this condition affect caregivers' mental health?. *Archives de Pédiatrie.* 2020; 27(5), 265-269.

Kovacs, M., Finkelstein, R., Feinberg, T. L., Crouse-Novak, M., Paulauskas, S., & Pollock, M. Initial psychologic responses of parents to the diagnosis of insulin-dependent diabetes mellitus in their children. *Diabetes Care.* 1985; 8(6), 568–575.

McConville, A., Noser, A. E., Nelson, E. L., Clements, M. A., Majidi, S., & Patton, S. R. Depression as a predictor of hypoglycemia worry in parents of youth with recent-onset type 1 diabetes. *Pediatric diabetes.* 2020; 21(5), 909-916.

Moreira, H., Frontini, R., Bullinger, M., & Canavarro, M. C. Caring for a child with type 1 diabetes: links between family cohesion, perceived impact, and parental adjustment. *Journal of Family Psychology.* 2013; 27(5), 731.

Nguyen, L. A., Pouwer, F., Lodder, P., Hartman, E., Winterdijk, P., Aanstoot, H. J., & Nefs, G. Depression and anxiety in adolescents with type 1 diabetes and their parents. *Pediatric Research.* 2022; 91(1), 188-196.

Noser, A. E., Dai, H., Marker, A. M., Raymond, J. K., Majidi, S., Clements, M. A., ... & Patton, S. R. Parental depression and diabetes-specific distress after the onset of type 1 diabetes in children. *Health Psychology.* 2019; 38(2), 103.

Patton, S. R., Dolan, L. M., Smith, L. B., Thomas, I. H., & Powers, S. W. Pediatric parenting stress and its relation to depressive symptoms and fear of hypoglycemia in parents of

young children with type 1 diabetes mellitus. *Journal of clinical psychology in medical settings.* 2011; 18(4), 345-352.

Streisand, R., Mackey, E. R., Elliot, B. M., Mednick, L., Slaughter, I. M., Turek, J., & Austin, A. Parental anxiety and depression associated with caring for a child newly diagnosed with type 1 diabetes: Opportunities for education and counseling. *Patient Education and Counseling.* 2008; 73(2), 333–338.

von Borries, D., Astudillo, P., Pérez, V., García, F. H., Rumie, K., & Garcia, B. H. Association between depressive symptoms in mothers and metabolic control in adolescents with type 1 diabetes. *Revista Chilena de Pediatria.* 2020; 91(2), 190-198.

Williams, L. B., Laffel, L. M. B., & Hood, K. K. Diabetes-specific family conflict and psychological distress in paediatric type 1 diabetes. *Diabetic Medicine.* 2009; 26(9), 908-914.

Appendix E: Reference list of studies excluded from the meta-analysis

Articles in which full texts were examined and subsequently excluded from the meta-analysis (k= 34)

Subheadings detailing the reason for exclusion are provided.

Prevalence of depression not reported (k= 27)

Berg, C. A., Wiebe, D. J., Beveridge, R. M., Palmer, D. L., Korbel, C. D., Upchurch, R., ... & Donaldson, D. L. (2007). Mother–child appraised involvement in coping with diabetes stressors and emotional adjustment. *Journal of Pediatric Psychology*, *32*(8), 995-1005.

Berg, C. A., Schindler, I., & Maharajh, S. (2008). Adolescents' and mothers' perceptions of the cognitive and relational functions of collaboration and adjustment in dealing with type 1 diabetes. *Journal of Family Psychology*, *22*(6), 865.

Blankfeld, D. F., & Holahan, C. J. (1996). Family support, coping strategies, and depressive symptoms among mothers of children with diabetes. *Journal of Family Psychology*, *10*(2), 173.

Butler, J. M., Skinner, M., Gelfand, D., Berg, C. A., & Wiebe, D. J. (2007). Maternal parenting style and adjustment in adolescents with type I diabetes. *Journal of Pediatric Psychology*, *32*(10), 1227-1237.

Butner, J., Berg, C. A., Osborn, P., Butler, J. M., Godri, C., Fortenberry, K. T., ... & Wiebe, D. J. (2009). Parent–adolescent discrepancies in adolescents' competence and the balance of adolescent autonomy and adolescent and parent well-being in the context of Type 1 diabetes. *Developmental psychology*, *45*(3), 835.

Cunningham, N. R., Vesco, A. T., Dolan, L. M., & Hood, K. K. (2011). From caregiver psychological distress to adolescent glycemic control: The mediating role of perceived burden around diabetes management. *Journal of pediatric psychology, 36*(2), 196-205.

Duru, N. S., Civilibal, M., & Elevli, M. (2016). Quality of life and psychological screening in children with type 1 diabetes and their mothers. *Experimental and Clinical Endocrinology & Diabetes, 124*(02), 105-110.

Feeley, C. A., Sereika, S. M., Chasens, E. R., Siminerio, L., Charron-Prochownik, D., Muzumdar, R. H., & Viswanathan, P. (2021). Sleep in parental caregivers and children with type 1 diabetes. *The Journal of School Nursing, 37*(4), 259-269.

Hannonen, R., Eklund, K., Tolvanen, A., Komulainen, J., Riikonen, R., Delamater, A. M., & Ahonen, T. (2015). Psychological distress of children with early-onset type 1 diabetes and their mothers' well-being. *Acta Paediatrica, 104*(11), 1144-1149.

Hauenstein, E. J., Marvin, R. S., Snyder, A. L., & Clarke, W. L. (1989). Stress in parents of children with diabetes mellitus. *Diabetes Care, 12*(1), 18-23.

Families with children with diabetes: Implications of parent stress for parent and child health. *Journal of pediatric psychology, 37*(4), 467-478.

Hessler, D., Fisher, L., Polonsky, W., & Johnson, N. (2016). Understanding the areas and correlates of diabetes-related distress in parents of teens with type 1 diabetes. *Journal of pediatric psychology, 41*(7), 750-758.

Jaser, S. S., Whittemore, R., Ambrosino, J. M., Lindemann, E., & Grey, M. (2008). Mediators of depressive symptoms in children with type 1 diabetes and their mothers. *Journal of pediatric psychology, 33*(5), 509-519.

Kovacs, M., Iyengar, S., Goldston, D., Obrosky, D. S., Stewart, J., & Marsh, J. (1990). Psychological functioning among mothers of children with insulin-dependent diabetes mellitus: a longitudinal study. *Journal of Consulting and Clinical Psychology, 58*(2), 189.

Makara-Studzińska, M., Somasundaram, S., Ashraf, G. M., Gogacz, M., Madej, A., Izydorczyk, B., ... & Aliev, G. (2019). Assessment of psychosocial functioning of mothers of children with diabetes mellitus compared to mothers of healthy children. *BioMed Research International*, 2019.

Monaghan, M., Herbert, L. J., Cogen, F. R., & Streisand, R. (2012). Sleep behaviors and parent functioning in young children with type 1 diabetes. *Children's Health Care, 41*(3), 246-259.

Moreira, H., Frontini, R., Bullinger, M., & Canavarro, M. C. (2014). Family cohesion and health-related quality of life of children with type 1 diabetes: The mediating role of parental adjustment. *Journal of Child and Family Studies, 23*(2), 347-359.

Olsen, B., Berg, C. A., & Wiebe, D. J. (2008). Dissimilarity in mother and adolescent illness representations of type 1 diabetes and negative emotional adjustment. *Psychology and Health, 23*(1), 113-129.

Prikken, S., Raymaekers, K., Oris, L., Weets, I., Moons, P., & Luyckx, K. (2020). Illness intrusiveness in parents of youth with type 1 diabetes: A longitudinal study. *Pediatric Diabetes, 21*(5), 890-899.

Robinson, E. M., Weaver, P., Chen, R., Streisand, R., & Holmes, C. S. (2016). A model of parental distress and factors that mediate its link with parental monitoring of youth diabetes care, adherence, and glycemic control. *Health Psychology, 35*(12), 1373.

Shapiro, J. B., Vesco, A. T., Weil, L. E., Evans, M. A., Hood, K. K., & Weissberg-Benchell, J. (2018). Psychometric properties of the Problem Areas in Diabetes: Teen and Parent of Teen versions. *Journal of Pediatric Psychology, 43*(5), 561-571.

Stanek, K. R., Noser, A. E., Patton, S. R., Clements, M. A., Youngkin, E. M., & Majidi, S. (2020). Stressful life events, parental psychosocial factors, and glycemic management in school-aged children during the 1 year follow-up of new-onset type 1 diabetes. *Pediatric diabetes, 21*(4), 673-680.

Stewart, S. M., Wang, J. T., Wang, Y. C., & White, P. C. (2009). Patient-versus parent-reported psychological symptoms as predictors of type 1 diabetes management in adolescents. *Children's Health Care, 38*(3), 200-212.

Van Gampelaere, C., Luyckx, K., van der Straaten, S., Laridaen, J., Goethals, E. R., Casteels, K., ... & Ghent University. (2020). Families with pediatric type 1 diabetes: A comparison with the general population on child well-being, parental distress, and parenting behavior. *Pediatric Diabetes, 21*(2), 395-408.

Van Gampelaere, C., Vervoort, T., Luyckx, K., De Paepe, A., Van Aken, S., & Goubert, L. (2018). Maternal distress in the context of their child's type 1 diabetes: Exploring the role of adaptive maternal emotion regulation on child outcomes. *Psychology, Health & Medicine, 23*(3), 337-346.

Whittemore, R., Urban, A. D., Tamboriane, W. V., & Grey, M. (2003). Quality of life in school-aged children with type 1 diabetes on intensive treatment and their parents. *The Diabetes Educator, 29*(5), 847-854.

Wiebe, D. J., Gelfand, D., Butler, J. M., Korbel, C., Fortenberry, K. T., McCabe, J. E., & Berg, C. A. (2011). Longitudinal associations of maternal depressive symptoms, maternal

involvement, and diabetes management across adolescence. *Journal of pediatric psychology, 36*(7), 837-846.

RCT/intervention study (n= 3)

Meral, D. K., & Yildlrim, E. A. (2020). The Effect of Psychodrama Group Therapy Applied to Mothers of Children with Type 1 Diabetes on the Role Skills, Adaptation Process, Quality of Life and Depression: A Mixed Methods Study. *Journal of Academic Research in Nursing, 6*(3), 465-475.

Mackey, E. R., Struemph, K., Powell, P. W., Chen, R., Streisand, R., & Holmes, C. S. (2014). Maternal depressive symptoms and disease care status in youth with type 1 diabetes. *Health Psychology, 33*(8), 783.

Tully, C., Wang, C. H., Sinisterra, M., Clary, L., Hilliard, M. E., Monaghan, M., ... & Streisand, R. (2022). Diabetes-specific functioning in parents of young children with recently diagnosed type 1 diabetes. *Health Psychology*. 41(6), 423-432.

Not the target population (n= 1)

Ray, G. T., Mertens, J. R., & Weisner, C. (2014). Comparison of health care needs of child family members of adults with alcohol or drug dependence versus adults with asthma or diabetes. *Journal of developmental and behavioral pediatrics: JDBP, 35*(4), 282.

Full text not available (n= 1)

Koizumi, S. (1992). Japanese mothers' responses to the diagnosis of childhood diabetes. J*ournal of Pediatric Nursing, 7*(2), 154-160.

Data not available (n= 1)

Nefs, G., Nguyen, L., Winterdijk, P., Hartman, E., Sas, T., Nuboer, R., ... & Pouwer, F. (2019). Study protocol of Diabetes LEAP: a longitudinal study examining emotional problems in

adolescents with type 1 diabetes and their parents/caregivers. *BMC pediatrics, 19*(1), 1-8.

No valid measure of depression (n= 1)

López-Bastida, J., López-Siguero, J. P., Oliva-Moreno, J., Vázquez, L. A., Aranda-Reneo, I., Reviriego, J., ... & Perez-Nieves, M. (2019). Health-related quality of life in type 1 diabetes mellitus pediatric patients and their caregivers in Spain: an observational cross-sectional study. *Current medical research and opinion.*

Appendix F: Author guidelines for empirical paper

Instructions to Authors

Contacts

View our full Editorial Board.

Editor-in-Chief

Avani C. Modi, Ph.D.
Cincinnati Children's Hospital Medical Center, University of Cincinnati, College of Medicine
Cincinnati, OH

Editorial Office

Susan Wood – jpepsy@gmail.com

General Information

The *Journal of Pediatric Psychology* is an official publication of the Society of Pediatric Psychology, Division 54 of the American Psychological Association, whose mission is to promote the health and psychological well-being of children, youth and their families through science and an evidence-based approach to practice, education, training, advocacy, and consultation. As such, the journal publishes articles related to theory, research, and professional practice in pediatric psychology.

We would like to inform our authors that we now detect plagiarism easily. *JPP* employs the CrossCheck plagiarism screening system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

Journal of Pediatric Psychology will not consider papers that have been accepted for publication or published elsewhere. Copies of existing manuscripts with potentially overlapping or duplicative material should be submitted together with the manuscript, so that the Editors can judge suitability for publication. The Editors reserve the right to reject a paper on ethical grounds.

Manuscript Preparation Instructions

The *Journal of the Pediatric Psychology* is an online only journal.

Cover Letter

The cover letter is an essential document and must be included with the submission of all new manuscript submissions and revisions. The cover letter should be addressed to the journal editor and include the following:

1. Manuscript title
2. Assurance that all authors agree with the content of the manuscript and order of authorship
3. Assurance the publication is not currently submitted to another journal
4. Information about duplicate and redundant publications
5. Notice of any conflicts of interest
6. Consideration for a special issue/series or if this is an invited commentary
7. Corresponding author contact information

Article Types

- Original research
- Review articles
- Invited commentaries (e.g., Student Journal Club Commentaries)

The *Journal of Pediatric Psychology* no longer accepts brief reports but will accept manuscripts that are shorter in length. Case studies and narrative reports of special cases that are more descriptive will not be considered for review.

Original Research

Original Research is the most common type of journal manuscript used to publish full reports of data from original research. Authors are also encouraged to visit the Equator Network for additional information on transparent reporting of all manuscript types.

See the following articles for detailed guidance concerning preparation of manuscripts:

- Editorial: Thoughts in Improving the Quality of Manuscripts Submitted to the *Journal of Pediatric Psychology*: How to Write a Convincing Introduction;
- Editorial: How to Report Methods in the *Journal of Pediatric Psychology*;
- Editorial: How to Write an Effective Results and Discussion Section for the *Journal of Pediatric Psychology*.

1. *Cohort and observational studies*. We welcome submission of the STROBE checklist; however, these are not required.
2. *Clinical Trials*
    - a. *Randomized controlled trials*: *JPP* is committed to enhancing the transparent reporting of all intervention studies. Please use the CONSORT checklist.
    - i. All Randomized Controlled Trials (RCTs) must be registered at or before the time of first patient enrollment in any primary registry of the WHO International

Clinical Trials Registry Platform (ICTRP) or in ClinicalTrials.gov. Provide the registry name and registry number in the cover letter and methods section.

- ii. If you are submitting a secondary data analysis from an RCT, please clearly indicate that it is a secondary data analysis in your manuscript and refer readers to the primary publication of outcomes. Consult with the editorial office if there are questions about reporting.
- b. *Pilot and feasibility trials*: Feasibility studies investigate whether something can be done and if/how it should proceed with further testing, while pilot studies test some aspect(s) of a future trial on a smaller scale. For pilot feasibility trials, we encourage authors to refer to our 2021 Editorial (Hilliard et al. 2021), which provides guidance on the reporting of pilot feasibility trials. Please use the CONSORT extension checklist.
- c. *Non-randomized trials*. A non-randomized clinical trial involves participants who are not assigned to different treatment groups by chance.

3. *Single Subject Studies*: As a journal that encourages submission of intervention studies, the Journal does accept, and encourages submission of, well-conducted single subject studies (N-of-1 designs). It is important to note that rigorous single subject designs are considered logical equivalents of Randomized Controlled Trials and include control conditions that support conclusions of causality. Previously published examples can be found in this journal including: Bernard, Cohen, & Moffett (2009). Authors considering submissions of case reports adopting N-of-1 methodology should consult the following sources within this journal: Cohen, Feinstein, Masuda, & Vowles (2014); Cushing, Walters, & Hoffman (2014); Rapoff & Stark (2008).

References:

- Bernard, R. S., Cohen, L. L., & Moffett, K. (2009). A token economy for exercise adherence in pediatric cystic fibrosis: A single-subject analysis. Journal of Pediatric Psychology, 34, 354-365.
- Cohen, L. L., Feinstein, A., Masuda, A., & Vowles, K. E. (2014). Single-case research design in pediatric psychology: Considerations regarding data analysis. Journal of Pediatric Psychology, 39, 124-137.
- Cushing, C. C., Walters, R. W., & Hoffman, L. (2014). Aggregated N-of-1 randomized controlled trials: Modern data analytics applied to a clinically valid method of intervention effectiveness. Journal of Pediatric Psychology, 39, 138-150.
- Rapoff, M., & Stark, L. (2008). Editorial: Journal of Pediatric Psychology statement of purpose: Section on single-subject studies. Journal of Pediatric Psychology, 33, 16-21.

Review articles

1. *Topical Reviews*: Topical reviews summarize contemporary findings, suggest new conceptual models, or highlight noteworthy or controversial issues in pediatric psychology. Topical reviews are not intended to provide short data summaries or

syntheses. Rather they are intended to foster new ways of thinking about a topic area and provide a direction for future research or practice.

2. *Systematic reviews and Meta-Analyses*: Systematic reviews provide a research synthesis of a body of literature using an explicit methodology to minimize bias and ensure conclusions are made from reliable findings. Authors of systematic reviews that do not include a meta-analysis must provide a clear justification in the manuscript explaining why such an analysis is not included for all or relevant portions of the report. Please note the PRISMA should be submitted with your manuscript.
3. *Scoping Reviews*: Scoping reviews determine the scope of a body of literature on a particular topic and identify the volume of the literature (i.e., available studies), and provide an overview of its focus. These are particularly helpful for emerging evidence. Please note the PRISMA-ScR should be submitted with your manuscript.

Please consult this editorial (New Guidelines for Publishing Review Articles in *JPP*) which further describes guidelines for review articles.

Invited commentaries

Commentaries are invited on all topics of interest in pediatric psychology, and the page length and scope should be discussed with the Editor. Un-invited commentaries will not be considered.

Reporting Guidelines

JPP requires that the relevant reporting guidelines be used for the following studies:

- Randomized trials: CONSORT
- Pilot and feasibility trials: CONSORT extension
- Non-randomized trials: TREND
- Scoping reviews: PRISMA-ScR
- Systematic reviews: PRISMA

Editable checklists for reporting guidelines may be found on the EQUATOR network site.

All intervention studies (RCTs and non-randomized trials) will undergo an additional review for transparent reporting conducted by the *JPP* Assistant Editor for Transparent Reporting. Review comments will be provided on the corresponding checklist. Authors will be required to address any identified reporting issues prior to publication.

Please clearly indicate the page numbers where each checklist item is reported in the manuscript. Please upload this checklist as supplementary material when you submit your manuscript for consideration. If a component of a checklist was not included in the manuscript, an explanation of the rationale for exclusion should be provided. Adherence to these reporting requirements provides standardization, ensures that important information has been included, and facilitates the peer review process.

We publish the final version of all required checklists as supplementary material. Thus, a final version of your CONSORT/TREND/PRISMA checklist will be requested as supplementary material prior to final acceptance of your manuscript. Please note the checklist should be reference in the methods section of your manuscript.

Organizing and Preparing Manuscripts

The *Journal of Pediatric Psychology* offers authors high-quality online publication. To ensure rapid and efficient publication, please follow the instructions below.

Type of Manuscript	Length Limit (Text, exclusive of title page, abstract, figures/tables, and references)	Total Number Figures/Tables	Maximum Number of references
Original	5,000 words (20 pages)	5	50
Reviews:			
• Topical	2,000 words	2	30
• Systematic/Scoping	6,250 words (25 pages)	8	Unlimited
Commentaries			
• Student	1,000 words	0	12
• General (Invited)	1,500 words	0	12

General Formatting

1. *File format*. Please save the main manuscript file as a .doc format.
2. *Font size and type*. Please use a standard font that is compatible with Windows, such as Times New Roman or Arial. Font size should be 12 pt.

3. *Double-spacing*. Submissions should be double-spaced throughout, with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12-15 characters per inch).
4. *Naming Files*. When naming your files, please use simple file names and avoid special characters and spaces. If you are a Macintosh user you must type the three-letter extension at the end of the file name you choose (e.g. .doc, .rtf, .tif).

Manuscript Formatting

The American Psychological Association Publication Manual (7th edition) should be used to guide manuscript formatting, with the exception of the title page and abstract as noted below.

Title Page

In addition to the APA Manual, the academic degrees of authors should be placed on the title page following their names.

Abstract

A structured double-spaced abstract of not more than 250 words should be included. The abstract should include the following parts:

- a. Objective (brief statement of the purpose of the study)
- b. Methods (summary of the participants, design, measures, procedure)
- c. Results (the primary findings of this work)
- d. Conclusions (statement of implications of these data)

Body of the Manuscript

- a. *Introduction*
- b. *Methods* - Informed consent and ethical treatment of study participants: Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s).
- c. *Results*
- d. *Discussion* - Clinical relevance of the research should be incorporated into the manuscripts. There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers.

Acknowledgements

Add appropriate acknowledgements, including information on the funding sources as noted below:

Funding

Details of all funding sources for the work in question should be given in a separate section entitled "Funding." The following rules should be followed:

- The sentence should begin: "This work was supported by . . ."
- The full official funding agency name should be given, i.e. "the National Cancer Institute at the National Institutes of Health" or simply "National Institutes of Health," not "NCI" or "NCI at NIH" (full RIN-approved list of UK funding agencies)
- Grant numbers should be complete and accurate and provided in parentheses as follows: "(grant number xxxx)."Multiple grant numbers should be separated by a comma as follows: "(grant numbers xxxx, yyyy)"
- Agencies should be separated by a semi-colon (plus 'and' before the last funding agency)
- Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number "to [author initials]."

Oxford Journals will deposit all NIH-funded articles in PubMed Central. See the Complying with funder policies page for details. Authors must ensure that manuscripts are clearly indicated as NIH-funded using the guidelines above.

Tables and Figures

Tables

Tables should be included as separate pages using acceptable formats (e.g., .doc files).

Figures

Figure resolution should be no less than 300 dpi for halftone color (photo) images, 600 dpi for combination halftones, and 1200 dpi for line art. Most standard figure formats are acceptable, such as .jpg, .gif, .tif, or .eps format. Please follow this link for useful information on preparing your figures for publication.

Permission for Illustrations and Figures

As an author, you must obtain permission for any material used within your manuscript for which you are not the rightsholder, including quotations, tables, figures, or images. In seeking permissions for published materials, first contact the publisher rather than the author. For unpublished materials, start by contacting the creator. Copies of each grant of permission should be provided to the editorial office. The permissions agreement must include the following:

- nonexclusive rights to reproduce the material in your paper in JPP
- rights for use in print and electronic format at a minimum, and preferably for use in any form or medium

- lifetime rights to use the material
- worldwide English-language rights

If you have chosen to publish under an open access license but have not obtained open access re-use permissions for third-party material contained within the manuscript, this must be stated clearly by supplying a credit line alongside the material with the following information:

- Title of content
- Author, Original publication, year of original publication, by permission of [rightsholder]
- This image/content is not covered by the terms of the Creative Commons license of this publication. For permission to reuse, please contact the rights holder.

Our publisher, Oxford University Press, provides detailed Copyright and Permissions Guidelines, and a summary of the fundamental information.

Diversity, Equity, and Inclusion Considerations

Terminology should be sensitive to the individual who has a disease or disability. The Editors endorse the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of children with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

Reporting and interpreting data related to Race and Ethnicity, including use of Bias-Free Language: Race and ethnicity are social constructs couched within a sociopolitical framework. Race and ethnicity are not genetic or biological categories. Care should be taken in the methods used to characterize samples in regard to race and ethnicity, reporting of this information, and interpretation of findings related to race and ethnicity categories.

Reporting of race and ethnicity (and associated intersectional factors such as culture, social structures, etc.) in the manuscript may vary across countries, languages, and cultures. Authors should provide sufficient rationale and justification for their data collection and reporting of race and ethnicity of their sample to be understood and appreciated by an international readership.

1. *Terminology*. Authors should follow the APA Style Guidelines on Bias-Free Language. The guidelines contain both general guidelines for writing about people without bias across a range of topics and specific guidelines that address the individual characteristics of age, disability, gender, participation in research, racial and ethnic identity, sexual orientation, socioeconomic status, and intersectionality.
    - Terms used to describe racial and ethnic groups (including spelling and capitalization) should adhere to bias-free language for Racial and Ethnic Identity
    - Similarly, authors should use systems centered language, showing awareness that disparities are due to inequities or deficiencies in social structures, systems, and processes rather than individual weaknesses or choices; for example, rather than stating that a population is “vulnerable” or “at risk”, identify the harms or social

structures that drive oppression and racism (see Upending Racism in Psychological Science: Strategies to Change How Science is Conducted, Reported, Reviewed & Disseminated for further details).

2. *Source used to identify race and ethnicity*. Clearly state the categories used to collect race and ethnicity data (e.g., Census data categories, funding agency categories) and the source of this information (e.g., participant self-report, electronic health record). Please indicate why those sources/categories were chosen (e.g., specified by the funding agency). For example, an author may state: "Reporting race and ethnicity in this study was mandated by the National Institutes of Health, consistent with the Inclusion of Women, Minorities, and Children policy".
3. *Reporting race and ethnicity for sample description*. Race/ethnicity of the study population should be reported in full in the Results section and/or in a participant characteristics table, as applicable. All race and ethnicity categories represented in the sample should be reported individually rather than collapsing data across groups (e.g., "Other"). Note: This reporting requirement does not dictate how race and ethnicity categories are used in analyses – authors may conduct statistical analyses with race and ethnicity variables combined as appropriate to their study goals and methods, with appropriate rationale.
4. *Interpretation of race and ethnicity findings and recognizing limitations*.
    - Avoid making assumptions and conclusions that whiteness is the norm; for example, do not assume White comparison groups are needed or that racial differences found in one group are abnormal in comparison to White individuals. For further details, see Upending Racism in Psychological Science: Strategies to Change How Science is Conducted, Reported, Reviewed & Disseminated
    - Consider the structural effects of racism, and histories of exclusion, mistreatment, and exploitation on the populations included in the research and/or in relation to the findings. Authors should avoid making conclusions that may be interpreted as placing blame on minoritized populations. As it relates to interpreting the study findings, racism should be named. Authors are encouraged to identify the form (interpersonal, institutional, systemic), the mechanism by which it may be operating, and other intersecting forms of oppression (such as based on sex, gender, sexual orientation, age, regionality, nationality, religion, or income) that may compound its effects. For further details, see: On Racism: A New Standard For Publishing On Racial Health Inequities
    - Authors should clearly acknowledge limitations of samples due to their lack of racial and ethnic representation (e.g., limited generalizability due to homogeneity of the sample). If data on racism or discrimination were not collected, authors should acknowledge this limitation in the interpretation of their findings. For further information on available scales of discrimination see Measuring Discrimination Resource [PDF]

Research Data Policy Statement

Where ethically feasible, *JPP* strongly encourages authors to make all data and software code on which the conclusions of the paper rely available to readers. Authors are required to include a data availability statement in their paper. When data and software underlying the research

article are available in an online source, authors should include a full citation in their reference list. For details of the minimum information to be included in data and software citations see the OUP guidance on citing research data and software.

Whenever possible, data should be presented in the main manuscript or additional supporting files or deposited in a public repository. Visit OUP's Research data page for information on general repositories for all data types, and resources for selecting repositories by subject area.

OUP is a signatory to the Center for Open Science's Transparency and Openness Promotion (TOP) Guidelines which served as a framework for our overall data policy approach, as well as the policies implemented by individual titles. OUP also supports the Joint Declaration of Data Citation Principles and the recommendations of the FORCE11 Software Citation Implementation Group, which is reflected in our data and software citation practices.

The *Journal of Pediatric Psychology* adheres to LEVEL 2 reporting of data availability and is defined as follows: Level 2: The journal encourages all authors, where ethically possible, to publicly release all data underlying any published paper. Authors must include a Data Availability Statement in their published article.

Data Availability Statements

The inclusion of a data availability statement is a requirement for papers published in *JPP*. Data availability statements provide a standardized format for readers to understand the availability of original and third-party data underlying the research results described in the paper. The statement should describe and provide means of access, where possible, by linking to the data or providing the required unique identifier.

Please use one of the following data availability statements within the Methods section of your manuscript.

Availability of data	**Sample statement**
Data are available in a repository and can be accessed via a DOI link.	*The data underlying this article are available in* [repository name, e.g. the Dryad Digital Repository], at https://dx.doi.org/[doi]
Data are available in a repository and	*The data underlying this article are available in* [repository name, e.g.

Availability of data	**Sample statement**
can be accessed using a unique identifier other than a DOI.	the GenBank Nucleotide Database] at [URL], and can be accessed with [unique identifier, e.g. accession number, deposition number].
All data are incorporated into the article and its online supplementary material.	*The data underlying this article are available in the article and in its online supplementary material.*
Data cannot be shared for ethical/privacy reasons.	*The data underlying this article cannot be shared publicly due to* [describe why the data cannot be shared, e.g. for the privacy of individuals that participated in the study]. *The data will be shared on reasonable request to the corresponding author.*
Data available on request.	Data available on request.
Data is owned by a third party.	*The data underlying this article were provided by* [third party] *under licence / by permission. Data will be shared on request to the*

Availability of data	Sample statement
	corresponding author with permission of [third party].
Data generated at a large-scale facility.	*The data underlying this article were accessed from* [name of large-scale facility, include URL and unique identifier for dataset, if available]. *The derived data generated in this research will be shared on reasonable request to the corresponding author.*
Data derived from a source in the public domain.	*The data underlying this article are available in* [repository name, e.g. Zenodo], at https://dx.doi.org/[doi]. *The datasets were derived from sources in the public domain:* [list sources, including URLs].
Data are subject to an embargo.	*The data underlying this article are subject to an embargo of* [period of embargo, e.g. 12 months from the publication date of the article]. *Once the embargo expires the data will be available* [give details of availability, e.g. in a repository plus embargoed link; upon reasonable request, etc.].

Availability of data	Sample statement
There are no new data associated with this article.	*No new data were generated or analyzed in support of this research.*

CRediT

The Journal uses the contributor roles taxonomy (CRediT), which allows authors to describe the contributor roles in a standardized, transparent, and accurate way. Authors should choose from the contributor roles outlined on the CRediT website and supply this information upon submission.

These include the following 14 roles: Conceptualization, Data curation, Formal Analysis, Funding Acquisition, Investigation, Methodology, Project Administration, Resources, Software, Supervision, Validation, Visualization, Writing-Original draft, Write-Review and Editing.

You may choose multiple contributor roles per author. Individual contributors can be assigned multiple roles and a given role can assigned to multiple contributor. Where multiple individuals serve in the same role, the degree of contribution should be specified as ‘lead,’ ‘equal,’ or ‘supporting.’

Corresponding authors should assume responsibility for role assignment, and all contributors should be given the opportunity to review and confirm assigned roles prior to submission. Any other individuals who do not meet authorship criteria and made less substantive contributions should be listed in your manuscript as non-author contributors with their contributions clearly described. Following manuscript submission, any changes to contributor roles require the approval of the editor.

Author Forms Required for Accepted Publications

- Certification of Compliance with APA Ethical Principles
- Conflict of Interest Statement

Author Checklist for Manuscript Central

Steps	Options
Step 1	
Manuscript Type	Original Research, Commentary, Systematic Review, Scoping Review, Topical Review, Editorial, Letter to the Editor, Introduction to Special Issue
Title	Please provide a title
Abstract	250 word maximum and double-spaced as noted above
Step 2	
File upload	• Main document including the title page; • All tables and figures separately • Appropriate checklists (e.g., CONSORT, PRISMA) • Supplementary materials, which includes the Cover Letter

Steps	Options
Confirmation statement	Please check the box that notes single blind review process and compliance with information in the title page
Step 3	
Key words	Choose at least 4 key words
Step 4	
Authors and Institution	Add all authors, co-authors and place them in the appropriate order of authorship.
CRediT	Please complete the contributions of each author to the manuscript, as well as whether they led, supported or equally led that role
Confirmation statement	Please check the box that User Account Details have been updated to ensure timely communication.
Step 5	

Steps	Options
Funding	Please note whether there was funding for the submission, including funder, grant/award number
Conflict of Interest	Provide appropriate details
Resubmission (if applicable)	Note whether this is a resubmission and provide prior manuscript number
Special/Themed Issue or Section	Please endorse this statement and provide information here and in the cover letter if this manuscript should be considered for a special series, special section, or special issue
Word count	Please provide a count of the complete text, including abstract, text, references, and figure legends
Number of Tables	Please add the number of tables
Number of Figures	Please add the number of figures

Steps	Options
Journal related conflicts	Please note if you serve as an Editor or Associate Editor for the *Journal of Pediatric Psychology*
Confirmation Statement	• APA ethical guidelines adherence • Editorial Policy and Authors Checklist
Research Data Availability Statement	Please ensure you check this box and add a statement in your manuscript and highlight the page number it is located. All manuscripts are required to have a statement as noted in the Data Availability Statements.
Intervention/Treatment Study Information (if applicable)	Please check the appropriate box on whether your study is an intervention/treatment study. If yes, please provide information on whether the trial is randomized and whether the trial has

Steps	Options
	been registered. Please upload the appropriate checklist.
Confirmation Statement	Please check the statement related to retention of the corresponding author's email address for communication purposes.
Step 6	
Review and Submit	Review all the proofs and once finalized, submit your manuscript.

Additional Guidance

The following links provide additional guidance for authors and reviewers:

- Conflicts of Interest
- NIH Policy
- Committee on Publication Ethics (COPE)
- Open Access Option for Authors

Language Editing

If you are not confident in the quality of your English, you may wish to use a language-editing service to ensure that editors and reviewers understand your paper. Language editing is optional and does not guarantee that your manuscript will be accepted. Edited manuscripts will still undergo peer review by the journal. Authors are liable for all costs associated with such services.

Submitting a Revised Manuscript

- Log on to the online submission web site as before and, in the 'Author Centre', click on 'Manuscripts with Decisions'. At the bottom of the screen you will see those manuscripts

that require a revision (or that have been revised). Create a revision of this manuscript by clicking on 'create a revision' under Actions. You will now be able to see the editor and reviewer comments and will be able to respond to these.

- You will need to upload the files that constitute your revised manuscript. To facilitate the production process, it is essential that you upload your revised manuscript as a .doc, .rtf, or .tex file, and not in .pdf format. If you wish to finish this another time, you will find the manuscript in your 'Revised manuscripts in draft' list.
- Please be sure to upload a title page with your article containing the title, author group, author affiliations, corresponding author, corresponding author's physical and e-mail address, key words, and any acknowledgments.
- If you click on 'View comments/respond' you will see the editor's letter to you together with the referees' comments. You may cut and paste your responses into the text areas at the bottom of the screen.

Appendix G: Generalised Anxiety Disorder Scale (GAD-7)

GAD-7

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

Total Score ___ = Add Columns ___ + ___ + ___

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

Appendix H: Patient Health Questionnaire (PHQ-9)

PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

ID #: _____ DATE:_____

Over the last *2 weeks,* how often have you been bothered by any of the following problems? *(use "✓" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite — being so figety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself	0	1	2	3
		add columns	+	+

(Healthcare professional: For interpretation of TOTAL, please refer to accompanying scoring card). TOTAL:

10. If you checked off *any problems,* how *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all _____ Somewhat difficult _____ Very difficult _____ Extremely difficult _____

A2663B 10-04-2005

Appendix I: Quality of Life Scale (QOLS)

Quality of Life Scale (QOLS)

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

	Delighted	Pleased	Mostly Satisfied	Mixed	Mostly dissatisfied	Unhappy	Terrible
Material comforts; home food, conveniences, financial security	7	6	5	4	3	2	1
Health – being physically fit and vigorous	7	6	5	4	3	2	1
Relationships with parents, siblings and other relatives – communicating, visiting, helping	7	6	5	4	3	2	1
Having and rearing children	7	6	5	4	3	2	1
Close relationships with spouse or significant other	7	6	5	4	3	2	1
Close friends	7	6	5	4	3	2	1
Helping and encouraging others, volunteering, giving advice	7	6	5	4	3	2	1
Participating in organizations and public affairs	7	6	5	4	3	2	1
Learning – attending school, improving understanding, getting additional knowledge	7	6	5	4	3	2	1
Understanding yourself – knowing your assets and limitations – knowing what life is about	7	6	5	4	3	2	1
Work – job or in home	7	6	5	4	3	2	1
Expressing yourself creatively	7	6	5	4	3	2	1
Socialising – meeting other people, doing things, parties etc.	7	6	5	4	3	2	1
Reading, listening to music, or observing entertainment	7	6	5	4	3	2	1
Participating in active recreation	7	6	5	4	3	2	1
Independence, doing for yourself.	7	6	5	4	3	2	1

Appendix J: Parent Trauma Response Questionnaire

Parent Trauma Response Questionnaire (PTRQ)

[Parent Appraisals Scale]

The following questions are about thoughts that some parents have after their child has had a very frightening experience. Please indicate how much you agree with each one.

		Don't agree at all	*Agree slightly*	*Agree quite a lot*	*Agree completely*
1	Our family will never be the same again.	[ ]	[ ]	[ ]	[ ]
2	I keep thinking how it could have been even worse than it was.	[ ]	[ ]	[ ]	[ ]
3	My child has been permanently damaged by the frightening event.	[ ]	[ ]	[ ]	[ ]
4	My child might easily go to pieces if I don't protect them from their fears.	[ ]	[ ]	[ ]	[ ]
5	Another parent would not have let this happen.	[ ]	[ ]	[ ]	[ ]
6	My child is not going to be able to cope in the future now.	[ ]	[ ]	[ ]	[ ]
7	I ask myself over and over why this happened to my child.	[ ]	[ ]	[ ]	[ ]
8	I get upset or angry when I am reminded of what happened to my child.	[ ]	[ ]	[ ]	[ ]
9	Others must wonder if I am safe looking after children.	[ ]	[ ]	[ ]	[ ]
10	My child would not be able to deal with being reminded of what happened.	[ ]	[ ]	[ ]	[ ]
11	If my child has any more stress it will seriously damage him/her.	[ ]	[ ]	[ ]	[ ]
12	I failed to look after my child properly.	[ ]	[ ]	[ ]	[ ]
13	My child is always going to be anxious and upset now.	[ ]	[ ]	[ ]	[ ]
14	I keep on wishing that I could go back in time and stop the event from happening.	[ ]	[ ]	[ ]	[ ]
15	My child was so badly scared by the frightening event that they won't get over it.	[ ]	[ ]	[ ]	[ ]

		Don't agree at all	*Agree slightly*	*Agree quite a lot*	*Agree completely*
16	Our family cannot recover from this sort of stress.	[ ]	[ ]	[ ]	[ ]
17	Our family will not get back to the way we were before the event happened.	[ ]	[ ]	[ ]	[ ]
18	I am not going to risk my child being hurt again in the future.	[ ]	[ ]	[ ]	[ ]
19	I should have done more to keep my child safe.	[ ]	[ ]	[ ]	[ ]
20	Others have judged me for what happened.	[ ]	[ ]	[ ]	[ ]
21	Others blame me for what happened to my child.	[ ]	[ ]	[ ]	[ ]
22	It is extremely upsetting to imagine how my child felt during the frightening event.	[ ]	[ ]	[ ]	[ ]
23	I find it hard to control my feelings about what happened to my child.	[ ]	[ ]	[ ]	[ ]
24	Our family cannot cope very well with stress now.	[ ]	[ ]	[ ]	[ ]
25	Anything could happen to my child when I am not around.	[ ]	[ ]	[ ]	[ ]
26	I could not bear it if my child was ever hurt or threatened again.	[ ]	[ ]	[ ]	[ ]
27	I can't bear to think about what happened to my child.	[ ]	[ ]	[ ]	[ ]
28	I keep wishing we could have the life we had before the event happened.	[ ]	[ ]	[ ]	[ ]
29	I can't stop thinking about what could have been done to stop the event from happening.	[ ]	[ ]	[ ]	[ ]
30	Others must think I am a terrible parent.	[ ]	[ ]	[ ]	[ ]

Appendix K: Internal consistency statistics for measures

	Number of items	Internal consistency	
		n	Cronbach's α
Measure			
GAD-7	7	74	.92
PHQ-9	9	73	.88
QOLS	16	70	.94
Parent appraisal subscales			
Permanent damage	12	73	.9
Rumination	11	73	.91
Parent blame	7	73	.91
Parent behaviour subscales			
Behavioural avoidance	3	73	.8
Cognitive avoidance	3	74	.74
Overprotection	6	74	.83

Appendix L: Parent information sheet (final version)

Participant Information Sheet

Psychological impact of Paediatric Intensive Care on parents and children; how does this impact on Quality of Life?

You are being invited to take part in a research study about the psychological impact on children and their primary caregivers after being admitted to a Paediatric Intensive Care Unit (PICU). The study aims to consider how the psychological impact of admission affects family's quality of life after they have been discharged. Before you decide if you would like to take part, we would like you to understand why the research is being done and what it would involve for you. Please take time to read the following information and take time to decide if you would like to take part.

What is the purpose of the study?

Being admitted to Paediatric Intensive Care can be a difficult time for children, and also for their parents and caregivers. As well as having a potentially physical impact, experiencing a traumatic event can also have a significant psychological impact. Research shows that people can experience higher levels of anxiety, lower mood and can sometimes develop Post Traumatic Stress Disorder (PTSD). PTSD is an anxiety disorder which is caused by very stressful, frightening or distressing events. It causes symptoms such as reliving the traumatic event through flashbacks or nightmares which often impacts on people's ability to sleep and can therefore have a general impact on their day-to-day life.

We are investigating if there are ways in which we can identify factors that predict the development of PTSD in children and their caregivers, what role the potential PTSD plays in the parent and child's quality of life following discharge and what the relationship is between parent and child quality of life and PTSD. The findings of this study will help us to understand more about the psychological impact of admission to Paediatric Intensive Care Units and to therefore identify better ways of helping and supporting children and their families.

The study is being completed in support of the University's Doctorate in Clinical Psychology course at the University of East Anglia (UEA). Trainee Clinical Psychologists will work on the project under the supervision of Professor Richard Meiser-Stedman, Chief Investigator

Why have I been invited to take part?

As you are a parent or caregiver of a child who has been admitted to a UK Paediatric Intensive Care in the last two years.

What does the study involve?
This online survey contains a number of questionnaires. The first 5 ask for information about your psychological well-being following your child's discharge from PICU. They ask about your current mood, anxiety levels, and quality of life. If your child is aged 3 or over, you will be asked to complete 2 further questionnaires. The following 2 questionnaires ask for information about your child's psychological well-being following their discharge from PICU. They ask about your child's mood, anxiety levels, their quality of life and their experience of being in a PICU. Both are completed by you. These questionnaires take around 25 minutes to complete in total.

Additionally, you will be asked about the length of your child's admission and the length of time they were ventilated on PICU.

What do I need to do to take part?
If you decide to take part in the study, you will need to electronically tick the consent form below. The questionnaires will be handled anonymously and the information will be analysed and then written about in an article without your name being mentioned.

Do I have to take part?
No. *It is up to you to decide whether or not to take part*. Your participation is optional. If you decide not to take part, that decision will not affect the care you or your child receive in any way.

If you do choose to take part, you are also free to withdraw your participation in the research at any point during the data collection period which is likely to be until January 2020. Any information you have provided up until this point will be confidentially destroyed, and your data will not be included in the analysis.

How will the information I provide be kept confidential?
All information you provide will be securely stored in a locked cabinet, in a locked office and kept anonymous and confidential. Your email address will be securely kept at the University of East Anglia. The reason for this, is so we can provide feedback on the study results if this requested. Your own GP will not be notified of your participation in the study.

Any data collected in the study may be looked at by individuals from the University of East Anglia, or from regulatory authorities or NHS Trusts for the purposes of auditing only. Otherwise, only those individuals involved in the research process will have access to the data.

What will happen to the results of the research study?
The results of this research will be written up as a thesis as part of the researcher's Doctorate in Clinical Psychology. All information will be reported as anonymous data. The results will also be written into articles and potentially published in academic journals so that others can learn from the findings. We will be pleased to send you a summary of the results in due course if you indicate this on the consent form.

The information collected in relation to the study will be kept for 10 years at the University of East Anglia in line with the UEA Research Data Management Policy.

Are there any benefits of taking part?
This study will improve our understanding of the long-term psychological impact of admission to paediatric intensive care on both children and their families. The study may identify specific groups of children or caregivers who need extra support and so may benefit from the development of support services following discharge in the future.

Are there any disadvantages or risks of taking part?
It is possible that some of the questions may be difficult to answer. If this is the case you can stop completing the questionnaire at any point. If you experience any distress or concerns after completing the questionnaires you can access support and advice through contacting:

- Your GP
- Samaritans is a charity which provides confidential emotional support for people who are experiencing feelings of distress, despair, or suicidal thoughts.
    - The support helpline is: 116 123 (UK)
    - Alternatively, you can access further information via their website: www.samaritans.org/

If your responses on the questionnaires indicate high levels of stress or anxiety or significant low mood, we will contact you to let you know this and would advise you to consider seeking support from your GP.

Complaints
If you have any concerns about this study please feel free to contact Professor Niall Broomfield, Norwich Medical School, Room 0.22, University of East Anglia, Norwich NR4 7TJ. Telephone: 01603 591217 or the Patient Advice and Liaison Service (PALS) at Addenbrooke's hospital, PALS and Complaints Department, Box 53, Cambridge University Hospitals NHS Foundation Trust, Hills Road, Cambridge, CB2 0QQ. Telephone: 01223 216756. Email: pals@adenbrookes.nhs.uk

Who is organising and funding the research?
This research is being run by Professor Richard Meiser-Stedman of the University of East Anglia, the Chief Investigator alongside Dr Nazima Pathan of the University of Cambridge and is funded by the University of East Anglia Doctoral Programme in Clinical Psychology. Trainee Clinical Psychologists will be involved in undertaking the research under supervision of Professor Meiser-Stedman.

Who has reviewed this study?
Before any research goes ahead in the NHS it needs to be checked by an independent group of people called a Research Ethics Committee. Their job is to ensure that any proposed research is ethical and to protect the safety, rights, well-being, and dignity of participants. This study has been reviewed and approved by Cambridge South Research Ethics Committee.

Further information If you have any questions, or would like more information, please contact Hayley Ryan, h.ryan@uea.ac.uk, Trainee Clinical Psychologist.

Alternatively, please find below contact details for the Chief Investigator and Primary Supervisor:

Chief investigator and primary supervisor:
Professor Richard Meiser-Stedman
Department of Clinical Psychology & Psychological Therapies, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ

Email: r.meiser-stedman@uea.ac.uk
Phone: 01603 593601

Thank you for taking time to read this information sheet, please keep this information for your records.

Appendix M: Parent consent form (final version)

Participant Identification number: _____

CONSENT FORM

Title of Project: Post Traumatic Stress Disorder and Quality of Life in children and their caregivers following admission to Paediatric Intensive Care.

Chief Investigator: |Prof Richard Meiser-Stedman, Clinical Psychologist.

Please initial **all** boxes:

1. I confirm that I have read and understood the information sheet dated **12.10.2021 (version 7)** for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my, or my child's, medical care or legal rights being affected. ☐

3. I agree to take part in the above study. ☐

4. I wish to be informed by email of the study findings in the future.

   Yes / No (please circle)

Appendix N: IRAS approval letter

NHS
Health Research Authority

East of England - Cambridge South Research Ethics Committee

Equinox House
City Link
Nottingham
NG2 4LA

Tel: +442071048276

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

29 December 2021

Miss Lucy Wilcoxon
[redacted]

Dear Miss Wilcoxon

Study title:	**Psychological Outcomes following Paediatric Intensive Care Admission for Children and their parents/caregivers: Predictors, Interactions and Impact on Quality of Life**
REC reference:	**18/EE/0035**
Protocol number:	**1**
Amendment number:	**Amendment 3**
Amendment date:	**12 October 2021**
IRAS project ID:	**230001**

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

Ethical opinion

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Amendment tool]	Amendment 3	12 October 2021
Other [Document to support PIPIC amendment tool 12.10.2021]	12.10.2021	12 October 2021
Other [Debrief letter]	2	12 October 2021
Other [IRAS_Form_21122021]		21 December 2021
Participant consent form [PIPIC plus consent form v6 12.10.2021]	6	12 October 2021
Participant information sheet (PIS) [PIPIC-PLUS Parent Information Sheet]	7	12 October 2021

Membership of the Committee

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

Working with NHS Care Organisations

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

Amendments related to COVID-19

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

Statement of compliance

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

HRA Learning

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

IRAS Project ID - 230001:	**Please quote this number on all correspondence**

Yours sincerely

Dr Leslie Gelling
Chair

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

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Miss Lucy Wilcoxon*

East of England - Cambridge South Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 06 December 2021

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Leslie Gelling	Principal Academic in Adult Nursing	Yes	
Dr Elisabeth George	Health Technology Assessment Expert	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Sarah Ferry	Approvals Administrator

Appendix O: Minor amendment approval

Amendment Tool

v1.5 25 Mar 2021

For office use

QC: No

Section 1: Project information

Short project title*:	PIPIC (Psychol. impact of Intensive Care on children & caregivers)
IRAS project ID* (or REC reference if no IRAS project ID is available):	230001
Sponsor amendment reference number*:	Amendment 3
Sponsor amendment date* (enter as DD/MM/YY):	12 October 2021
Briefly summarise in lay language the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study. If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained (note: this field will adapt to the amount of text entered)*:	Change of Chief Investigator; change of named contact (i.e PIS and consent forms, debrief sheet, distress follow up letter); add team member (Hayley Ryan). See separate word document for fuller description.

Project type (select):	◉ Specific study ○ Research tissue bank ○ Research database			
Has the study been reviewed by a UKECA-recognised Research Ethics Committee (REC) prior to this amendment?:	◉ Yes	○ No		
What type of UKECA-recognised Research Ethics Committee (REC) review is applicable? (select):	◉ NHS/HSC REC ○ Ministry of Defence (MoDREC)			
Is all or part of this amendment being resubmitted to the Research Ethics Committee (REC) as a **modified amendment** (i.e. a substantial amendment previously given an unfavourable opinion)?	○ Yes	◉ No		
Where is the NHS/HSC Research Ethics Committee (REC) that reviewed the study based?:	England	Wales	Scotland	Northern Ireland
	◉	○	○	○
Was the study a clinical trial of an investigational medicinal product (CTIMP) OR does the amendment make it one?:	○ Yes	◉ No		
Was the study a clinical investigation or other study of a medical device OR does the amendment make it one?:	○ Yes	◉ No		
Did the study involve the administration of radioactive substances, therefore requiring ARSAC review, OR does the amendment introduce this?:	○ Yes	◉ No		
Did the study involve the use of research exposures to ionising radiation (not involving the administration of radioactive substances) OR does the amendment introduce this?:	○ Yes	◉ No		
Did the study involve adults lacking capacity OR does the amendment introduce this?:	○ Yes	◉ No		
Did the study involve access to confidential patient information outside the direct care team without consent OR does the amendment introduce this?:	○ Yes	◉ No		
Did the study involve prisoners OR does the amendment introduce this?:	○ Yes	◉ No		
Did the study involve children OR does the amendment introduce this?:	◉ Yes	○ No		
Did the study involve NHS/HSC organisations prior to this amendment?:	◉ Yes	○ No		
Did the study involve non-NHS/HSC organisations OR does the amendment introduce them?:	○ Yes	◉ No		
	England	Wales	Scotland	Northern Ireland
Lead nation for the study:	◉	○	○	○
Which nations had participating NHS/HSC organisations prior to this amendment?	☑	☐	☐	☐
Which nations will have participating NHS/HSC organisations after this amendment?	☑	☐	☐	☐

Section 3: Declaration(s) and lock for submission

Declaration by the Sponsor or authorised delegate

- I confirm that the Sponsor takes responsibility for the completed amendment tool
- I confirm that I have been formally authorised by the Sponsor to complete the amendment tool on their behalf

Name [first name and surname]:*	Tracy Moulton
Email address:*	researchsponsor@uea.ac.uk

Lock for submission

Please note: This button will only become available when all mandatory (*) fields have been completed. When the button is available, clicking it will generate a locked PDF copy of the completed amendment tool which must be included in the amendment submission. Please ensure that the amendment tool is completed correctly before locking it for submission.

Lock for submission

After locking the tool, proceed to submit the amendment online. The "Submission Guidance" tab provides further information about the next steps for the amendment.

Section 4: Review bodies for the amendment

Please note: This section is for **information only**. Details in this section will complete automatically based on the options selected in Sections 1 and 2.

	Review bodies																	
	UK wide:						England and Wales:				Scotland:				Northern Ireland:			
	REC	Competent Authority MHRA - Medicines	Competent Authority MHRA - Devices	ARSAC	Radiation Assurance	UKSW Governance	REC (MCA)	CAG	HMPPS	HRA and HCRW Approval	REC (AWIA)	PBPP	SPS (RAEC)	National coordinating function	HSC REC	HSC Data Guardians	Prisons	National coordinating function	Category:
Change 1:	Y					Y				(Y)									C
Change 2:	N					N				N									N/A
Change 3:	N					(Y)				(Y)									C
Overall reviews for the amendment:																			
Full review:	Y					Y				N									
Notification only:	N					N				Y									
Overall amendment type:	Substantial																		
Overall Category:	C																		

For national coordinating function office use:	
Update HARP:	This amendment may involve an update to contact details, project end date, or other project details. Ensure that HARP is updated with the current details. If this is the only change, no further study-wide review is required.

Appendix P: Letter of access for research

Research and Development Department

Hayley Ryan

Trainee Clinical Psychologist

CPFT

9th June 2021

Box 277
Addenbrookes Hospital
Hills Road
Cambridge
CB2 0QQ

R&D Manager: Stephen Kelleher

stephen.kelleher@addenbrookes.nhs.uk
HR Manager: Nacha Samaila
01223 274660
nacha.samaila@addenbrookes.nhs.uk
HR Advisor: Charlotte Wain
01223 348496
charlotte.wain@addenbrookes.nhs.uk

Dear Hayley

Letter of access for research – A094772 - PIPIC

Accepting this letter, confirms your right of access to conduct research through Cambridge University Hospitals NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on **9th June 2021** and ends on **27th September 2023** unless terminated earlier in accordance with the clauses below.

As an existing NHS employee you do not require an additional honorary research contract with Cambridge University Hospitals NHS Foundation Trust. This organisation is satisfied that the research activities that you will undertake in the organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in this organisation. Evidence of checks should be available on request to Cambridge University Hospitals NHS Foundation Trust

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project and you have provided the Trust's R&D department with written evidence that you have completed GCP training from an EU institution before you start your research.

You are considered to be a legal visitor to Cambridge University Hospitals NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this organisation, in particular that of an employee.

While undertaking research through Cambridge University Hospitals NHS Foundation Trust , you will remain accountable to your employer **CPFT** but you are required to follow the reasonable instructions of your nominated manager **Dr Nazima Pathan and Dr Anna Maw** in this organisation or those given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Cambridge University Hospitals NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Cambridge University Hospitals NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Cambridge University Hospitals NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and Cambridge University Hospitals NHS Foundation Trust R&D HR Office prior to commencing your research role.

You are required to ensure that all information regarding patients or staff remains secure and strictly confidential at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 2018. Furthermore, you shouldbe aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The organisation will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 2018. Any breach of the Data Protection Act 2018 may result in legal action against you and/or your substantive employer.

You must keep confidential any information regarding the design, conduct or management or results of any research unless authorised in writing by the Trust to disclose it. You must acknowledge the Trust's contribution in any publication arising out of this Agreement.

Subject to any agreement with your employer to the contrary (e.g. as part of a multi-centre study), any Intellectual Property (IP) resulting from research carried out under this Agreement will be the property of the Trust and you will do all things necessary or desirable to give effect to the assignment of this IP.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the organisation accepts no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend the organisation terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation(s) or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

INDUCTION AND MANDATORY TRAINING

You are responsible for familiarising yourself with the Trust's policies and mandatory training courses such as Moving and Handling, Health and Safety, Fire Training etc and be aware of the responsibility to maintain a safe environment for patients, staff and visitors

Your host Manager will ensure that you receive a comprehensive Departmental Induction. They will also provide you with details of Corporate Induction, research specific induction and annual Mandatory Refresher Training.

If your letter of access is for more than 3 months, you must attend Corporate Induction. Where your letter of access is for more than 12 months, you must attend annual Mandatory Refresher Training.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to

conduct research, or your role in research changes, you must inform the organisation that employs you through its normal procedures. You must also inform your nominated manager in this organisation and the R&D office in this organisation.

Yours sincerely

Stephen Kelleher

R&D Manager, Cambridge University Hospitals NHS Foundation Trust

cc: Lucy Smith – lucy.smith@cpft.nhs.uk

Dr Nick Oliver – nick.oliver@cpft.nhs.uk

PI – Dr Nazima Pathan - nazima.pathan@addenbrookes.nhs.uk

Appendix Q - Current trainee involvement in recruitment

Previous trainee involvement (FW):

The empirical study within this thesis formed part of an ongoing research project. A previous trainee (FW) had completed a cross-sectional questionnaire-based study focusing on the acute responses of parents during their child's admission to a paediatric intensive care unit (PICU). Parents completed the Posttraumatic Adjustment Screen (PAS) during their child's admission. This is a 10-item screening questionnaire based on known risk factors for the development of depression and PTSD following a traumatic experience.

The original intention for the project at this stage was to ask these parents to complete the Generalised anxiety disorder Questionnaire (GAD-7), Patient Health Questionnaire (PHQ-9), Quality of Life Scale (QOLS) and Parent Trauma Response Questionnaire PTRQ and Impact of Events Scale (IES) at 3-months and 12-months post-admission. This would have enabled the research term to look at psychological distress, appraisals and behaviours at three different time-points. FW sent the questionnaires to these parents 3 months post-admission, to which 53 participants responded and completed the measures. FW then sent an email asking for parents to complete questionnaires 12 months post-admission. However, the retention rate was only 45%. Therefore, with an aim to increase the sample size, it was decided that further recruitment would be established through social media streams. FW posted adverts on social media PICU groups describing the study and prompting people to email FW if they would like to participate in the study. This method of recruitment yielded a further 13 participants. Information regarding time since trauma was not collected. This is reported as a potential confounding variable in the empirical study.

Unfortunately, due to an IT issue, the IES was not properly administered and data relating to PTSD could not be used.

Current trainee involvement (HR):

With an aim to increase the sample size further, the current trainee and author of this thesis (HR) approached additional social media PICU groups and gained consent to post the advertisement. Due to challenges with recruitment, this yielded only 2 participants. In supervision, discussions were had about what the barriers to recruitment could have been. For example, the limited number of social media PICU groups, the impact of COVID-19, and parents not having the time and energy to participate in research.

Following guidance in research supervision, it was decided to pool together data from the 53 participants who completed the measures at 3 months post-admission, data from an additional 6 participants who had completed the measures at 12 months post-admission, but not at 3 months, and data from the 15 participants recruited through social media. This led to the total sample size of 74 participants reported in the empirical study of this thesis.