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CHILD ILLNESS AND PARENTAL MENTAL HEALTH AND WELL-BEING

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Summary of the Major Research Project

Section A: This report aimed to provide an updated review of the literature on parent sleep in the context of having a child with a physical illness. It focused on psychological factors that may explain sleep difficulties and explores potential consequences of sleep disturbance. A systematic search of four databases yielded 36 studies that were eligible for review. Studies showed a high proportion of parents experiencing sleep disruptions and explored the relationship between parent sleep and mental health. Factors associated with sleep disruption included child illness-related factors, environmental and social factors.

Section B: Infant Gastroesophageal Reflux Disease (GORD) occurs when symptoms of reflux require medical intervention. Parents whose infants experience some of the symptoms of GORD are at risk of poorer mental health. This study aimed to estimate the prevalence of mental health difficulties in this population, to test predictors of parental mental health, and to explore differences between different types of GORD. Participants reported significantly higher rates of anxiety and depression than those found in perinatal or general population samples. Results provided support for the predictive power of self-compassion, illness perceptions and illness uncertainty, above and beyond parent satisfaction with sleep, social and relationship support and infant feeding.

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Major Research Project (MRP) Section A: Literature Review

The relationship between parental sleep and mental health in the context of child illness: A narrative review.

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Abstract

A previous review found an increased prevalence of sleep disruption in parents of children with a chronic illness. The authors identified a range of potential factors associated with sleep disruptions and possible consequences on mental health. Since then a substantial amount of additional research has explored sleep in this population. This paper aimed to provide an updated review of the literature on parent sleep in the context of having a child with a physical illness. It focuses on psychological factors that may explain sleep difficulties and explores potential consequences of sleep disturbance. A systematic search of four databases yielded 36 studies that were eligible for review. Studies covered a range of child illnesses and used a variety of measures of sleep. Most studies were quantitative, employing a cross-sectional design. The majority of studies show a high proportion of parents experiencing sleep disruptions. Factors associated with sleep disruption included child illness-related factors, environmental and social factors. Sixteen studies explored parent sleep and its relationship with mental health, providing evidence suggestive of a relationship. However, methodological issues limit the ability to draw conclusions regarding apparent associations. Further research using longitudinal designs with age-matched control groups is needed.

Keywords: Child Illness, Parent, Sleep, Parent Mental Health, Chronic illness

1. Introduction

1.1. Parental Well-being and Parent-Child Attachment

The importance of the attachment relationship (Bowlby, 1969) between the mother (or primary caregiver) and child from is well documented. Babies with a primary caregiver who is responsive to their physical, social and emotional needs typically thrive (Waldfogel, 2006). To meet these needs, parents must be readily available and psychologically attuned with their baby (Jonsson et al., 2001). Securely attached infants, whose needs are consistently met, have a range of better outcomes including more positive social relationships, better cognitive function, physical and mental health as they progress through child and adult life (Ranson & Urichuk, 2008; Manning & Gregoir, 2006). Parental mental health difficulties in this early period can negatively impact on the attachment relationship formed (Puckering et al., 2010).

Whilst the early years appear particularly critical in forming attachment relationships and setting foundations, parent mental health and well-being is not just important during a child's infancy. Extensive literature details the negative impact of parental (specifically maternal) depression on child social and emotional well-being and behaviour (Goodman et al., 2011). For example, research has shown that adolescents with a parent who had experienced an episode of depression were at increased risk of developing depression themselves following exposure to a stressful event (Bouma et al., 2008) and parental depressive symptoms have been strongly related to child reports of stress and internalizing problems (Sieh et al., 2013). Additionally, parent anxiety has been related to child anxiety and depressive symptoms (Burstein et al., 2010). A wide range of factors may influence parental mental health, one of which is the impact of childhood illness.

1.2. Impact of Child Illness on Parental Well-being

Children frequently become unwell throughout childhood, and caring for a transiently sick child is a normal part of parenting (Chandran, 2017). Chronic illnesses however affect a smaller (although substantial) number of families, with prevalence estimates ranging from 13-27% (Van Cleave et al., 2010). Whilst there is variability in how chronic illness is defined, there is agreement that to be considered “chronic” a condition must be persistent (requiring medical follow-up or lasting at least three months) and have an impact on the development of the child (Chandran, 2017; Van der Lee, 2007).

Given the wide range of illness “types”, severity levels, and age at which they may be diagnosed, there are an equally large range of symptom clusters which will undoubtedly have a unique physical, emotional and social impact on the child and family. However, in addition to the impact of any particular condition, families with chronically ill children have a variety of challenges in common (Suryavanshi & Yang, 2016).

In recent years, the body of literature about the impact of a wide range of chronic child physical illnesses on parental well-being has grown substantially. A wealth of research highlights how parenting a child with an ongoing or chronic illness can be extremely difficult and distressing (e.g. Zhao et al., 2019; Cohn et al., 2020; Sanchez-Egea et al., 2019). Numerous studies and reviews demonstrate how caring for a child with an illness can impact on the psychological health of parents (e.g. Wen & Chu, 2020, Biber et al., 2019; Fairfax et al., 2019).

Understandably, there is a significant emotional impact on parents when their child is chronically unwell. Parents of children with a range of chronic illnesses consistently report increased distress (Ellard & Barlow, 2006; Hunfeld et al., 2001). Research shows higher prevalence rates of acute stress disorder and post-traumatic stress symptoms (Woolf et al.,

2016), fear for the child's life and/or anxiety about their future (Hall et al., 2005) and feelings of helplessness, guilt, anger and sadness related to their child's diagnosis (Coffey, 2006).

Additionally, when faced with a child's chronic physical illness, parents may be faced with an array of practical challenges such as taking on additional roles and responsibilities related to their child's health needs (Kepreotes et al., 2010), and altering daily routines to accommodate for monitoring the child's health, medication and use of medical equipment (Compas et al., 2012).

1.3. Theoretical Foundations

There are a number of psychological theories that can be drawn upon to aid understanding of parent well-being in this context. Resiliency models propose mechanisms by which parent adjustment to child illness is influenced (e.g. Thompson & Gustafson, 1996.). Such models propose that parent adjustment is determined by the interplay between numerous child and parent intra- and inter-personal variables including illness-related and demographic factors as well as cognitive processes, coping strategies and social support (Mullins et al., 2015).

Illness beliefs and appraisals theories offer key insights into parent coping. The transactional theory of stress (Lazarus & Folkman, 1984) would define an illness appraisal as a cognitive process through which a person decides whether the illness is a threat to their well-being and whether they perceive themselves to have the resources necessary to cope. This is important as it conceptualises the appraisal of the illness as the determinant of outcomes, rather than the illness itself.

Leventhal's self-regulatory model of illness representation proposes five key components of illness cognition that guide illness appraisals: namely the perceived identity, timeline, consequence, control-cure and cause of the illness (Leventhal et al., 2003). Evidence from numerous studies provides support for the relationship between these five components and the expected links between illness perceptions and psychological outcomes (Moss-Morris et

al., 2002). The majority of research on the role of illness perceptions and their association with psychological outcomes has been done in the context of adult physical health and well-being, however more recently this has been extended to child illness populations and parental coping (e.g. Beinke et al., 2016; Roberts et al., 2019). In line with Leventhal's model, more threatening perceptions of illness have been consistently linked with poorer parental well-being and adjustment in a range of adult and childhood physical health conditions (e.g. Broadbent et al., 2015; Beinke et al., 2016). With the emergence of new research this area would benefit from review. However, the use of differing terminologies and definitions by researchers when describing such concepts is a barrier to conducting a systematic literature search in this area. Leventhal's model would refer to "illness perceptions" as the distinct construct described above, however this is not used uniformly, with researchers attributing a range of experiences as "perceptions" or differing "appraisals".

One particular appraisal that has been frequently studied and associated with parent psychological functioning in childhood illness is that of illness uncertainty (Wright et al., 2009). First defined by Mishel (1984), illness uncertainty refers to the meaning attributed by a person following an ambiguous illness-related event (e.g. unknown outcomes of treatment). In the context of this review, illness uncertainty refers to uncertainty a parent or caregiver might have about their child's illness. A large number of studies have explored this over a range of diagnoses and child developmental stages, and a recent review and meta-analysis concluded that greater levels of uncertainty experienced by parents were associated with greater difficulties coping (Szulczewski et al., 2017).

Another construct that has been linked with adaptive coping in adult illness populations is self-compassion (e.g. Brion et al., 2014; Terry & Leary, 2011). Self-compassion refers to one's ability to treat oneself with kindness and acceptance in times of difficulty (Neff, 2003) and has also been consistently linked with parental well-being (e.g. Neff, 2011). However,

there is currently insufficient evidence exploring the role of self-compassion in parent adaptation to child illness to warrant a review.

An aspect of caring for a child with a physical illness that is commonly described and well-documented in the literature is the impact on parents' sleep. Numerous reviews document a link between sleep and mental health (Scott et al., 2017), and the importance of adequate sleep in maintaining good mental health is well established (National Health Service, 2018). A review by Meltzer and Moore (2008) highlighted how sleep disruptions are commonly experienced in parents of children with a physical illness. This may provide an additional mechanism to further explain elevated rates of mental health difficulties and poor daytime functioning in this population.

1.4. Rationale and Aims

When a child is unwell, parents are faced with a challenging (often unexpected) situation which may pose a threat to their mental health and well-being. This may impact on the relationship between parent and child with numerous consequences proposed by the literature. Recent reviews have demonstrated the role of various predictors of well-being in parents with a child with an illness offering valuable information that may be used to inform interventions to support parents.

One area that has not been recently reviewed in the child illness context is the role of parental sleep. Meltzer and Moore's (2008) review demonstrated an increased prevalence of sleep difficulties in this parent population and elucidated a range of potential causes and consequences with regards to the relationship between parent sleep and mental health. However, significant limitations in the methodological quality of studies were noted, limiting the extent to which the literature was able to guide interventions and support for parents. Since then a substantial amount of additional research has explored sleep in this population that has not yet been reviewed.

A more recent review (McCann et al., 2015) on sleep in a population of parents of children with complex developmental, physical and psychological needs also highlighted increased levels of sleep deprivation and consequent impacts on mental health and daytime functioning. However, the participants included in this review were distinctly different, including primarily parents of children with complex developmental conditions (including learning disabilities and ASD diagnoses). Although some physical health conditions (e.g. eczema) were also included, other physical illnesses were not considered, and certain conditions (e.g. cancer) were excluded.

Given the critical nature of the relationship between parent well-being and their ability to parent effectively, it is essential to understand mechanisms that may contribute to parents' mental health in the context of child illness. The primary aim of this review is to provide an updated, comprehensive review of the literature on parent sleep in the context of having a child with a physical illness or health condition. Building on Melzter and Moore's (2008) review, this review looks at new evidence (published in the last decade; January 2009-December 2019) concerning sleep disruptions in parents who have a child with a 'chronic' physical illness. It explicitly focuses on potential causes and consequences of parental sleep disturbance in this population and sought to address the following questions:

- 1) What is the evidence for an association between having a child with a physical illness and sleep problems in parents?
- 2) What factors (including psychological factors) may explain this association?
- 3) What are potential consequences of sleep disruptions in this population?

2. Methodology

2.1. Eligibility Criteria

To meet the aims of this review, papers were included if they met the following criteria:

- 1) The study sample includes parents (or primary caregivers) of youth (0-18 years old) with a physical health condition.
- 2) The study includes a direct measure or report of parent sleep problems or disruptions and explores either the possible causes or consequences of such sleep problems.
- 3) The study is published in the English language and in a peer review journal.
- 4) Studies were only included if they were published in the last decade (from January 2009-December 2019). This was due to the large body of literature in this field and because the aim of this review was to explore recent developments in the literature beyond what was previously reviewed.
- 5) Both qualitative and quantitative studies were included if they met all the above criteria.

The following exclusion criteria was also applied:

- 1) The study population includes parents or youth where the condition reported on is a pre-existing sleep disorder.

2.1. Literature Search

All literature searches were conducted on December 12th 2019 and included Web of Science, Medline, Psychinfo and CINAHL. Initial searches using Google Scholar were undertaken to inform the search terms, which were based upon the search strategies used in other relevant reviews (Melzter & Moore, 2009; McCann et al., 2015).

The following search terms were used:

parent* OR caregiv* OR mother* OR father* OR matern* OR patern* OR
perinatal OR famil*

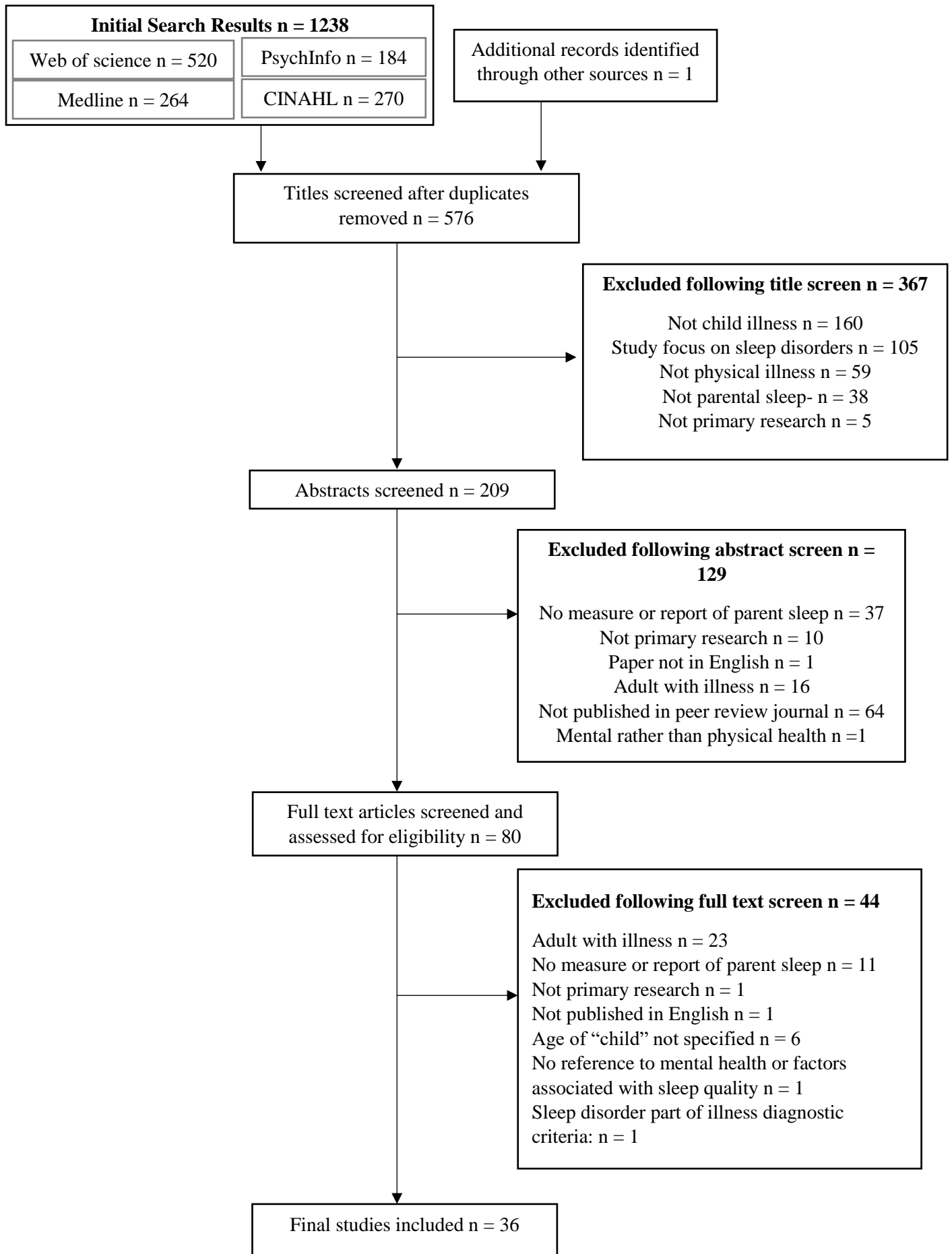
AND

sleep* OR fatigue*

AND

disease* OR ill* OR disorder* OR disibilit* OR pediatric OR paediatric OR chronic OR
syndrome OR injur* OR asthma* OR cancer* OR leukaemia OR oncology OR respirat*
OR diabet* OR epilep* OR seizure OR gastro* OR reflux* OR GORD OR GERD OR sick*
OR allerg* OR genetic* OR cardi* OR cerebral palsy OR NICU OR neonat* OR pain* OR
kidney* OR renal OR cystic fibrosis OR endocrin* OR prematur* OR intensive care OR
sickle cell OR transplant* OR headache* OR migraine* OR crohn* OR burn* OR muscular
OR spina* OR eczema* OR dermatitis OR stroke OR technology-dependent OR immun*
OR ventilat* OR otitis.

Papers were initially screened by title and then abstract to assess eligibility. Reference sections of included studies were checked to ensure no relevant studies had been missed in the search. See Figure 1 for PRISMA diagram (Moher et al., 2009).

Figure 1*PRISMA Flow Diagram*

2.3. Quality Assessment

The Mixed Methods Appraisal Tool (MMAT), developed by Pluye et al. (2009a) and revised by Hong et al. (2018) was chosen to appraise the quality of studies in this review due to the range of study designs included. The MMAT has been used in recent systematic reviews in the child illness literature (e.g. McCann et al., 2015) and is a validated and effective tool for appraising study quality in a mixed methods systematic review (Hong et al., 2019).

The MMAT consists of two screening questions, followed by five criteria (specific to the design of the study) by which to assess the quality of the study design. Scores range from zero (where no criteria are met) to five (where all criteria are met). See Appendix A for MMAT criteria and individual study quality appraisal. Hong et al. (2018) discourage exclusion of studies from review based on poor methodological quality and so all studies meeting inclusion criteria are reviewed in this paper.

2.4. Review Structure

Due to the large number of studies and the variety of outcomes measured and concepts explored, the papers will be grouped by themes arising in their content. Themes were based broadly upon themes outlined in Meltzer and Moore (2008). Papers within each theme are described and critiqued alongside one another. Only findings relevant to this review are discussed.

Table 1*Summary of Reviewed Studies*

Study Number	Study: authors, date & title. Quality Score (MMAT; range 0-5).	Population: parents, child age range and illness type.	Aims (relevant to this review)	Design	Outcome Measures (relevant to this review)	Results (relevant to this review)
1)	Ramirez et al. (2019). Assessment of Sleep Disturbances and Exhaustion in Mothers of Children with Atopic Dermatitis (AD). MMAT: 3	This study used data from mother-child pairs (n = 11,649) who had data on AD and sleep outcomes from at least 1 survey. Child age ranged from 6 months to 11 years old.	To (a) compare sleep disturbances over time between mothers of children with and without AD and (b) determine whether these disturbances are associated with the child's disease severity and the child's sleep disturbances	Longitudinal, population-based cohort study with longitudinal and cross-sectional analysis.	Standardized questionnaire to assess severity of AD at 10 time points between child age 6 months-11 years. Five maternal sleep outcomes were measured at various time points using single standardized questions: Sleep duration: " <i>How many hours of sleep do you get altogether now during an average night?</i> " Difficulty falling asleep: " <i>Can you go to sleep alright?</i> " Early morning awakening: " <i>Do you wake unusually early in the morning even when you haven't been woken by your child or family?</i> " Subjectively getting enough sleep: " <i>Do you feel that you are getting enough sleep?</i> " Daytime exhaustion: " <i>In the</i>	<ul style="list-style-type: none"> - Cross-sectional and longitudinal logistic regression analyses were performed. - Sleep disturbance was relatively consistent across time. - Sleep duration and early morning awakening showed no significant differences between mothers of children with and without AD. - Mothers of children with AD reported significantly more difficulty falling asleep, subjectively insufficient sleep and daytime exhaustion. - Larger effects were found when AD severity was greater. - Mothers of children with severe AD, had significantly greater chance of reporting sleep duration less than 6 hours per night. - Adjusting for child sleep disturbance did not significantly change mothers' sleep outcomes.

Study Number	Study: authors, date & title. Quality Score (MMAT; range 0-5).	Population: parents, child age range and illness type.	Aims (relevant to this review)	Design	Outcome Measures (relevant to this review)	Results (relevant to this review)
					<i>past month, how often have you felt exhausted?"</i>	
2)	Reilly et al. (2018). Child and parental sleep in young children with epilepsy: A population-based case-control study MMAT: 3	Parents of young children (aged 1–7 years) with epilepsy (n = 48). Parents of developmental ly, age, and gender-matched children with non-epilepsy related neuro disability (n = 48).	To (a) assess prevalence of sleep difficulties in young children with epilepsy and their parents. To (b) compare sleep difficulties in the epilepsy group with a group of controls. To (c) consider factors that may contribute to sleep difficulties.	Population case-control study using a cross-sectional survey design with matched control group.	Child sleep: Children Sleep Habits Questionnaire (CSHQ), a parent-completed 33 item validated measure for paediatric sleep problems. Caregiver sleep: Pittsburgh Sleep Quality Index (PSQI), a validated 19-item measure assessing sleep quality and disturbance. Parental fatigue: Iowa Fatigue Scale (IFS), an 11-item validated scale used in previous paediatric epilepsy research. Maternal mental health: DASS-21) – validated self-report measure of anxiety, depression and stress. Clinical and socio-demographic information was also collected.	- Child sleep: 81% scored above clinical cut off indicating sleep disturbance. No significant differences were found between groups (p=0.23). - Parent Sleep: No significant differences between groups. - Parent fatigue: Mothers of children with epilepsy scored significantly higher, indicating greater fatigue on the productivity subscale (p = 0.004). No other significant between group differences were found. - Regression analyses with PSQI: The only factor significantly associated with total score was mothers' mental health (p = 0.040), with greater mental health problems being associated with greater sleep problems.
3)	Wright (2011). Children Receiving Treatment for Cancer	34 caregivers of children ages 2 years and above,	To describe and gain an understanding of the sleep	Mixed methods Cross-sectional survey design with semi-structured	Survey measures were developed and validated in a previous study	- Caregivers of children receiving cancer treatment reported fewer hours of sleep relative to the comparison caregivers. This was not a significant difference

Study Number	Study: authors, date & title. Quality Score (MMAT; range 0-5).	Population: parents, child age range and illness type.	Aims (relevant to this review)	Design	Outcome Measures (relevant to this review)	Results (relevant to this review)
	and Their Caregivers: A Mixed Methods Study of Their Sleep Characteristics MMAT: 2	who had been receiving treatment for cancer for more than 1 month. (Those receiving intensive or palliative care were excluded). Data from 64 healthy children with typical development and their caregivers were available for comparison.	characteristics of children receiving treatment for cancer and their caregivers.	interviews and qualitative content analysis.	to investigate sleep issues in children with physical disabilities and their families. Questions collected information on demographics, diagnoses, sleep quality, latency and duration, associated body functions and structures, sleep environments, daytime functioning and participation, and strategies to deal with sleep problems.	<p>during the week, but was significant at weekends ($p < .001$).</p> <ul style="list-style-type: none"> - Caregivers of children receiving cancer treatment had significantly worse trouble falling asleep ($p = .001$), were more likely to be woken by their child during the night ($p = .001$), with a greater mean time of being woken ($p = .002$). - Caregivers of children with cancer reported their sleep has having significantly greater impact on daytime functioning in a range of areas: not feeling rested ($p = .002$), feeling irritable, exhausted and forgetful due to lack of sleep and using more caffeine ($p < .001$), social activities affected ($p = .001$), feeling sleepy while driving ($p = .009$) and sleepiness impacting employment ($p = .003$). - These parents were also more likely to feel their sleep was impacted negatively by their child's sleep; 21 (62%) versus 23 (39%), $p = 0.03$ "Like you are caring for a new-born, same patterns of sleeplessness." In particular, they were more likely to be wakened because of their children during the night; 91%

Study Number	Study: authors, date & title. Quality Score (MMAT; range 0-5).	Population: parents, child age range and illness type.	Aims (relevant to this review)	Design	Outcome Measures (relevant to this review)	Results (relevant to this review)
						<p>versus 59%, $P < 0.001$, with a greater mean number of times being woken.</p> <ul style="list-style-type: none"> - Sleep environment influenced sleep quality, with hospitalization having a negative impact on child sleep.
4)	<p>Safer et al. (2016). Effects of botulinum toxin serotype A on sleep problems in children with cerebral palsy (CP) and on mothers' sleep quality and depression.</p> <p>MMAT: 3</p>	<p>24 children with CP and their mothers were recruited from a research hospital in Turkey when attending for BoNT-A injection. Mean age of child = 7.05 years (2.69 SD).</p>	<p>To evaluate botulinum toxin serotype A (BoNT-A) effects on sleep problems in children with CP and on mothers' sleep quality and depression at multiple time points.</p>	<p>Observational cross sectional and longitudinal survey.</p>	<p>Child clinical history (including gross motor function classification) and child and mother demographic information was collected.</p> <p>Child sleep: CSHQ abbreviated form (33 items in 8 domains) in Turkish which had been previously validated and had reliability ascertained.</p> <p>Mother sleep: The validated Turkish version of PSQI.</p> <p>Mother depression: The Turkish version of the Beck Depression Inventory (BDI) was used which authors report has excellent reliability ($\alpha = 0.90$).</p>	<ul style="list-style-type: none"> - A moderate correlation at baseline between CSHQ scores of children with CP and PSQI of mothers ($r = 0.36$), however this was not significant ($p = 0.08$). - The effects of BoNT-A were shown to be at their maximum in the first month following injection. Mothers' sleep significantly improved one month and three months after the BoNT-A injection. ($p \leq 0.001$). - Mothers' depression: At baseline, 25% had moderate or severe depression and 75% had minimal depressive symptoms. - At baseline, moderate significant correlations were found between the mothers' BDI and PSQI scores ($r = 0.57$, $p < 0.001$). - BDI scores decreased for the first and third months and then slightly increased

Study Number	Study: authors, date & title. Quality Score (MMAT; range 0-5).	Population: parents, child age range and illness type.	Aims (relevant to this review)	Design	Outcome Measures (relevant to this review)	Results (relevant to this review)
5)	Neu (2014). Exploring Sleep-Wake Experiences of Mothers during Maintenance Therapy for Their Child's Acute Lymphoblastic Leukemia (ALL) MMAT: 5	20 mothers of children between three and twelve years old who were receiving maintenance therapy for ALL and had no other concurrent illness or disability.	To explore sleep-wake experience of mothers of children in maintenance treatment for ALL.	Qualitative descriptive approach using interviews and thematic analysis.	Interview questions were open ended and semi-structured. Mothers were asked to describe their sleep during their children's treatment. Researchers asked probing questions about the mothers' sleep habits before the ALL diagnosis and coping mechanisms to manage sleep deprivation or induce sleep.	in the sixth month. This was still significantly lower than at baseline. Two main themes emerged: "It's a whole new cancer world" and "I don't remember what it's like to have sleep." It's a Whole New Cancer World contained four sub-themes: (a) Losing Normality, (b) Being Off-Balance/Insecure, (c) Juggling Duties, and (d) Making Transitions. Although this theme did not specifically address maternal sleep, it enhanced understanding of issues that potentially influenced sleep. I Don't Remember Sleep theme also contained four sub-themes: (a) Sleeping Trouble before and after ALL, (b) Child Feeling Sick at Night, (c) Worrying, and (d) Coping with Exhaustion - Consequences of exhaustion were described as being irritable, less patient with their children, sluggish, and less productive than they wished to be
6)	Stremler et al. (2010). Factors influencing sleep for parents of critically ill hospitalised children: a qualitative analysis.	118 parents of 91 children (aged <18 years) were recruited during their child's stay in	To (a) describe factors affecting the sleep of parents of critically ill children, and (b) to determine	Qualitative study using qualitative descriptive methodology.	Participants provided demographic, child illness and parent sleep information to situate sample.	Seven themes emerged relating to parents' experience of sleep. The child's condition: Uncertainty and worry about child's health influenced sleep. Changes in the child's condition could affect sleep either positively or negatively.

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MMAT: 5	an intensive care unit. (Note 61% of children were aged <1 year old) Parents were excluded if they had a diagnosed sleep disorder or were unable to understand English language.	strategies used to improve their sleep.		Participants provided written answers to the following questions: It is often difficult to sleep whilst your child is in hospital. What things got in the way of sleeping well for you? What things helped you get to sleep whilst your child was in hospital? What things would you suggest other parents should do to help them sleep better when their child is in the hospital? What could the staff or the hospital do to help you sleep better when your child is in the hospital?	Being at the bedside or not: being present at the bedside limiting time for sleep, but also providing with more reassurance making it easier for parents to sleep. Difficult thoughts and feelings: Interfering with sleep, unable to clear minds, anticipating bad news preventing sleep. Changes to usual sleep: long travel times to accommodation and more time in hospital reducing time available for sleep, sleeping in unfamiliar surroundings having an impact. Caring for self and family: felt sense of multiple demands and meeting needs of other family members impacting on ability to and time for sleep. The hospital environment: excessive light, uncomfortable room temperatures, noise levels, lack of provisions etc. impacting on sleep. Access to sleep locations: Not enough places for parents to sleep given demand for rooms in hospital making it practically difficult to sleep.	
7)	Edell-Gustafsson, et al. (2014). Hindering and buffering factors for parental sleep in neonatal care. A phenomenographic study	Twelve Swedish speaking parents of infants in neonatal care who stayed for at least 24 hours.	To explore and describe how parents of preterm and/or sick infants in neonatal care perceive their sleep.	Qualitative phenomenographic study with an inductive and exploratory design.	Semi-structured interviews comprised of general questions about the parent and infant as well as specific questions about sleep with follow-up questions to further explore parent responses.	Four descriptive categories emerged: The impact of stress on sleep – stress caused by anxiety, uncertainty and powerlessness, and difficult feelings oscillating between hope and despair had a negative influence on sleep. Practical support from staff made it possible for parents to sleep for a few hours. How the environment affects sleep: Having a private room where the door could be closed and

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	MMAT:3	Eight mothers and four fathers participated.			Interviews lasted 20-40 minutes.	being with the infant were considered to improve sleep. Not being able to use mobile phones contributed to sense of isolation. Lots of equipment made environment feel stressful and noises from machines impacted sleep. Keeping the family together improves sleep: Enabled parents to bond more easily with infant and gave parents sense of independence being able to care for their infant.
8)	Vardar-Yagli et al. (2017). Hospitalization of Children with Cystic Fibrosis (CF) Adversely Affects Mothers' Physical Activity, Sleep Quality, and Psychological Status. MMAT: 2	The study group consisted of 61 mothers of 23 CF patients who were hospitalized and 38 who were outpatients, and 37 mothers of age-matched healthy children served as controls. Children were all aged ≤ 18 years old	To compare physical activity level, sleep quality, anxiety and depression in mothers of hospitalized CF patients, CF outpatients and healthy controls.	Cross sectional survey design with three groups including comparison group	Demographic variables and time since CF diagnosis were recorded. Mothers' fatigue levels, sleep disturbances, stress levels and perceptions of disease severity were evaluated using a 10cm visual analogue scale (VAS). Mother's sleep also measured using PSQI. A Turkish short version of the International Physical Activity Questionnaire (IPAQ) is a reliable and valid measure that assessed physical activity level in hospitalized CF group. Mothers' psychological status: was screened using	<ul style="list-style-type: none"> - Mothers of hospitalised CF children had significantly higher perception of disease severity, fatigue, sleep disturbance and stress level compared to mothers of outpatient CF children ($p < .05$). - Mothers of hospitalised and outpatient CF children had significantly higher fatigue, sleep disturbance and stress than mothers of healthy controls ($p < .05$). - Poor sleep quality was found in 78% of hospitalised CF mothers, 26% of CF outpatient mothers and 8% of healthy children. - HADS anxiety, depression and total scores were significantly different among the three groups ($p < .05$). 84% of hospitalised CF mothers, 24% of CF outpatient mothers and 0% of healthy control mothers had clinical anxiety/depression.

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					the Turkish version of the Hospital Anxiety and Depression Questionnaire (HADS) which has demonstrated validity and reliability in medically ill patients and healthy controls.	- Perception of fatigue, sleep disturbance, stress level, child's disease severity perception, PSQI subscale and total scores were all significantly correlated with HADS total scores for anxiety and depression ($p < .05$) in mothers of children with CF.
9)	Larson et al. (2012). Impact of pediatric epilepsy on sleep patterns and behaviors in children and parents. MMAT: 1	105 households with a child with epilepsy and 79 controls who had attended outpatient general paediatric care at a hospital. Child age ranged from 2-10 years.	To explore the effect of paediatric epilepsy on child sleep, parental sleep and fatigue and parent-child sleeping arrangements.	Cross sectional survey design with comparison group.	Information was collected on child seizure history and treatment (Early Childhood Epilepsy Severity Scale), child sleep (CSHQ), caregiver sleep (PSQI) and fatigue (Iowa Fatigue Scale), and household sleeping arrangements and routines. Demographic information was also collected	<ul style="list-style-type: none"> - Children with epilepsy had greater sleep disturbance than those in the comparison group. - Parents in the epilepsy group had higher PSQI total scores and were also found to be more fatigued by IFS total scores. - Significant correlations were found between severity of epilepsy and parent and child sleep dysfunction and parent fatigue. - 44% of epilepsy parents reported rarely or never feeling rested. 69% reported feeling concerned about their child having nocturnal seizures which were associated with parent sleep problems. - Households with a child with epilepsy reported increased rates of both parent-

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10	McLoone et al. (2013). Parental sleep experiences on the pediatric oncology ward. MMAT:2	52 parents of children with cancer receiving inpatient treatment and 62 parents of age-matched healthy comparisons.	To provide prevalence estimates of self-reported sleep quantity and quality among parents staying on a pediatric oncology ward compared to parents of age matched comparisons.	Mixed methods: Cross sectional survey design with comparison group. Thematic analysis	Sleep: The St Mary's Hospital Sleep Questionnaire, a validated scale developed to measure parental sleep in a hospital setting was used. Parents were also asked to describe their typical sleep experience prior to their child's diagnosis. Anxiety and Depression: DASS-21. Three open ended questions were included to allow parents to define the reasons for their poor sleep and provide additional information. Demographic, clinical and situation data was also collected.	child room sharing and co-sleeping compared to comparisons. - Parents sleeping on the ward reported significantly poorer sleep outcomes than comparison parents. - Total sleep duration was significantly less, the time taken to fall asleep was significantly greater, night time awakenings were more frequent and satisfaction with sleep was poorer. - Parents of children with cancer reported significantly higher levels of depression, anxiety and stress. - Predictors of sleep: group (cancer vs non cancer), anxiety and caffeine consumption were independently associated with sleep duration. Parent reported ability to fall asleep pre diagnosis, time since diagnosis, number of nights on ward, treatment intensity and parent and child gender were not significant predictors of sleep. Qualitative: three themes emerged as perceived reasons were sleep disruption. Environmental causes e.g. monitor noises, child related causes e.g. frequent urination due to treatment and individual causes e.g. anxiety (about child/future).

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11)	Bishop et al. (2019). Parenting Stress, Sleep, and Psychological Adjustment in Parents of Infants and Toddlers with Congenital Heart Disease (CHD). MMAT:5	69 parents of infants and toddlers with CHD. (91% were mothers). Age of child ranged from 15 days to 3 years.	To examine the associations of parenting stress, sleep and psychological adjustment in parents of infants and toddlers with CHD.	Cross sectional survey with descriptive design.	Parent sleep: PSQI. Parenting Stress: Paediatric Inventory for Parents (PIP). A 42 item self-report scale the measures the intensity and frequency of stress for parents associated with raising a child with a chronic illness. In current study internal consistency was excellent ($\alpha=0.97$). Psychological Adjustment: Brief Symptom Inventory-18. In current study internal consistency was high ($\alpha=0.90$). Parent and demographic and health history information was collected.	<ul style="list-style-type: none"> - 80% of parents met criteria for poor sleep (PSQI >4). - The only significant correlation was between parenting stress and psychological maladjustment ($r=.615$, $p<.01$). - Sleep significantly mediated the effect of parenting stress on maladjustment, i.e. parenting stress significantly predicted sleep, which in turn predicted maladjustment. - The direct effect of parenting stress on psychological maladjustment remained significant when accounting for the indirect effect, indicating partial mediation.
12)	Nassery & Landgren (2019). Parents' Experience of Their Sleep and Rest When Admitted to Hospital with Their Ill Child: A Qualitative Study. MMAT:3	17 parents (12 mothers and five fathers) admitted to a paediatric ward in Sweden with their ill child.	To explore parents' experiences of sleep and rest when admitted to hospital with their ill child.	Qualitative exploratory interview study and content analysis.	Interviews were semi-structured and analysed with content analysis. Questions included: "Would you please share your experience of sleeping at the hospital with your ill child?" "Can you mention factors that influence your sleep and rest at the hospital?"	<p>One key theme emerged: "Factors influencing sleep and rest".</p> <p>This was broken down into three subthemes: "Environmental factors", "interpersonal factors" and "organisational factors".</p> <p>Environmental: descriptions of noise from hospital machines and nurses during the night reportedly influenced sleep. This was worse for parents who had been in the ward a longer time.</p>

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					<p><i>“Do you find that good sleep affects your parenthood?”</i></p> <p><i>“Do you find the staff trying to facilitate the sleep and rest of parents?”</i></p> <p>Further probing questions were asked to elicit greater depth of information.</p>	<p>Parents discussed difference between having their own rooms vs shared rooms.</p> <p>Interpersonal: Parents reported impact of dealing with a “jumble of emotions” and not feeling “real” as parents.</p> <p>Organisational: parents discussed aspects that caused stress even before the hospital admission e.g. waiting for operations, delays in treatment, unclear information and shortage of healthcare professionals.</p>
13	Shaki et al. (2011) Pediatric Epilepsy and Parental Sleep Quality. MMAT: 3	<p>Hebrew speaking parents of epileptic (n = 39) and nonepileptic (n = 42) children ≤18 years.</p> <p>The comparison group was recruited from parents waiting in the paediatric emergency room.</p>	To evaluate the effects of paediatric epilepsy on sleep in parents of epileptic children	Cross-sectional cohort design with comparison group.	<p>Parent sleep: PSQI (translated into Hebrew which has been validated).</p> <p>Demographic and medical history were also collected.</p>	<ul style="list-style-type: none"> - Parents of children with epilepsy had significantly less sleep and significantly greater sleep disturbance than the comparison group. - No correlations were found between sleep disturbance in parents and any of the characteristics of severity of epilepsy in the child.
14)	Ridolo et al. (2014). Quality of sleep in	90 parents of children	To evaluate the presence of	Cross sectional survey design.	Parent sleep: PSQI (Italian version).	<ul style="list-style-type: none"> - 75% of parents had a PSQI score of ≥5, indicating bad quality sleep.

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	allergic children and their parents. MMAT: 2	suffering from allergic diseases. Mean child age: 7.7years (SD 4.3)	disturbed sleep in parents of children with atopic disorders, and its relationship with clinical features and the presence of sleep disturbance in children.		Child sleep: Measured using the Sleep Disturbance Scale for Children (Italian version).	<ul style="list-style-type: none"> - Correlations between illness severity and sleep showed no significant association between severity and sleep. - PSQI correlated highly and significantly with SDSC ($p < .001$, $r = .34$)
15)	Adiga et al. (2014). Sleep disorders in children with cerebral palsy (CP) and its correlation with sleep disturbance in primary caregivers and other associated factors. MMAT: 1	50 mothers of children with CP aged 6.5-15 years old.	To observe the prevalence of sleep disturbance in children with CP and its correlation with sleep disturbance in primary caregivers.	Cross-sectional observational and survey design	Demographic information, perinatal and medical history were collected. Gross Motor Function Classification System was used to determine children's present abilities and limitations in gross motor function. Parent sleep: PSQI. Child sleep: Measured using the Sleep Disturbance Scale for Children.	<ul style="list-style-type: none"> - 50% of caregivers had sleep disturbance. This correlated significantly with their child having disturbed sleep. - There was no significant correlation between sleep disturbance and severity as measured by the GMFCS - 70% of children shared bed with their mothers. Bed-sharing had no association with sleep disturbance in children, but was significantly associated with sleep disturbance in caregivers ($p < .001$)
16)	Macaulay et al. (2019). Sleep and Night-time Caregiving in Parents of Children and	10 mothers and 10 fathers of children <18 years old	To explore diabetes-related factors affecting, and solutions	Mixed methods: Qualitative study design using semi-	Parents provided basic demographic data on themselves and their child. Parent sleep: PSQI	<ul style="list-style-type: none"> - 90% of mothers and 40% of fathers had poor sleep based on PSQI scores. <p>Four overarching categories emerged:</p>

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	Adolescents with Type 1 Diabetes Mellitus - A Qualitative Study. MMAT:5	with type 1 diabetes in New Zealand.	proposed to improve parent sleep	structured interviews and thematic analysis	Parent and child sleep: Parents and children also wore an Actigraph for 7 days and nights to provide an objective measure of sleep.	Perceived sleep disturbance related to child's illness and care Aspects of diabetes care affecting parental sleep e.g. nocturnal blood glucose monitoring Perceived impacts of sleep disturbance e.g. on cognitive functioning, emotional wellbeing and physical health
17)	Monaghan et al. (2012). Sleep Behaviors and Parent Functioning in Young Children with Type 1 Diabetes. MMAT:2	24 parents (88% mothers) of young children (ages 2–5 years) with type 1 diabetes.	To evaluate sleep characteristics among young children with type 1 diabetes and associations with parent sleep and emotional functioning and diabetes care.	Cross-sectional survey design used for relevant results in this paper. (as part of a larger RCT design)	Demographic and medical information was collected by parents completing a 32-item questionnaire and medical record review Child Sleep: modified version of the Child Sleep Questionnaire (CSQ), parent-report measure designed to assess sleep habits and disorders among healthy children ages 2 to 18. Parent sleep: 4 additional items were added to the CSQ to assess parent sleep and sleep disruption due to diabetes management. Parents were asked to report total hours of sleep each night, how frequently they checked their child's	<ul style="list-style-type: none"> - Parents received an average of 6.57 hours of sleep per night (SD = 1.11, Range = 3–8.50) - 79% of parents indicated that their own sleep was disrupted by nocturnal blood glucose checks. <p>Note: correlational analyses were conducted in order to investigate the relationship between child sleep behaviours and parents' psychosocial functioning (Not parent sleep and functioning). Increased child behavioural insomnia was correlated with parenting stress and depressive symptoms ($p < .05$), however no information on parental sleep in this relationship.</p>

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					<p>blood glucose level after their child was asleep, and whether or not night-time blood glucose checks disrupt child and parent sleep. This amended version reached acceptable internal consistency for this sample ($\alpha = .76$).</p> <p>Illness-related parenting Stress: The self-report Pediatric Inventory for Parents (PIP) which assesses parents' perceptions of 42 stressful situations related to parenting a child with a chronic illness within the past week. Internal consistency was excellent in the current sample ($\alpha = .96$).</p> <p>Parent anxiety: measured using the State-Trait Anxiety Inventory, a 20 item self-report measure with good internal consistency (current sample = .92).</p>	

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18)	Coleman et al. (2018). Sleep disruption in caregivers of pediatric stem cell recipients. MMAT: 1	17 parents with no prior diagnosis of a sleep disorder, who stayed at least 5 days per week with their child in the hospital. The median age of the child was 10 years (range = 1.1–15.2).	To evaluate sleep in parents/ caregivers of children undergoing hematopoietic stem cell transplant	Cross sectional survey with descriptive design	Parent depression: Measured using the centre for Epidemiological Studies- Depression (CES-D) scale, a 20-item self-report measure designed to assess the frequency of depressive symptoms during the previous week. Internal consistency was good (current sample = .91). Caregiver sleep disturbance and quality: General Sleep Disturbance Scale (GSDS), which showed high internal reliability in this sample (alpha = 0.87). An additional questionnaire was developed to collect demographic information, caregiver's impressions of their own sleep before and during the hospitalization, and factors caregivers believed affected their sleep in the hospital setting.	<ul style="list-style-type: none"> - 71% of caregivers GSDS indicated a significant level of sleep disturbance. - Sleep quantity, quality, and sleep interruptions were significantly worse during hospitalization than prehospitalization (p< 0.001). - Cardiac monitor alarms (76%), infusion pump alarms (82%), staff assessments (82%), and door openings (71%) were the most commonly reported causes of sleep disruptions in caregivers.

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19)	Meltzer & Booster (2016). Sleep disturbance in caregivers of children with respiratory and atopic disease. MMAT: 3	Caregivers of 35 children with atopic dermatitis (AD), 57 children with AD and asthma (AS), 61 ventilator-assisted children (VENT) and 63 healthy controls took part.	To examine sleep patterns and sleep disturbances in caregivers of children with chronic illness.	Cross-sectional survey with comparison group	Parent sleep: PSQI Parent Insomnia and distress caused by sleep problems: Insomnia Severity Index with 3 additional items exploring reason for sleep disruption.	<ul style="list-style-type: none"> - Caregivers of healthy controls reported better global sleep quality ($p < .001$) than all illness groups. - No significant difference was found between illness groups on PSQI or ISI total scores. - Caregivers of children in all illness groups were more likely to wake at least one a week for medical caregiving and stress about child's health. - No difference was found in waking due to general stress between parents of children in illness groups and healthy children.
20)	Feeley et al. (2018). Sleep in caregivers of children with Type 1 Diabetes. MMAT: 1	22 caregivers of children aged 10-18 years with type 1 diabetes	To explore caregivers' descriptions of their experience of night-time sleep	Non-experimental cross-sectional descriptive study	Two questionnaires were designed for the study to explore caregivers' sleep and care-giving and Demographic and diabetes-related data.	<ul style="list-style-type: none"> - Caregivers reported short sleep duration (mean 5.8hours). 64% indicated trouble falling asleep at night. 86% reported that caregiving interfered with their sleep. - Those whose children had been diagnosed more than 5 years ago had shorter sleep durations than those whose child had been diagnosed in 4 or less years. <p style="text-align: right;">Content analysis of open-ended questions revealed 2 themes, 1- anxiety about the child's blood glucose levels and 2- night time disruptions e.g. blood glucose monitoring.</p>

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21)	Jaser et al. (2016). Sleep in children with type 1 diabetes (T1D) and their parents in the T1D Exchange. MMAT: 3	515 Parents of 2-12-year olds with T1D	To characterise sleep in children with T1D and their parents and to examine associations between child sleep, glycaemic control and adherence, parent sleep and wellbeing, parent fear of hypoglycaemia and nocturnal caregiving.	Cross sectional survey with descriptive design	Child sleep: CSHQ Parent Sleep: PSQI Parent emotional well-being: WHO Five Wellbeing Index and Hypoglycaemia fear Survey Demographic and clinical data also collected.	<ul style="list-style-type: none"> - 67% of children met criteria for poor sleep quality. - Poorer child sleep quality was associated with poorer parental sleep quality, parental wellbeing and fear of hypoglycaemia. - Parent mean duration of sleep was 6.5 +- 1.2hr and 53% met criteria for poor sleep score. - 32% met WHO-5 criteria for low mood. - 65% often or always had to check child's blood glucose after child's bedtime. - Parents with more fear of hypoglycaemia were more likely to more frequently check child blood glucose after bedtime.
22)	Matthews et al. (2014). Sleep in mother and child dyads during treatment for pediatric acute lymphoblastic leukemia MMAT: 5	26 dyads of mothers and children with ALL and matched controls.	To compare the sleep of children with ALL during maintenance treatment with controls and to measure the effect on maternal sleep.	Cross sectional, survey with comparison group design	Parent sleep: Actigraphy and Sleep diary Parent fatigue: Insomnia severity index. Child sleep: CSHQ Parent mental health: Hospital anxiety and depression scale (HADS). Parent stress: Perceived stress scale with internal consistency ranging from 0.75-0.86 and test-re-test reliability of 0.85 over two	<ul style="list-style-type: none"> - Maternal groups did not differ on diary or actigraphy sleep outcomes – both groups experienced fragmented sleep. - Mothers of children with ALL reported greater insomnia compared to controls which correlated with anxiety, depressive symptoms and stress. - There was a weak correlation between mother and child's sleep in the ALL group, but not in control group

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					weeks and Cronbach alpha of 0.78-0.91. Demographic data also collected.	
23)	Feeley et al. (2019) Sleep in Parental Caregivers and Children with Type 1 Diabetes (T1D). MMAT: 2	18 Parents of children aged 6-12 years with T1D.	To examine to correlations in sleep between caregivers and young children with T1D.	Cross sectional descriptive pilot study	Parent and child sleep: 7-day actigraphy and sleep diary. Parent Sleep: PSQI and Patient-Reported Outcome Measures Information System (PROMIS) – sleep disturbance measure. Parent stress: Perceived Stress Scale Parent depressive symptoms: Centre for Epidemiological studies depression scale (CES-D).	<ul style="list-style-type: none"> - 72% of parents reported 7 or less hours of sleep per night. - Moderate to large correlation between child and parents sleep based on actigraphy. - No significant relationship between child sleep and parent outcomes (stress or depressive symptoms). - Parent depressive symptoms were associated with PSQI total score - Perceived stress was negatively associated with mean daily parent sleep based on actigraphy. - Worse glycaemic control correlated with shorter parent sleep duration.
24)	Meltzer & Pugliese (2017). Sleep in young children with asthma and their parents. MMAT: 1	364 parents of young children (1-4 years) with asthma.	To characterise sleep in young children with and without asthma and their parents.	Cross sectional survey design with comparison group	Parent and child sleep: PROMIS Sleep Disturbance Item Bank (Short Form) and additional items added on parent sleep. Demographic and clinical information including	<ul style="list-style-type: none"> - Compared to children with well-controlled asthma or no asthma, children with poorly controlled asthma had poorer sleep patterns, more difficulty falling asleep, and more sleep disruptions. - Parents of children with poorly controlled asthma indicated their own sleep was regularly disrupted, and they had frequent night awakenings due to attending to, and

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					measures of asthma and asthma severity.	stress caused by, their child's health needs. - No significant differences in parent sleep disturbance between those with poorly controlled asthma and those with well-controlled asthma
25)	Meltzer et al. (2015). Sleep patterns, sleep instability, and health related quality of life in parents of ventilator-assisted children. MMAT: 2	79 mothers and 33 fathers from 24 VENT families and 40 HEALTHY families	To compare the sleep patterns of parents of ventilator assisted children and healthy comparisons. To examine the relationship between sleep variability and HRQoL.	Cross sectional survey with comparison group	Parent sleep: Actigraphy for 2 weeks. Parent health related quality of life: SF 36 a self-report survey that has been normed on large representative samples and previously demonstrated adequate reliability and validity.	- VENT parents showed sig later bedtimes, less total sleep and lower sleep efficiency than healthy comparisons. - Wake after sleep onset and sleep efficacy associated with poorer SF-36, but average sleep values were not. - Type of ventilation (invasive vs non-invasive) and amount of nursing support not significantly associated with parent sleep. -
26)	Wayte et al. (2012). Sleep problems in children with cerebral palsy and their relationship with maternal sleep and depression. MMAT: 2	Mothers of 57 children with cerebral palsy (CP) aged 4-12 years Children's sleep habits (but not maternal variables) were compared to	To compare sleep problems in children with CP to typically developing children. To study the relationship between sleep problems in children with CP and maternal	Cross sectional survey design with partial control group	Maternal sleep: PSQI Maternal mood: Major Depression Inventory. Child sleep: CSHQ. Demographic and child clinical data were also collected.	- 40% of CP mothers had poor sleep quality, of whom 44% had depressed mood. - Indicators of severity such as visual and cognitive impairment and presence of epilepsy were measured. Visual loss was the only significant predictor of child sleep - Child and maternal sleep disturbance were significantly correlated. - Maternal sleep quality predicted 50% of the variance in maternal depression.

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		102 typically developing childrens	sleep quality and depression.			-
27)	Stremler et al. (2013). Sleep, sleepiness, and fatigue outcomes for parents of critically ill children. MMAT: 5	118 parents of 91 children recruited during their child's Paediatric Intensive Care Unit (PICU) stay	To describe sleep quantity, patterns, fatigue and sleepiness of parents of critically ill hospitalised children.	Prospective cross-sectional observational & survey design	Parent sleep: Actigraphy and sleep diary data collected for 5 days and nights. Parent fatigue: Fatigue Visual Analogue Scale (good internal consistency reported: $\alpha=0.94$) Parent sleepiness: Stanford Sleepiness Scale. Parents also reported on sleep location. Demographic and child illness data also collected.	- Mean amounts of nocturnal sleep were less than recommended. Parents woke frequently and spent over an hour awake at night. - Morning fatigue levels indicated clinically significant fatigue. - Sleeping in a hotel, parent room or residence was associated with 3.2 more wakes per night than sleeping in a hospital lounge/waiting room.
28)	Paddeu et al. (2014). Sleeping problems in mothers and fathers of patients suffering from congenital central hypoventilation syndrome (CCHS). MMAT: 1	Parents of 23 subjects with CCHS and 23 healthy subjects.	To investigate how CCHS affects mothers and fathers by producing poor sleep quality, sleepiness, anxiety and depression.	Cross sectional survey with comparison group	Parent Sleep: PSQI and Epworth Sleepiness Scale Parent mental health: Beck Depression Inventory and Beck Anxiety Inventory.	- CCHS parents had poorer sleep quality, greater sleepiness and higher BDI scores compared to parents of healthy subjects. Specifically, mothers of patients had poorer sleep quality and higher BDI scores compared to mothers of controls. Fathers showed greater levels of sleepiness. - However, this was only found in parents whose child was aged 1-5years old.

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						- No correlational analyses looking at relationship between sleep and depression.
29)	Al Maghaireh et al. (2017). Stress, Anxiety, Depression and Sleep Disturbance among Jordanian Mothers and Fathers of Infants Admitted to Neonatal Intensive Care Unit: A Preliminary Study. MMAT: 4	310 parents of infants in the NICU.	To investigate stressors and stress levels among Jordanian parents of infants in the Neonatal Intensive Care Unit (NICU) and their relationship to anxiety, depression and sleep disturbance.	Cross sectional survey with descriptive design	Parent Stress: Parental Stressor Scale: NICU. Has been tested for reliability in Jordanian sample and in this study ($\alpha = 0.71-0.94$). Parent sleep, anxiety, depression and fatigue were all measures using the relevant PROMIS items. All constructs had excellent reliability results ($\alpha = 0.95-0.96$). Demographic and child illness data were also collected.	- Both parents experienced high levels of stress, anxiety depression and sleep disturbance. - Stress was highly correlated with anxiety and depression. Stress was moderately correlated with sleep disturbance - Infant behaviour and appearance were identified as the highest stress factors. - There was a statistically significant difference between mothers and fathers sleep, with mothers experiencing higher disturbance.
30)	Daniel et al. (2018). The relationship between child and caregiver sleep in acute lymphoblastic leukemia (ALL) maintenance. MMAT: 3	Caregivers of 68 children with ALL, ages 3 to 12 years old	To describe sleep quality and disturbance among caregivers of children in the maintenance phase of ALL and to examine the relationship	Cross sectional survey with descriptive design	Child sleep: abbreviated version of CSHQ with acceptable internal consistency for this sample. Parent Sleep: PSQI ($\alpha = 0.79$ in this sample). With addition of two additional questions assessing perceived reasons for sleep disturbance.	- 56% of caregivers reported clinically significant poor sleep and less than 40% were obtaining adequate sleep durations. - Caregiver sleep was significantly related to child age at diagnosis, child sleep, and caregiver guilt and worry. - The PSQI total score was significantly positively correlated with child sleep disturbance. However post-hoc probing suggested that for parents with high stress, child and caregiver sleep were not

Study Number	Study: authors, date & title. Quality Score (MMAT; range 0-5).	Population: parents, child age range and illness type.	Aims (relevant to this review)	Design	Outcome Measures (relevant to this review)	Results (relevant to this review)
			between sleep quality, child sleep disturbance, and caregiver guilt and worry.		Parent stress related to child illness: Parent experience of child illness questionnaire ($\alpha = 0.87$ in this sample). Caregiver measures of guilt, worry, sleep quality Child developmental and medical history and demographic data also collected.	related but for parents with lower stress, parent and child sleep were positively related - Caregiver sleep not associated with type of steroid treatment taken by the child, risk group, child's current age, length of time in treatment, SES, number of children living at home, gender (of child or parent) or ethnicity. - Caregiver guilt and worry was a significant predictor of caregiver sleep, but did not moderate the relationship between child sleep and caregiver sleep. - 70% indicated that sleepiness impairs daytime functioning. -
31)	Meltzer et al. (2010). The relationship between home nursing coverage, sleep, and daytime functioning in parents of ventilator-assisted children. MMAT: 2	36 primary caregivers of ventilator assisted children (VAS).	To examine the relationship between home-care nursing support, sleep and daytime functioning in caregivers of VAS.	Cross sectional survey with descriptive design	Parent sleep- 24-hour sleep patterns inventory. This has been piloted and shown to be valid and feasible for measuring sleep in adults. Parent fatigue: Iowa Fatigue Scale and Stanford Sleepiness Scale Parent depression: CES-D Parents were asked additional questions on level of support required by	- Caregivers with regular night nursing had 1-hour additional sleep time to those with no or less frequent night nursing. - Caregivers with significant symptoms of depression and sleepiness received sig fewer hours of night nursing per week.

Study Number	Study: authors, date & title. Quality Score (MMAT; range 0-5).	Population: parents, child age range and illness type.	Aims (relevant to this review)	Design	Outcome Measures (relevant to this review)	Results (relevant to this review)
					their child, home nursing support and sleep experience.	
32)	Angelhoff et al. (2018b). To Cope with Everyday Life, I Need to Sleep - A Phenomenographic Study Exploring Sleep Loss in Parents of Children with Atopic Dermatitis (AD). MMAT: 5	12 parents (11 mothers and 1 father) of children with AD.	To explore and describe perceptions of sleep in parents of children under 2 years old with AD. To explore consequences of parental sleep loss and what strategies the parents used to manage sleep loss.	Qualitative: Phenomenographic study	An interview guide was developed for this study based upon interview guides used in previous studies exploring parent sleep. Questions were designed to elicit information about parent sleep and factors to do with the child's illness that may affect parent sleep.	Three categories were found: Acceptance and normalisation of parental sleep loss; Changed routines and behaviour to compensate for sleep loss; and Support is needed to gain sleep and manage daily life- feeling supported and sharing responsibility with partner and practical support from extended family helped parents to "recover sleep". Sleep loss affected parents emotional state, mood, well-being, cognitive function, sensitivity to stress and ability to concentrate and take initiative.
33)	Ledet et al. (2015). A Pilot Study to Assess a Teaching Intervention to Improve Sleep-Wake Disturbances in Parents of Children Diagnosed with Epilepsy. MMAT: 2	12 parents of children with epilepsy	To assess the impact of screening and teaching interventions for sleep-wake disturbance in parents of children with epilepsy	Intervention pilot study with pre and post measures of parent sleep,	Parent Sleep: Epworth Sleepiness Scale and the PSQI Perceived seizure severity: Parent Perception of Childhood Epilepsy questionnaire Demographic and clinical information was also collected.	<ul style="list-style-type: none"> - No significant differences were found between pre and post intervention test scores - 100% of pre intervention and 83% of post intervention PSQI scores indicated poor sleep quality. - No sig relationship between parent perception of severity of their child's seizures and sleep (possibly due to no variation in baseline PSQI scores, all of which indicated poor sleep).

Study Number	Study: authors, date & title. Quality Score (MMAT; range 0-5).	Population: parents, child age range and illness type.	Aims (relevant to this review)	Design	Outcome Measures (relevant to this review)	Results (relevant to this review)
34)	Angelhoff et al. (2018a). Sleep quality and mood in mothers and fathers accommodated in the family-centred paediatric ward. MMAT: 4	82 parents (61 mothers and 21 fathers) with children (median age 6.25 years).	a) To describe sleep quality and mood in parents accommodated with their sick child in a family centred paediatric ward. b) To compare mothers' and fathers' sleep quality and mood and to compare sleep quality and mood between the ward and daily home after discharge.	Prospective descriptive study with a cross-sectional survey design	Parent Sleep before admission: Uppsala Sleep Inventory ($\alpha= 0.89$ in this sample). Current parent sleep: sleep diary which collected data on a 5-point scale on various aspects of sleep. One open ended question was added to explore what parents perceived influenced their sleep. Parent mood: Mood Adjective Checklist. ($\alpha= 0.73-0.90$ on different mood dimensions in this sample). Demographic and clinical information was also collected.	<ul style="list-style-type: none"> - 53% reported good sleep quality. No significant difference between habitual sleep quality and sleep quality in the hospital. - No significant effects of child's diagnosis on sleep quality were found. - Parents rated sleep quality as being significantly higher at home. - There was a positive but weak correlation between sleep quality and mood. - <p>6 categories influencing sleep were detected: the child (normal care e.g. breastfeeding as well as child being awake due to pain or coughing), staff, medical treatment, environment, worries and nothing. The main reason for nocturnal awakening was the child.</p>
35)	Albayrak et al. (2019). Assessment of pain, care burden, depression level, sleep quality, fatigue and quality of life in the mothers of children	101 mothers who had children with CP and 67 mothers who had a healthy child as the	To evaluate pain, care burden, depression level, sleep quality, fatigue and quality of life (QoL) among a group of mothers	Cross sectional survey design with comparison group	Measure of child pain & motor disability: Gross Motor Function Classification System, GMFCS). Parent depression: BDI Parent Sleep: PSQI	<ul style="list-style-type: none"> - Sleep correlated with parent depression, care burden, fatigue, but not well-being. - The CP group showed higher scores for ZCBS, BDI, PSQI, total CIS and SF-36 subscales of general health and vitality whereas the scores for role physical, role emotional, mental health and mental component summary were found to be

Study Number	Study: authors, date & title. Quality Score (MMAT; range 0-5).	Population: parents, child age range and illness type.	Aims (relevant to this review)	Design	Outcome Measures (relevant to this review)	Results (relevant to this review)
	with cerebral palsy (CP). MMAT: 1	comparison group.	of children with CP and to compare their results with a group of healthy comparisons.		Parent QoL: SF-36 Parent care burden: Zarit Care Burden Scale (ZCBS) Chronic fatigue: The multidimensional checklist individual strength (CIS).	lower in the patients, compared to the comparison group (p< .05).
36)	Safa et al. (2012). Correlation of Anxiety-Depression and sleep quality in mothers of children with cystic fibrosis and asthma. MMAT: 1	148 mothers of children with cystic fibrosis (CF) and asthma who were hospitalised during 2008-2010.	To evaluate the correlation between depression-anxiety and sleep quality in mothers of hospitalised children with CF and asthma.	Descriptive cross-sectional study	Parent sleep: PSQI Anxiety and depression: HADS (measures translated into Persian language and showed acceptable psychometric properties in Persian illness population). Demographic data also collected.	<ul style="list-style-type: none"> - 37% of mothers scored “high” for anxiety - 29% scored “high” for depression - 39% reported “poor” sleep quality. - A significant association was found between sleep quality and depression-anxiety (p<.005)

3. Review: A Narrative Synthesis of the Literature

A total of 209 abstracts were reviewed from the original search. The majority of these did not meet the inclusion criteria, leaving 80 articles remaining for full text review. Of these, 44 were eliminated, resulting in the final 36 studies included in this review (Table 1). Due to the heterogeneity of outcomes measured, statistical measures of integrating the data in this review were not used.

3.1. Overview

3.1.1. Samples

Table 1 summarises the sample characteristics. Most studies (n=27) included mothers and fathers, however it should be noted that overall, the majority of participants were mothers. The remaining studies (n=9) included only mothers. Children in the reviewed studies ranged in age from birth to 18 years old, with 14 studies specifically focusing on children aged 0-12 years.

Across the 36 studies reviewed, there were a wide range of different childhood illness populations. Parents of children with diabetes and cancer were the most frequently studied (n=5), followed by children with epilepsy and cerebral palsy (n=4). Other less frequently studied childhood illnesses included, but were not limited, to atopic dermatitis (n=3), heart disease (n=2) and cystic fibrosis (n=2). The majority of studies were comprised of parents of children attending outpatient care, however there were a substantial number that were based in inpatient hospital settings (n=9). For those studies in inpatient settings, almost all parents either slept on the ward or in the room with the child. Only one study included parents who stayed overnight in alternative hospital accommodation (Stremmer et al., 2013).

The research was primarily conducted in Western societies and in the English language. Research was however conducted in a range of countries and 12 studies were conducted in a

language other than English. The majority of studies did not present data on participant ethnicity (n=20). Where such data were presented, studies noted that the majority of participants were Caucasian (n=14).

3.1.2. Design

As outlined in Table 1, the majority of studies were quantitative (n=28), with a small number being qualitative (n=5) or mixed methods (n=3). Most employed a cross-sectional design (n=26) and only three also had a longitudinal component. Of the 31 studies with quantitative components, 17 used a single group design with no comparison, 12 utilised comparison groups of parents of healthy children, one used a comparison group of parents of children in a different illness group and one paper used both a “healthy child” and “different illness” group.

3.1.3. Measures

Only five papers used an objective measure of sleep (actigraphy), whilst the majority relied purely on self-report measures. None of the studies used polysomnography which is considered the gold standard for measuring sleep (Marino et al., 2013). A wide range of self-report measures were used to assess parent sleep across the included studies. The most commonly used measure of parent sleep was the Pittsburgh Sleep Quality Index (PSQI, n=18). Generally speaking, measures used were well established and validated with a range of citations provided for papers reporting on their psychometric properties. A range of papers also calculated and reported on internal consistency within the study sample, with adequate-excellent results. Four studies opted to design their own questionnaires and six papers adapted existing measures by adding additional questions to seek further detail on parents’ experience of sleep.

The studies in this review also included self-report measures used to assess various factors associated with parent sleep in this context. For example, measures of depression, anxiety,

stress and parental psychological adjustment to child illness were measured amongst a wide range of other factors. Measures used across studies were generally well established and validated measures with data provided on validity and reliability.

3.1.4 Analyses

The cross-sectional nature of the majority of the study designs means that the majority of quantitative papers report on correlations between variables (n=18). The use of primarily correlational designs means that the research presented in this review is able to inform thinking regarding associations between variables. However, the extent to which causal inferences can be drawn is limited. A minority of papers (n=6) reported on regression analyses and only two papers looked at mediation/moderation, both of which have the added benefit over correlational analyses of being able to control for potential confounding variables.

Tests of difference between illness and comparison groups were used in the 14 papers where a comparison group of some form was utilised. Such tests were also employed in two single group intervention studies looking at differences in parental sleep pre- and -post intervention. In addition, eight papers used qualitative methodology to explore parents' experiences of sleep in the context of their child's illness.

3.1.5 Methodological quality (MMAT)

All 36 studies were assessed using the MMAT Pluye et al. (2009a) and were assigned an overall quality rating. Study ratings ranged from 0-5 and are presented in Table 1. Full details of MMAT scoring including each study rating can be found in Appendix A. Studies ranged in overall quality of design and due to the majority of studies using cross-sectional designs and correlational analyses, caution should be taken in drawing causal conclusions or inferences regarding directionality of relationships between variables. Further consideration of the

quality and methodological limitations of the studies will be covered in detail alongside the findings below.

3.2. Themes Arising in the Literature

3.2.1. Prevalence of sleep disruptions

All reviewed studies either measured or described parent sleep in the context of child illness. Seventeen studies did not use a comparison group meaning that comparisons cannot be drawn with regards to prevalence of sleep disturbance in other populations. However, they provide useful information on levels of parent sleep disruption within various child illness populations. Of these 17, ten studies, used the Pittsburgh Sleep Quality Index (PSQI) to report the proportion of participants meeting criteria for poor sleep. This is defined as a score of ≥ 5 which represents a diagnostic sensitivity of 90% in distinguishing good versus poor sleep (Buysse et al., 1989), and ranged from 26-100%. Mean hours sleep per night ranged from 5.8 – 6.9 and proportions of parents reporting disruptions to sleep ranged from 53-79%. Two of these 17 used actigraphy to measure sleep, both of which found that the majority parents recorded ≤ 7 hours of sleep per night (Stremmler et al., 2013; Feeley et al., 2019). This is less than the recommended amount of approximately eight hours per night (NHS, 2018). Two intervention studies measured sleep longitudinally, both finding that parents reported high levels of poor-quality sleep and this was consistent over time despite intervention (Ledet et al., 2015; Safer et al., 2016).

In the 13 studies where comparison groups of parents with healthy children were used, the findings were relatively uniform. Parents in the illness groups consistently reported poorer sleep quality and duration compared with controls. Only two studies had contrary findings; Matthews et al. (2014) found no differences between groups; however, the authors noted that both groups experienced fragmented sleep. Ramirez et al. (2019) also found no significant differences in sleep duration between groups, however they found that mothers of children in

the illness group reported significantly more difficulty falling asleep and subjectively greater insufficient sleep. As noted in Meltzer and Moore's (2008) review, healthy children may not be the most appropriate comparison group due to the significant variation in caregiving demands across different childhood illnesses. Only two studies included comparisons between more than one illness groups and both found no significant differences between groups in terms of parent sleep quality (Reilly et al., 2018; Meltzer & Booster, 2016). However, both of these studies have small sample sizes therefore it is worth considering whether type II errors may have been made.

Finally, the eight studies with qualitative elements reported on themes related to parents' experience of poor-quality sleep and sleep disruption. Themes largely described experience of poor sleep and perceived causes and consequences of sleep disruptions.

Taken as a whole, these papers demonstrate relative uniformity in their findings, offering reasonably strong evidence to suggest that sleep is an issue for parents of children with a chronic physical illness. The overwhelming majority of studies show a high proportion of parents scoring above thresholds in a variety of self-report and objective measures, and higher levels of sleep disruption in parents of children with an illness compared to healthy controls.

It should be noted however that the methodological quality of the studies described varies. Given the nature of studying parent sleep there are a huge number of potential confounding variables. Some studies appear to have addressed such variables appropriately in the design by adjusting for covariates such as child sleep, age at diagnosis and parent perception of child illness (e.g. Daniel et al. 2018); however, others fail to consider this issue, making it more difficult again to draw causal inferences from the data. Sample sizes vary between studies, however many use large samples meeting requirements from a priori power calculations.

Despite the large sample sizes, the majority of authors acknowledge that their samples may not be representative of the overall target populations due to methodological issues such as use of convenience sampling and self-selection bias. Finally, whilst a range of validated self-report measures have been implemented in the reviewed studies it should be noted that only five studies used actigraphy (an objective measure of sleep) and so results risk being subject to self-report bias.

In summary, whilst it is not possible to draw a causal conclusion from the data based on the limitations described, the convergence of findings from a large number of studies offers good evidence of an association between impaired parental sleep and child illness.

3.2.2 Child illness-related factors and their association with parent sleep

Of papers reviewed, 30 studies described at least one child illness-related factor that was associated with or described as impacting on parent sleep. Whilst direction of relationships between variables cannot be assumed and casual conclusions cannot be definitively drawn due to limitations in the methodology, five key themes arose describing factors associated with poor parental sleep in this population.

Anxiety about the child's health. Thirteen papers discussed how anxiety about the child's health was associated with parent sleep. Five qualitative papers reported on themes indicating that worry and anxiety about the child's health were perceived causes of disrupted sleep. Three papers also reported a brief content analysis where the themes of anxiety about the child's health condition emerged (Feeley et al., 2018; Wright, 2011; Angelhoff et al., 2018a). Comments included: "When your child is ill you don't really sleep at all; you are constantly worried and stressed" and [there being] "always something to worry about". Other anxieties included themes such as worry about whether the child will live a normal life, anxiety about child's prognosis and fear of relapse. Quantitative findings highlighted

caregiver guilt and worry, and stress about the child's health to be significant predictors of parent sleep, when controlling for a range of other variables (Daniel et al., 2018; Meltzer & Booster, 2016). Descriptive statistics in Larson et al. (2012) showed a high proportion of parents reporting that concerns about their child having nocturnal seizures impacted on sleep. Meltzer and Pugliese (2017) found that stress regarding the child's health needs was associated with disrupted sleep. Whilst these papers refer to such factors as "causing" parents disrupted sleep, and it seems plausible that the relationship may be in this direction, due to the study design, only tentative claims should be drawn regarding directionality.

Stress from other factors. Seven studies commented on how stress and anxiety from other factors 'impacted' on parents' sleep. Themes included dealing with changes to the usual day and night-time routine (Neu, 2014; Stremmer et al., 2010), financial worries (Neu, 2014), caring for the rest of the family and dealing with multiple demands (Stremmer et al., 2010), child anxiety (Feeley et al., 2019), delays in treatment, unclear information and waiting for operations (Nassery & Landgren, 2019). One study however found no significant differences in general stress between parents in the illness versus healthy control groups (Meltzer & Booster, 2016).

The relationship between child and parent sleep. Following recommendation from Meltzer and Moore (2008) for more research to explore the relationship between child and parent sleep, thirteen papers looked at this with varying results. Six papers reported simple linear correlations and found significant positive associations between poor child and poor parent sleep. Qualitative and descriptive findings from other studies add further insight to this relationship. Parents in illness groups were: more likely to feel their sleep was impacted negatively by their child's sleep (62% versus 39%; Wright, 2011), described their child needing someone to sleep with them (Neu, 2014) or keeping them awake due to illness symptoms e.g. coughing or being in pain (Angelhoff et al., 2018a), and itching (Angelhoff et

al., 2018b). However, the findings were not unanimous across papers. Matthews et al. (2014) found only a weak correlation between child and parent sleep. Reilly et al. (2018) found that the correlation between child and parent sleep did not hold significance when included in multivariate analysis, and Ramirez et al. (2019) found that controlling for child sleep did not change parent sleep outcomes. These findings suggest that while parental sleep disturbances may be in part explained by child sleep disturbances, there are likely to be other factors involved in this relationship. Significant correlations between variables alone is insufficient indicator of a true association.

Child illness severity. Child illness severity was considered as a variable that may influence parent sleep in twelve studies. Seven used a correlational design with two finding significant correlations between child illness severity and parent sleep (Larson et al., 2012; Feeley et al., 2019). However, five found no such significant relationship (Albayrak et al., 2019; Shaki et al., 2011; Ridolo et al., 2014; Adiga et al., 2014; Ledet et al., 2015). Four studies compared illness severity using between-groups analyses. Of these, two found significant differences in parent sleep between child illness severity groups (Vardar-Yagli et al., 2017; Ramirez et al., 2019) and two did not (Meltzer & Pugliese, 2017; Daniel et al., 2018). A limitation of these studies is the extent to which confounders were controlled for. Whilst some accounted for a range of possible confounding variables, the authors acknowledged that there were likely to be others that were not considered. Additionally, given the wide range of child illnesses investigated (each with varying symptomology), it is possible that severity may influence parent sleep in some but not all child conditions. This heterogeneity makes it difficult to ascertain the extent of the relationship between illness severity and parent sleep. Four papers explore whether the type of treatment the child has relates to parent sleep. Quantitatively, type of treatment across three papers was not found to be associated with parent sleep (McLoone et al., 2013; Meltzer et al., 2015; Daniel et al.,

2018). However qualitative findings suggest that in childhood oncology treatment, taking steroids has an impact on the child's sleep, which then impacts on parent sleep (Neu, 2014).

Night-time caregiving. A final theme was the impact of night-time caregiving on parent sleep. This was particularly prevalent in studies looking at childhood diabetes, with four out of the five studies on this group reporting that nocturnal blood-glucose checking was a factor in parents' disrupted sleep (Macaulay et al., 2019; Monaghan et al., 2012; Feeley et al., 2018; Jaser et al., 2016). Descriptively, 65-79% of parents reported night time blood glucose checking as affecting their sleep and this is supported by themes arising in qualitative studies about parents' experience.

To summarise, the literature reveals several factors that may be associated with parent sleep in the context of having a child with a physical illness. Meltzer and Moore's (2008) review identified four factors as to "potential causes of sleep disruption in parents". These were: providing care through the night, night-time monitoring of the child's condition, false monitor alarms and the stress of caring for a youth with a chronic illness. The current review provides additional support for these themes and also specifically contributes consideration of the role of a range of additional factors. Specifically, the current review breaks down Meltzer and Moore's theme of "stress" and looks at this in more detail (anxiety about the child's health and stress from other factors). It also invites greater consideration of the role of severity of the child's condition and the relationship between child and parent sleep.

Methodological limitations with study design mean that it is not possible to definitively draw conclusions regarding cause and effect, nevertheless there are some areas where it seems relatively uncontroversial that the child's illness plays a causal role in disrupting sleep. The wide range of illness types investigated means that it may not be possible to determine the extent of the relationship between variables. Despite this, the studies offer valuable

insight into factors associated with parent sleep that would benefit from further investigation using more rigorous methodology and longitudinal designs.

3.2.3. Environmental and social factors and association with parent sleep

Twenty-two studies explore the relationship between wider environmental and social factors and parent sleep. Of the nine studies in inpatient settings, seven report on factors at hospital that may influence parent sleep. All studies use descriptive or qualitative methodology, meaning that it is not possible to establish the extent to which factors described are associated with sleep. However, they offer helpful and plausible ideas as to factors likely to impact on parent sleep which would benefit from further research. Factors frequently described as impacting on parent sleep whilst their child was an inpatient included: noise from hospital machines or staff and lack of privacy or uncomfortable sleeping space (Edell-Gustafsson et al., 2014; McLoone et al., 2013; Nassery & Landgren, 2019; Coleman et al., 2018; Angelhoff et al., 2018a).

Six studies reported on factors that may be associated with parent sleep quality at home. These included co-sleeping with the child and room sharing (Larson et al., 2012; Adiga et al., 2014), amount of nursing support available (Meltzer et al., 2015; Meltzer et al., 2010) and amount of support from family and friends (Angelhoff et al., 2018b; Neu, 2014).

Finally, demographic characteristics and their relationship with parent sleep were explored in twelve studies. Most explored relationships between child and parent gender and age and found no significant relationships between these variables and sleep. Four studies explored time since the child's diagnosis as a variable, with two finding a significant relationship (with parents of children who had been diagnosed longer ago or at a younger age having poorer sleep; Feeley et al., 2018; Daniel et al., 2018) and two not (Feeley et al., 2019; McLoone et al., 2013). As with the above critiques, it is not possible to draw firm conclusions as to the impact of various demographic variables. However, reviewing the body of research as a

whole, it appears unlikely that the demographic factors analysed are sufficient alone to account for variance in parent sleep in this context.

3.2.4. Parent sleep and associations with mental health and daily functioning

Sixteen studies explored parent sleep and its relationship with mental health. Fourteen explored constructs including anxiety, stress, well-being, quality of life, psychological adjustment, mental health and mood. Twelve of those explored the relationship between one of these constructs and parent sleep using correlational analyses, with seven finding a significant correlation (Reilly et al., 2018; Vardar-Yagli et al., 2017; Jaser et al., 2016; Feeley et al., 2019; Al Maghaireh et al., 2017; Angelhoff et al., 2018a; Safa et al., 2012). One study found that sleep significantly statistically mediated the effect of parenting stress on psychological adjustment (Bishop et al., 2019); i.e. parenting stress significantly predicted sleep, which in turn predicted maladjustment. Another (McLoone et al., 2013) found that anxiety was a significant predictor of poorer sleep, however due to design limitations directionality of the relationship cannot be concluded. Two studies using actigraphy found that average sleep time was not correlated with health-related quality of life (Meltzer et al., 2015) or stress (Matthews et al., 2014), but that sleep efficiency and wake after sleep onset were significantly associated. Whilst these papers both used objective measure of sleep, the authors note limitations which may impact on findings. The low participation rate (Meltzer et al., 2015) may have limited the generalisability of the study results, and that the lack of variation in total sleep time (Matthews et al., 2014) may have limited the ability to accurately assess the relationship between variables. Qualitative findings provide further evidence in support of the relationship between parent sleep and overall mental health/well-being, with parents reporting that disrupted sleep impacts on their well-being, mood and sensitivity to stress (Macaulay et al., 2019; Angelhoff et al., 2018b).

Depression was a construct that was measured somewhat distinctly. Six papers (Safer et al., 2016; Vardar-Yagli et al., 2017; Feeley et al., 2019; Wayte et al., 2012; Albayrak et al., 2019; Safa et al., 2012) found a significant relationship between parent sleep and depressive symptoms, with Wayte et al. (2012) finding that maternal sleep quality predicted 50% of the variance in maternal depression scores. The cross-sectional designs and lack of matched comparison groups limit the ability to build a direct link between variables; however, it is worth considering when interpreting these findings that sleep disturbance is well-established as a symptom of depression (NHS, 2019). Other studies looking at depression in this context and using between-groups analyses found that group (illness versus comparison) predicted sleep and depression scores, however did not explore this relationship further (McLoone et al., 2013; Paddeu et al., 2014; Meltzer et al., 2010). Additionally, one study noted that 53% of participants met the criteria for poor sleep and 32 % met criteria for low mood (Jaser et al., 2016). However, the analysis does not explore the relationship between these variables.

Eight studies reported on the perceived impact of sleep disruptions on parents' daily functioning. Four used between-groups analysis with three highlighting that caregivers in illness groups indicated significantly higher levels of daytime exhaustion (Ramirez et al., 2019), lower productivity (Reilly et al., 2018) and greater feelings of irritability, exhaustion and forgetfulness (Wright, 2011) than caregivers in the healthy control groups. One found no differences between groups for levels of daytime fatigue (Meltzer et al., 2010). Although these study designs allow comparisons between groups to be made, which are overall suggestive of a relationship between disrupted sleep and functioning, causation cannot be assumed. Macaulay et al. (2019) did not use a control group and found that daytime functioning was impaired in participants although analysis does not explore this further. Finally, three qualitative papers highlight parents' views that sleep loss affects their cognitive function (Angelhoff et al., 2018b; Macaulay et al., 2019), ability to concentrate and take

initiative (Angelhoff et al., 2018b), productivity and relationship with their children (Neu, 2014).

To summarise, this review expands upon Meltzer and Moore's (2008) "prevalence, causes and consequences of sleep disruptions" and describes associations between various factors and lack of sleep, and the impact on parents' mental health. Despite methodological limitations, given the relatively large number of studies, the evidence is certainly suggestive of a relationship between child illness and disrupted sleep, and disrupted sleep and poorer mental health.

4. Discussion

4.1. Overview of Findings

This review synthesised the most up-to-date literature on parental sleep in the context of childhood illness. This consisted of 36 studies published in the last decade with varying aims, designs and child age and illness populations. Taken as a whole, this body of research offers reasonable evidence demonstrating sleep disruptions in parents of children with a chronic physical illness. This is consistent with findings from previous reviews in similar populations (Meltzer & Moore, 2008; Mcann et al., 2015).

This review expands upon previous reviews and provides a range of tentative theoretical explanations for understanding why sleep might be disrupted in this parent population. Such factors include those related directly to the child's illness (such as parental anxiety about the child's health, symptom severity and night-time care-giving demands) as well as indirect factors associated with child illness (including impact of the environment and support availability). The positive association between high parental anxiety about the child's health and poorer sleep fits with the theory described earlier in this review. For example, Leventhal's (2003) model of illness representation would hypothesise that those with more threatening perceptions of the illness are at greater risk of poorer adjustment which may

include increased anxiety but also increased sleep disturbance. Additionally, Whilst the relationship between symptom severity and parent sleep is not conclusive in this review, research has shown a link between increased symptom severity and higher experience of illness uncertainty (e.g. Kang, 2003; Johnson et al., 2006). The direction of this relationship is not clear in the literature and future research may benefit from exploring the interaction between these variables further.

This review also explores the relationship between sleep disruptions and parental mental health, largely providing evidence for a relationship between sleep disturbance and psychological functioning in this population. This is consistent with the wider literature whereby numerous reviews have demonstrated a relationship between sleep disturbance and a variety of mental health complaints (e.g. Cox & Olatunji, 2016; Bhati & Richards, 2015; Lovato & Gradisar, 2014).

These findings are of utmost importance given the known link between parent mental health and a wide range of child emotional, social and physical outcomes (Goodman et al., 2011). They are of additional importance in this population as these parents also have the additional responsibility of caring for a child with an illness which may involve frequent monitoring and making important decisions about the child's health.

Alarmingly, despite the consistent finding (in this and other reviews) that child illness is associated with parent sleep disruption, only two studies looked at the impact of interventions on improving parent sleep. Both had small sample sizes and did not detect significant changes in sleep as a result of the intervention. Given the potential for significant implications of disrupted sleep on parental mental health and subsequently on the child's well-being, future research should explore this further.

4.2. Critique

The large number of studies included demonstrates the importance of understanding the impact of childhood illness on parental sleep and the potential causes and consequences of this, and adds weight to the findings of this review. Overall, the sample size is large and diverse, with participants from a range of different countries and backgrounds. Additionally, many of the concepts described are derived from multiple sources, strengthening the face validity of the conclusions made.

However, many of the studies evaluated lacked the use of robust research methodology. Using the MMAT as a quality assessment tool, only nine studies scored either four or five out of a possible five and most of these were qualitative. Only one of these utilised a comparison group (Matthews et al., 2014) and none used longitudinal multivariate designs. Eighteen studies scored only one or two out of five and as described above, methodological limitations warrant caution in interpreting the findings.

4.2.1. Defining and measuring constructs

As described in Meltzer and Moore (2008) there are a number of different ways in which sleep is defined and measured in the literature. For example, constructs include total sleep time, sleep onset latency (time taken to fall asleep), frequency of night waking's and sleep quality. Whilst all studies measured or described at least one of these variables, there is distinct variability across studies regarding which constructs are measured and reported on, making direct comparisons difficult. The inability to make direct comparisons is further exacerbated by the wide range of outcome variables measured, in different child illness populations with different age groups of children and using varied data collection techniques.

Whilst most studies used established validated self-report measures of sleep, several adapted existing questionnaires, designed new questionnaires and/or failed to provide validity

data of measures in the study's sample. Only five studies used actigraphy as an objective measure of sleep and no study used polysomnography.

4.2.2. Longitudinal data

Only three studies (Ramirez et al., 2019; Safer et al., 2016; Ledet et al., 2015) reported on longitudinal data, all of which found that sleep quality was consistent over time (despite interventions described in two studies). This should be interpreted with caution due to small sample sizes in the intervention studies. Given the relative dearth of longitudinal studies in this field, claims regarding “causality” and “consequences” of sleep disturbance remain tentative at best. Whilst this body of literature identifies a range of plausible mechanisms through which such variables may influence one another, more longitudinal research is needed to identify and clarify direct causes and consequences of sleep disruptions. Such longitudinal data would provide a greater depth of understanding regarding sleep quality (Galland et al., 2012) and may path the way for further research into tailored interventions to support parents when facing child illness in the family.

4.2.3. Bias and validity

A common limitation was the recruitment strategy used in studies in which participants were consistently self-selecting, which may have introduced bias. It is plausible that participants who agreed to participate had experiences in common (such as greater sleep disturbance), and that this may have been a motivating factor to participate in such research. Additionally, despite the overall sample representing a range of population demographics, the majority of studies themselves report issues with their sample not being representative of the immediate target population

The validity of these largely observational cross-sectional studies is further threatened by unmeasured variables that may confound results. Unmeasured exposures of factors that affect parent sleep and their mental health may have led to associations being assumed incorrectly.

Whilst a number of studies controlled for confounding, none controlled for unmeasured confounding which may have resulted in a level of biased effect estimates (Vanderweele & Arah, 2011). Additionally, many studies made attempts to control for confounders such as developmental norms related to sleep disturbance through the use of age-matched controls. However, the wide age range of participants in most studies means that analysis into age-appropriate sleep disturbances in healthy children was not possible.

4.3. Research and Clinical Implications

The results of this review offer reasonable evidence demonstrating sleep disruptions in parents of children with a physical health condition or illness and provides suggestions for factors that may play a role in this relationship. The methodological flaws described above limit confidence in interpreting the findings; however, the literature points to a number of areas that would benefit from future research.

There is a particular need for research to use more robust methodology such as longitudinal studies with multivariate designs to test relationships between variables outlined in this review. This would allow for greater inferences regarding directionality to be made which may guide development of interventions. Future research would also benefit from recruiting more diverse and representative samples. The samples in this review are disproportionately made up of Caucasian mothers, despite being sourced from a range of countries and geographical regions.

The use of objective measures of sleep as well as consistent use of validated self-report questionnaires would strengthen the quality of future research and would better enable comparison and aggregation of findings across studies. Future research would benefit from a focus on developing interventions which may be guided by the findings from this and other reviews. The dearth of research on interventions in this population represents an opportunity

to explore possible protective factors that may be utilised to support parents and improve their experience of sleep and mental health in the context of child illness.

Finally, there are a number of common childhood conditions in which sleep disturbance is known to be highly prevalent; an example being infant Gastroesophageal Reflux Disease (GORD; Blanch & Reflux Infants Support Association Inc, 2010). Despite this there is little research looking at parental mental health in this illness context. Anecdotally, there is evidence that parents of infants with GORD may be at greater risk of mental health difficulties (e.g. Reflux Infants Support Association, 2013). Therefore, it is important that further research looks at predictors of parental mental health in this context.

In terms of clinical implications, this review offers several avenues that may serve to improve well-being in parents. Despite not being able to define the direction of the relationship between a range of variables, there is likely a level of circularity in such relationships (e.g. Cox & Olatunji, 2016). This means that interventions to improve parent sleep may improve parents' mental health, whilst at the same time, interventions targeting parent mental health in this context may improve parents sleep.

Finally, clinicians should be aware of the impact of childhood illness on parent sleep; the reasons for this and the associations between this and parents' mental health and well-being. This greater awareness may enable greater support systems to be implemented targeted to this population's needs.

5. Conclusion

The findings of this review are consistent with and build upon previous reviews. Overall, this review shows that this population of parents are at greater risk of sleep problems and proposes a range of factors associated with the child's illness may contribute to this. This review goes further to demonstrate the association between sleep difficulties and parental mental health. Methodological limitations significantly limit the ability to draw firm

conclusions regarding apparent associations. Further research is needed to clarify this and to explore different child illness populations. This may enable and guide development of interventions to support families when a child is unwell. Future research should utilise more robust methodology including longitudinal designs, use of age-matched controls and objective, well-defined measures of sleep. This review offers several avenues for future research to explore interventions which may improve parent sleep and reduce distress in this context.

6. References

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Major Research Project (MRP) Section B: Empirical Research Paper

Paediatric Gastroesophageal Reflux Disease and Parental Mental Health: Prevalence and Predictors.

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Abstract

Background: Infant Gastroesophageal Reflux Disease (GORD) occurs when symptoms of reflux become severe enough to require medical intervention. Parents whose infants experience some of the symptoms of GORD are at risk of poorer mental health, however little research has looked at parental mental health when caring for an infant with GORD.

Objectives: The present study aimed to estimate the prevalence of mental health difficulties in this population. It also aimed to test predictors of parental mental health and to explore differences between different types of GORD. **Methods:** Parents took part in an initial online survey (N=309) and a follow-up survey (N=103). **Results:** Participants reported significantly higher rates of anxiety and depression than those found in perinatal or general population samples. Results provided support for the cross-sectional and longitudinal predictive power of self-compassion, illness perceptions and illness uncertainty, above and beyond parent satisfaction with sleep, social and relationship support and infant feeding. No differences were found between parents of infants with silent GORD compared to GORD with visible regurgitation. **Conclusions:** This study provides evidence that this is a population in which there is a high demand for research and a need for emotional and practical support to be offered.

Keywords: Infant Reflux, Parent Mental Health, Infant Gastroesophageal Reflux Disease, GORD, GERD, Well-being.

1. Introduction

Reflux Versus Gastro-Oesophageal Reflux Disease

Infant reflux is a normal physiological process that occurs when a baby brings up milk, or vomits, during or shortly after feeding. It usually starts before a baby is eight weeks old, is very common (affecting up to 40% of infants), usually gets better on its own and does not require medical investigation or treatment (National Health Service (NHS), 2019a; National Institute for Health and Care Excellence (NICE), 2015). One distinct type of reflux (silent reflux) occurs when the contents of the stomach move up the oesophagus, but don't enter the mouth, resulting in no visible regurgitation (NICE, 2015).

Infant gastroesophageal reflux disease (GORD) may be diagnosed “when symptoms of reflux become severe and need medical treatment” (NICE, 2016). Common characteristics of GORD in infants include effortless regurgitation of feeds, displays of pain or marked distress, sleep disturbances and persistent crying (Mir, 2010; NICE, 2015; Blanch & The Reflux Infant Support Association (RISA), 2010).

In clinical practice there is a continuum of symptoms ranging from reflux to GORD. There is no simple or reliable test or diagnostic tool for GORD and defining when symptoms become severe enough to warrant medical treatment is difficult, depending largely on caregiver and health professionals' subjective interpretation of symptoms (Gonzalez-Ayerbe, et al., 2019). Additionally, the symptoms of infant GORD are broad and not specific to GORD, due to overlap with other conditions such as cow's milk protein allergy (Iacono et al., 1996), making it more difficult to diagnose reliably. Furthermore, whilst babies with silent reflux may have a number of other signs of reflux (e.g. frequent crying, frequent waking), silent reflux is often more difficult to diagnose due to the cause of the infant's distress being less obvious, i.e. no vomiting (Blanch & RISA, 2010).

Consequently, the most widely adopted assessments of GORD and its prevalence are based on symptoms only rather than diagnostic tests (NICE, 2015; Singendonk et al., 2019). Similarly to reflux, GORD often occurs when an infant is very young and is most commonly diagnosed between the age of one week and two months old. (Iacono et al., 2005). It has been found to occur in up to 25.5% of infants aged one month on a daily basis, dropping to only 2.9% by the age of six months (Singendonk et al., 2019).

The terms “reflux” and “GORD” are used interchangeably by health professionals, families and in the clinical and academic literature. This is problematic in part due to the difficulty in distinguishing between the two, but also because of the minimising impact this has on the challenges faced by parents of infants with GORD. Using the term “reflux” may normalise or trivialise the experience, leading to others not understanding the huge impact GORD can have on families’ lives (RISA, 2012). In attempt to not feed into this, this report will use the term “GORD” throughout; however, it should be noted that because “reflux” is more commonly used with and amongst families, this has been used throughout the study advertisements and surveys.

In summary, GORD may be diagnosed when symptoms of reflux become severe enough to require medical intervention. It is characterised by frequent regurgitation of feeds, persistent infant crying, pain and sleep disturbances, all for which are likely to result in practical and emotional challenges for parents.

Postnatal mental health and GORD characteristics

Whilst definitions vary, this report uses the term “postnatal” to refer to the first year after birth (e.g. NHS, 2018). This period can be a time of happiness and excitement, but also a time of challenge (Schmied, 2020). New parenthood is a known period of vulnerability for onset and/or relapse of parental mental health problems (most commonly depression and anxiety disorders; Aktar et al., 2019), and postnatal mental health disorders affect up to 20% of

women (World Health Organisation, 2020; Werner et al., 2015). Mental health care during this time has been recognised as a NHS priority area (NHS, 2019b) due to the potential negative consequences of poor mental health on the mother–infant attachment relationship (Martins & Gaffan, 2000) and a range of child outcomes (Netsi et al., 2018).

A volume of literature has investigated the impact of the individual symptoms of infant GORD on parental mental health during the postnatal period. Persistent infant crying or infantile colic is defined by Wessel et al. (1954) as outbreaks of irritability or crying lasting for a more than three hours a day and occurring more than three days in a week. This has been linked to a range of poor outcomes including: tiredness and fatigue in mothers (Botha et al., 2019; Kurth et al., 2011), maternal depression (Petzoldt, 2018; Zeifman & St James-Roberts, 2017; Vik et al., 2011), insecure attachment style (Akman et al., 2006), lower maternal self-efficacy (Stifter & Bono, 2002), and higher levels of parenting stress (Miller-Loncar et al., 2004). Sleep disturbance and feeding difficulties are key features of infant GORD which have been consistently linked with poorer parental mental health outcomes including higher levels of maternal depression (Muscat et al., 2014; Chaput et al., 2016; Roomruangwong et al., 2016), anxiety (Meltzer & Moore, 2008) and maternal stress (Henshaw et al., 2015).

Given the potential impact of the features of infant GORD on parental mental health as well as the challenge of getting an accurate diagnosis, it is not surprising that there is a wealth of anecdotal evidence suggesting that parents with infants with GORD may at greater risk of mental health difficulties (e.g. RISA, 2013). However, very little research to date has looked explicitly at the impact of GORD on parental mental health. Looking more broadly at infant gastro-intestinal problems, a systematic review by Mahon et al. (2017) highlights how symptoms are often extremely distressing for parents which may result in anxiety and repeated healthcare consultations. However, this review does not include any papers looking

specifically at parental mental health in this context. Another review by Salvatore et al. (2018) concluded that infant gastro-intestinal problems can have heavy personal and financial costs including parental anxiety and reduced quality of life. However, the majority of studies in this review look more broadly at infant colic rather than GORD.

Research that has been done into infant GORD has found that mothers of infants with GORD communicate less with their infant compared with those without reflux (Neu et al., 2014). Another study found that mothers of infants with GORD reported higher levels of anger and frustration and lower enjoyment related to their infants feeding than mothers of infants without GORD (Mathison et al., 1999). However, only one study to date has looked at prevalence of mental health problems in a population of parents in Australia, and it is not peer reviewed. This survey by the Reflux Infant Support Association in Australia (RISA, 2017) found that 29% of respondents had a diagnosis of postnatal anxiety or depression, significantly higher than the general population rate (RISA, 2017; NHS Choices, 2016).

Predictors of parental wellbeing in the context of child illness

As demonstrated above, there is a dearth of evidence exploring the impact of infant GORD on parental mental health. Understanding factors that may predict or mediate parental mental health in this context may enable the development of interventions to better support parents through this difficult experience. Whilst no known research seeks to identify such factors in parents of infants with GORD, a range of psychological theories can be drawn upon to guide exploration into this population.

Illness beliefs and appraisals theories have been drawn upon to offer a theoretical explanation into such factors in other childhood illnesses. Leventhal's model of illness representation is frequently cited in the literature. It proposes five key components of illness cognition that guide illness appraisals; identity, timeline, consequence, control-cure and cause (Leventhal et al., 2003). More threatening perceptions of illness are consistently

linked with poorer parental adjustment in a range of adult and childhood illnesses (e.g. Broadbent et al., 2015; Beinke et al., 2016).

Illness uncertainty is a particular appraisal that might be very relevant to infant GORD. Given the difficulties diagnosing GORD, inconsistent language used and perhaps lack of acknowledgement or recognition of there being a problem, it is likely that parents experience high levels of uncertainty when faced with caring for an infant with reflux. Research has linked parental experience of uncertainty (in the context of having an unwell child) with poorer parental adjustment, increased distress, maladaptive coping and lower quality of life in a number of childhood illnesses (Mullins et al., 2016; Szulczewski et al., 2017; Wright et al., 2009). Considering the potential mediating role of uncertainty might also be helpful in exploring any differences between GORD and silent-reflux in terms of parent experience.

Another distinct theoretical construct that has been drawn upon extensively in the literature on parental well-being is self-compassion. Gilbert (2010) frames self-compassion within an attachment theory framework and proposes that self-compassion involves providing care to oneself. Others have described self-compassion as having a caring attitude towards oneself and responding to oneself with kindness in the face of difficult times or perceived failures (Zessin et al., 2015; Neff, 2003). It has been theorised that self-compassion may be particularly relevant to well-being in new parents (Neff, 2011; Kirby, 2016). Little research has explored the role of parent self-compassion in the context of child illness however self-compassion has been linked with parental well-being in the postnatal period (Cree, 2010; Felder et al., 2016). It has been shown to be a strong predictor of negative adjustment in parents of children with autism (Neff & Faso, 2015). Whilst self-compassion may be considered somewhat separately from illness appraisals, it is likely that a degree of overlap may exist. For example, individuals with high self-compassion may be less likely to appraise

difficult life events (such as illness) as having negative implications for their sense of self (Finlay-Jones, 2017).

Additional factors that have been linked with parental mental health that are likely to be relevant in the postnatal period and child illness context include, sleep (Meltzer & Moore, 2008), partner relationship satisfaction (Rosand et al., 2011), perceived social support (Tak & McCubbin, 2002) and satisfaction with infant's feeding (Hall & Hauck, 2007).

In summary, parents of infants with GORD may face a range of practical and emotional challenges. The importance of postnatal mental health has been well documented and the current literature identifies potential predictors and mediators of parental wellbeing in the context of child illness. However, this has not yet been looked at in a population of parents whose infants have GORD. Understanding predictors and mediators of parental mental health in this context may provide a platform to enable development of psychological interventions to support parents.

1.1. Aims and Hypotheses

Aim 1: To estimate the prevalence of mental health difficulties in a population of parents who have an infant with GORD.

To test the following hypotheses and questions regarding predictors and mediators of parental mental health and well-being in this population based on the psychological theory described above.

1: Parents perceptions of their infant's GORD predicts parental anxiety, depression and well-being. More threatening perceptions of the infant's GORD predict higher anxiety and depression, and lower well-being scores at baseline and at two-month follow-up.

2: Higher levels of perceived uncertainty regarding their infant's GORD predicts high higher parental anxiety and depression, and lower well-being scores at baseline and at two-month follow-up.

3: Higher levels of parent self-compassion predict lower levels of parental anxiety and depression, and higher well-being scores at baseline and at two-month follow-up.

4: Do parents' perceptions of their infant's GORD, experience of uncertainty and self-compassion predict anxiety, depression and well-being above and beyond satisfaction with infant's feeding, sleep, personal/partner relationship and social support (all measures collected at baseline)?

5: Do parent's perceptions of their infant's GORD, experience of uncertainty and self-compassion at baseline predicts anxiety, depression and well-being at two-month follow-up above and beyond satisfaction with infant's feeding, sleep, partner relationship and social support (at baseline)?

6: Parents whose infants have silent reflux have higher anxiety and depression and lower wellbeing scores compared with those whose infants have reflux that is not silent. This relationship is statistically mediated by illness uncertainty.

Aim 2: An additional and final aim of this study was to explore parents' views about the impact of caring for an infant with GORD on their mental health.

2. Method

2.1. Design

The study employed a cross-sectional survey consisting of a series of self-report outcome and experience measures as well as demographic and GORD-related questions. Measures reflux severity and outcome variables were also collected at two-month follow-up. A

longitudinal element was incorporated into the study in order to observe variables over time and to explore the endurance of possible predictors over time. Whilst the methods of this study do not allow for claims regarding causality to be made, a longitudinal design adds weight to the study's ability to determine relationships between variables (Caruana et al., 2015).

2.2. Participants and Recruitment

Participants were recruited from the online social media website, Facebook. Twelve Facebook groups for parents of children with reflux were contacted with information about the study (Appendix B). A social media post (Appendix C) containing a link to the survey was posted on eight Facebook group pages where consent to advertise was granted. Interested participants were invited to follow a link to the participant information sheet (Appendix D).

Participants were eligible if they identified as a parent or primary caregiver of an infant, aged between 3-12 months, with a diagnosis of GORD made by a prescribing physician (e.g. paediatrician or GP), who was currently receiving treatment for GORD. Participants who did not fully meet the inclusion criteria (e.g. if it was not clear whether a formal diagnosis of GORD had been made) were excluded. At the end of the survey, participants were asked for their consent to be sent an eight-week follow-up survey. If consented, participants were asked to provide an email address in order to receive the follow-up survey. Those who consented were contacted approximately eight weeks from the date on which they completed the baseline survey. The email (Appendix E) contained a second participant information sheet detailing the purpose of the study and a link to the follow-up survey (Appendix F).

Field (2013) suggested a minimum of 119 participants were required to sufficiently power the study based on a medium effect size for a conventional level of power (.80) and an alpha of .05. A larger sample size was aimed for in order to account for possible attrition in the

longitudinal element of the study and the possibility that the effect size might be smaller. Participant flow and characteristics of the sample are presented in the results section.

2.3. Measures

Participation in the study took place online and data was collected using Qualtrics, a secure survey data collection platform. (See Appendices D & F for a copy of the measures).

Outcome Variables

Parental anxiety was measured using the GAD-7, a widely used self-report screening measure of generalised anxiety (Spitzer et al., 2006). Scores range from 0-21, with higher scores indicating higher anxiety and a clinical cut-off of ≥ 10 . The GAD-7 has been validated in large clinical and general population samples (Löwe et al., 2008; Spitzer et al., 2006), and has shown good internal consistency ($\alpha > 0.89$). In this study's sample, internal consistency was calculated using Cronbach's Alpha and found to be excellent ($\alpha=0.91$).

Parental symptoms of depression were measured using the Patient Health Questionnaire (PHQ-8; Kroenke et al., 2009). It is an eight-item self-report scale and has demonstrated good validity in clinical and general population samples ($\alpha = 0.86-0.89$, Kroenke et al., 2001; Kroenke et al., 2009). Scores range from 0-24, with higher scores indicating higher levels of depression and a recognised clinical cut-off of scores ≥ 10 (Kroenke et al., 2009). Internal consistency in this sample was good ($\alpha=0.88$).

Parental well-being was measured using the Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS). The SWEMWBS is a short version of the Warwick-Edinburgh Mental Well-Being Scale, a measure of psychological well-being over the past two weeks (Tennant et al., 2007). Scores are summed to total scores and then converted to metric scores, ranging from 7-35, with higher scores representing higher well-being. The SWEMWBS has been shown to have good internal consistency and reliability ($\alpha = 0.84- 0.86$; Haver et al., 2015). Internal consistency in this sample was adequate ($\alpha=0.86$).

It should be noted that the term “outcome” variable is used throughout this report. This is not intended to imply that causal conclusions can be drawn from the study, only to highlight that anxiety, depression and well-being are the dependent variables in the analysis.

Predictor Variables

Parent perception of uncertainty in the context of having an infant with GORD was measured using the Parent Perception of Uncertainty Scale (PPUS, Mishel, 1983). Responses are summed to calculate a total score ranging from 31-155, with higher scores indicating higher perceived experience of illness uncertainty. The reliability and validity of the PPUS are acceptable ($\alpha > 0.91$, Mishel, 1983)

As the PPUS was designed to measure uncertainty experienced by parents of children who have been hospitalised, the wording of two questions was altered to make to questions more applicable to this study’s population:

- a) “It is vague to me how I will manage the care of my child after he/she leaves hospital” was changed to "It is vague to me how I will manage the care of my child"
- b) “I can depend on the nurses to be there when I need them” was changed to "I can depend on health professionals to be there when I need them"

Following these changes, internal consistency in this sample was tested and found to be excellent ($\alpha = 0.92$).

Parents’ illness perceptions were measured using the Brief Illness Perception Questionnaire (B-IPQ, Broadbent et al., 2006), based on the revised Illness Perception Questionnaire (IPQ-R, Moss-Morris et al., 2002) and assesses five cognitive and emotional representations of illness (e.g. Leventhal et al., 1997). Scores are summed to compute a total score, with higher scores reflecting greater sense of perceived illness threat. The B-IPQ has good concurrent validity, good predictive validity of outcomes over time and sensitivity to

change in illness perceptions over time (Broadbent et al., 2015). Internal consistency in this sample was acceptable ($\alpha=0.80$).

Parent self-compassion was measured using the Self-Compassion Scale (Short Form; SCS-SF; Raes et al., 2011), based upon the Self-Compassion Scale (SCS, Neff, 2003). The mean of the total score is used as the measure of self-compassion, with higher scores indicating higher levels of self-compassion. Using a large sample ($N=415$), Raes et al. (2011) found the SCS-SF to demonstrate good internal consistency ($\alpha \geq 0.86$) and a near-perfect correlation with the long form SCS ($r \geq 0.97$). Internal consistency in this sample was acceptable ($\alpha=0.80$).

Control Variables

All control variables were measured using single item measures. This was to reduce the length of the survey and hence reduce participant burden (Hoepfner et al., 2011). Whilst it is not possible to ascertain internal consistency of single item measures, the measures selected for this survey all had existing data indicating adequate psychometric properties.

Sleep was measured using the Sleep Quality Scale (SQS; Cappelleri et al., 2009), an eleven-point Likert scale. Cappelleri et al. (2009) investigated the psychometric properties of the SQS in two large sample studies ($N=748$ and $N=745$), finding it to have excellent test-retest reliability (0.90-0.91). Scores on the SQS also correlated significantly ($p<0.01$) with the Medical Outcomes Study Sleep Scale, a commonly used and validated measure of sleep (Hays et al., 2005).

Social support was measured using the Brief Measure of Social Support (BMSS; Atroszko et al., 2015), a nine-point Likert scale. The authors found the BMSS to have a satisfactory test-retest reliability coefficient of 0.64 in a large student sample ($N= 1451$). They also noted that the measure related predictably to other valid indicators of well-being.

Support from personal relationships was measured using the Scale of Satisfaction with Personal Relationships (SSPR; Atroszko et al., 2015), a nine-point Likert Scale. Atroszko et al. (2015) found the SSPR to have a good test-retest reliability coefficient (0.80) in the same large student sample (N= 1451). The SSPR also related predictably other commonly used and valid measures.

A single item from the Maternal Breastfeeding Evaluation Scale (MBES), namely overall satisfaction with breastfeeding, was selected for use as a single item measure in this study due to its high correlation with the full scale ($r=0.83$, $p<.001$; Leff et al., 1994). This item was adapted to account for experiences of parents who may not have been breastfeeding their infants and to capture recent experience.

The MBES question: “Overall how satisfied have you been with breastfeeding your baby? 0 (*Very dissatisfied*) – 10 (*very satisfied*)” was changed to “In the last 2 weeks, overall, how satisfied have you been with your babies' feeding? 0 (*Very dissatisfied*) – 10 (*very satisfied*)”.

Qualitative Questions

To address the study’s final aim of exploring parents’ views about the impact of caring for an infant with GORD on their mental health, two open ended questions were asked:

“What (if anything) about caring for an infant with reflux had the biggest impact on your well-being?” and “What do you think could help improve your wellbeing?”.

These questions were designed for this study to elicit information from parents as to what they perceive determines and influences their well-being.

Demographic and illness context questionnaires

Following consultation with the literature, a demographic questionnaire was developed. In addition, participants provided information about their infant’s GORD diagnosis (e.g. “at what age did your infant receive their reflux diagnosis?” and “how well managed is your infant’s reflux at the moment?”).

2.4. Ethical Considerations

Ethical approval for this study was granted by the Salomons Ethics Panel, Canterbury Christ Church University (Appendix G). The information sheet fully informed participants about the study and the potential risks of taking part. Participants received information on where they could seek support if needed both in the information sheet and debrief page. As participants from outside the UK were eligible to participate, individuals were encouraged to seek support from their GP, family doctor or primary care physician if needed. Participants were also signposted to a large infant reflux support organisation for more information on caring for an infant with GORD.

To protect participant anonymity and confidentiality, all data were stored securely on a password-protected computer. Participants were asked to provide an email address if they consented to participate in the follow-up survey and to receive a summary of the results. Once data were matched, email addresses were removed and stored in a separate secure file.

2.5. Data Analysis Plan

The statistical software package, IBM SPSS version 24 was used to analyse the data. Little's (1998) Missing Completely at Random (MCAR) test was run to determine whether data from partially completed questionnaires was missing completely at random or whether missing data were related to other variables in the data set. Assumptions for statistical tests were checked and met for all relevant variables (see results section). Whilst data provided from Likert scales are typically considered to be ordinal in nature, the data met assumptions such that it was reasonable to consider it as approximating interval data (Norman, 2010; Jamieson, 2004). Analyses were run accordingly.

Descriptive statistics and confidence intervals were used for prevalence data. Simple linear regressions were calculated to explore the relationship between all predictor (and control) variables and outcomes at baseline and follow-up. Multiple linear regressions were employed

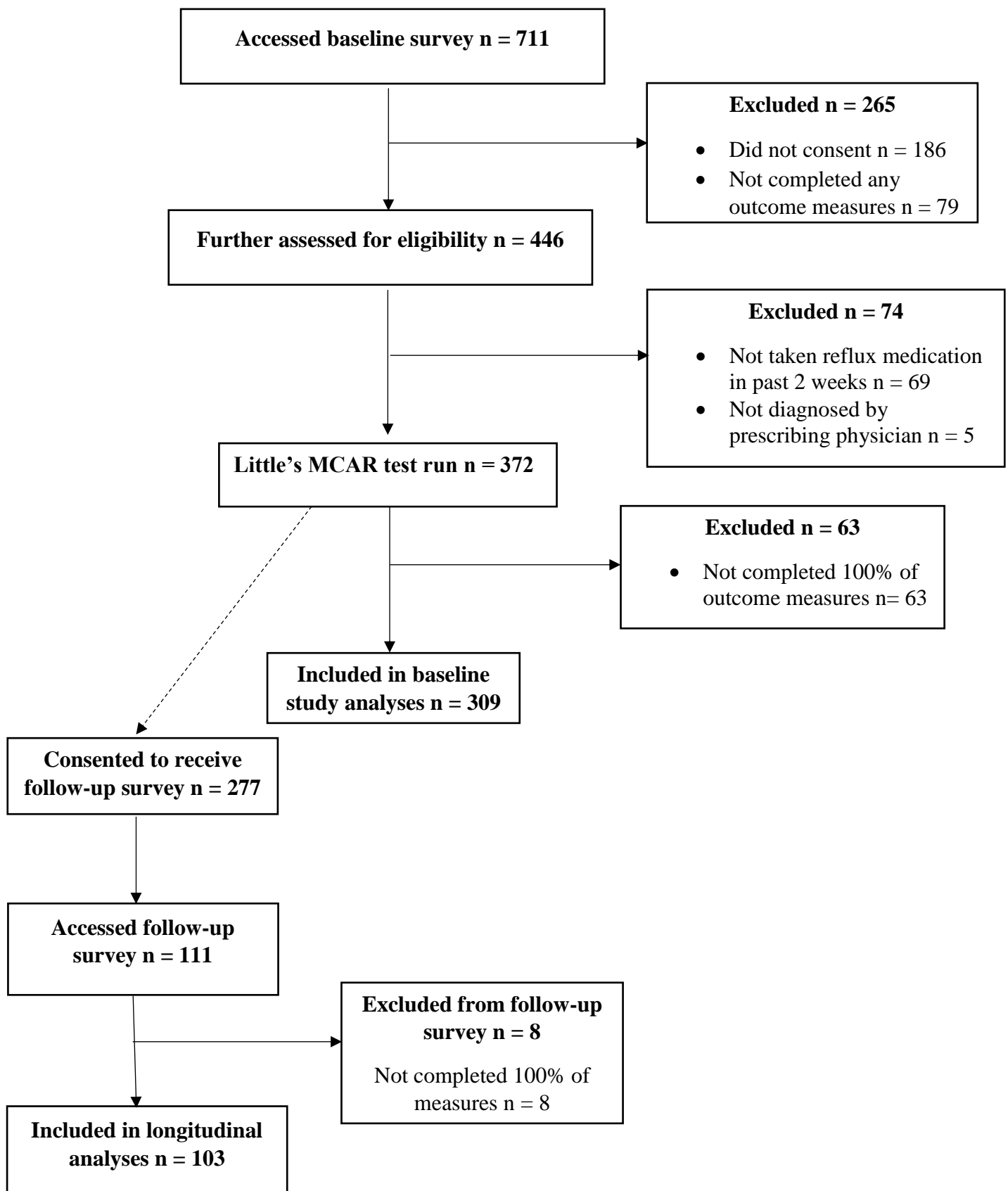
to further explore this relationship and to ascertain the predictive power of the predictor variables beyond controls. Paired sample *t*-tests tested whether there was a difference between GORD and silent-reflux in terms of parent outcomes.

Finally, inductive content analysis was used to identify patterns in the qualitative data (e.g. Erlingsson & Brysiewicz, 2017). Initially a randomly selected sample of 10% of the meaning units was identified for review of categories and sub-categories with a second researcher. Following in depth discussion and refining of the categories and sub-categories, a second sample of another 10% the meaning units was assessed for inter-rater reliability (Landis & Koch, 1977).

3. Results

3.1. Participant Characteristics

As can be seen in Figure 1, 711 participants followed the advertising link to enrol in the study. Of these, 446 were assessed for eligibility and 74 did not meet inclusion criteria, resulting in 372 complete and partial responses for analysis. Schlomer et al. (2010) recommend determining whether there is a pattern to the missing data in partial responses, in order to decide upon how to best handle such data. Little's (1998) MCAR test was not significant ($X^2 = 19.32.801$, $DF=2070$, $p=0.985$). Thusly, there was no evidence from this test that the data departed from being MCAR and so they were treated as such and listwise deletion was chosen as the method to handle missing data. Only cases where 100% of the quantitative portion of the survey had been completed were included in the analyses. Whilst this method resulted in a loss of data, participant numbers were large enough to achieve sufficient power when only including complete datasets.

Figure 1*Flow Diagram of Participants*

3.2. Demographic and Reflux Data

As can be seen in Table 1, the sample was nearly entirely female and had little representation from Black, Asian and Minority Ethnic (BAME) groups. The majority of participants were from the United Kingdom and identified as being white British.

Table 1

Demographic Details of Participants

Baseline survey	
N= 309	
	<u>Mean (SD)</u>
Age (Years)	31.72 (4.75)
Number of children	1.76 (0.85)
	<u>N (%)</u>
Gender	
Female	307 (99.4%)
Country	
United Kingdom	263 (85.1%)
United States & Canada	28 (9.1%)
Other	18 (5.8%)
Ethnicity	
White British	250 (80.9%)
White Other	48 (15.5%)
Mixed	5 (1.6%)
Black or Black British	2 (0.6%)
Other	4 (1.3%)
Employment status	
Full time	136 (44.0%)
Part time	99 (32.0%)
Homemaker	44 (14.2%)
Unemployed/unable to work	14 (4.6%)
Student	8 (2.6%)
Other	8 (2.6%)
Education	
Undergraduate degree	106 (34.3%)
No degree	102 (33.0%)
Postgraduate degree	54 (17.5%)
Professional degree	47 (15.2%)
Marital Status	
Married	195 (63.1%)
Co-habiting	88 (28.5%)
Single	18 (5.8%)
Divorced/Separated	3 (0.9%)
Other	5 (1.6%)

Characteristics of the infant's GORD are outlined in Table 2. The mean age of onset of symptoms was 1.24 months (SD=0.63, range = 1-6 months). The mean age of receiving a diagnosis of GORD was 2.22 months (SD = 1.54, range = 1-12 months). The sample is mixed in terms of the type of GORD (silent or not) and parents' perceptions on how well managed the GORD was and their satisfaction with feeding was varied. Most infants were diagnosed by either a GP, paediatrician, or specialist nurse, however a minority were diagnosed by a non-prescribing physician (health visitor or other). These participants were checked against other inclusion criteria (such as type of medication) to ensure that a prescribing physician was in agreement with the diagnosis. Interestingly, almost 80% of infants had another diagnosis that parents reported was related to the GORD, of these the majority indicated Cow's Milk Protein Allergy (CMPA) either alone or with other allergies.

Table 2

Infant with GORD Characteristics

	Baseline survey N = 309		Follow-up where applicable N= 103	
	<u>Mean (SD)</u>	<u>Range</u>	<u>Mean (SD)</u>	<u>Range</u>
Age of infant with GORD (months)	6.86 (2.90)	3-12	-	-
Age reflux symptoms started (months)	1.24 (0.63)	1-6	-	-
Age of GORD diagnosis (months)	2.22 (1.54)	1-12	-	-
Time to diagnosis (months)	0.98 (1.34)	0-9	-	-
How well GORD is managed (100 = very well; 0 = very poorly)	56.93 (27.23)	0-100	70.73 (23.42)	4-100
Parent satisfaction with infant's feeding (10 = very satisfied; 0= very dissatisfied)	5.53 (2.80)	0-10	6.72 (2.33)	0-10
		<u>N (%)</u>		<u>N (%)</u>
Infant Gender				
Male		169 (54.7%)		54 (52.4%)
Female		140 (45.3%)		49 (47.6%)

Type of GORD		
Reflux with regurgitation	142 (46.0%)	49 (47.6%)
Silent Reflux	147 (47.6%)	50 (48/5%)
Other	20 (6.5%)	4 (3.9%)
Diagnosing professional		
General Practitioner (GP)	157 (50.8%)	48 (46.6%)
Paediatrician	102 (33.0%)	36 (35.0%)
Health Visitor	29 (9.4%)	10 (9.7%)
Specialist Nurse	8 (2.6%)	4 (3.9%)
Other	13 (4.2%)	5 (4.9%)
Any other diagnoses related to GORD		
Yes	246 (79.6%)	84 (81.6%)
No	63 (20.4%)	19 (18/4%)
Any other physical or developmental diagnoses		
No	268 (86.7%)	95 (92.2%)
Yes	41 (13.3%)	8 (7.8%)

3.3. Participant Retention

Of the 309 participants who met eligibility criteria and completed the baseline survey, 103 (33.3%) also completed the follow-up survey. Consistent with the data appearing to be MCAR, there was no evidence of bias introduced by participant attrition at follow-up. There were no significant differences in any baseline questions or measures between participants who only completed the initial survey and those who went on to complete the follow-up (all p -values $> .05$; Appendix H).

3.4. Testing Aims and Hypotheses

3.4.1. *An estimation of prevalence of mental health problems (Aim 1).*

Descriptive statistics were produced for each of the variables at both time points (Table 3). Paired sample t -tests were run to test for differences between scores at baseline and follow up. Anxiety, depression and well-being scores all significantly improved ($p < .001$). Feeding and sleep satisfaction also significantly improved ($p < .05$). Although not included as a control variable, parents' perceptions of how well the symptoms of their infant's GORD was managed was also assessed at both time points, significantly improving at follow-up.

Table 3*Descriptive Statistics and Paired Sample t -Tests*

Measure (Range)	Mean Baseline (SD) N=309	Mean Follow- up (SD) N=103	t -value (df=102)	Mean Difference	Std. Error Mean	95% Confidence Interval of the Difference
GAD-7 (0-21)	12.34 (6.02)	8.17 (5.75)	6.881***	3.505	.509	2.495 - 4.515
SWEMWBS (0-35)	18.79 (3.62)	20.57 (4.29)	-4.217***	-1.693	.402	-2.489 - -.987
PHQ-8 (0-24)	11.84 (6.19)	9.20 (5.66)	4.455***	2.359	.530	3.410 – 4.455
B-IPQ (0-80)	49.33 (11.93)	-	-	-	-	-
PPUS (35-155)	100.36 (18.57)	-	-	-	-	-
SCS-SF (0-5)	2.49 (0.72)	-	-	-	-	-
Sleep (0-10)	6.61 (2.18)	6.10 (2.06)	2.046*	.505	.247	.015 - .994
Social Support (0-10)	5.04 (2.61)	5.25 (2.22)	-1.112	-.243	.218	-.676 - .190
Relationship Support (0-10)	5.90 (2.52)	6.28 (2.42)	-.510	-.107	.209	-.522 - .308
Feeding Satisfaction (0-10)	5.53 (2.80)	6.72 (2.33)	-3.300**	-.816	.247	-1.306 - -.325
Symptom management (0-100)	56.93 (27.23)	70.73 (23.42)	-5.091***	-11.398	2.239	-15.839- 6.957

***p<0.001; **p<0.01; *p<0.05

Spitzer et al. (2006) and Kroenke et al. (2009) propose that a score of ≥ 10 in the GAD-7 and PHQ-8 respectively indicates clinically significant anxiety and depression symptoms.

Table 4 shows the proportion of participants scoring above this clinical cut off at both time points. Visual representation of participants' scores can be seen in Figures 2 and 3.

Table 4

Participants Scoring Above Clinical Cut-Off in Measures of Anxiety and Depression

Measure	Number above clinical cut off (≥ 10) indicating mental health difficulties.			
	Initial Survey Sample (N= 309)	95% Confidence Interval for Proportion Above Cut-Off	Follow-up Sample (N=103)	95% Confidence Interval for Proportion Above Cut-Off
	<u>N (%)</u>		<u>N (%)</u>	
GAD-7 (Anxiety)	204 (66.0%)	60.4-71.3%	41 (39.8%)	30.3-49.9%
PHQ-8 (Depression)	196 (63.4%)	57.8-68.8%	50 (48.5%)	38.6-58.6%

Figure 2

GAD-7 Total Scores at Baseline and Follow-up

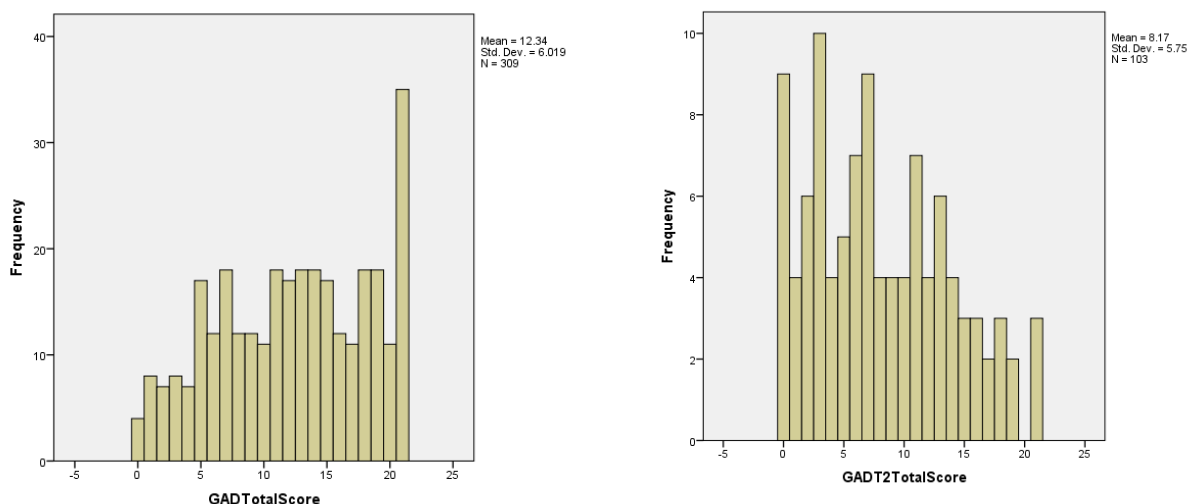
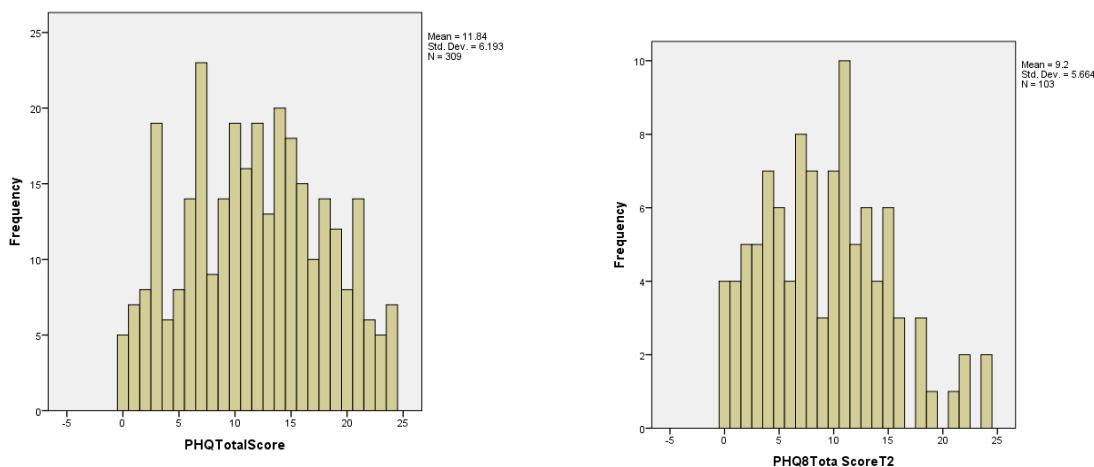


Figure 3

PHQ-8 Total Scores at Baseline and Follow-up.



3.4.2. Predictors of mental health and well-being (Hypotheses 1-3)

Assumptions of a linear regression were tested for all variables. P-P plots and scatterplots were inspected to check for normal distribution of residuals and homoscedasticity (Field, 2013). These were deemed satisfactory for all variables. Correlation coefficients and variance inflation factor (VIF) values were checked, all of which were satisfactory levels to ascertain an absence of multicollinearity in the data.

Simple linear regression analyses were used to test Hypotheses 1, 2 and 3, by separately examining the extent to which baseline illness perceptions, uncertainty and self-compassion predicted anxiety, depression and well-being scores at baseline and follow-up (Table 5). They also examined the extent to which the baseline control variables, considered individually, did the same. Please note that each row in Table 5 represents a separate linear regression.

Table 5*Linear Regression Analyses for Hypotheses 1, 2 & 3 and Control Variables*

Outcome variable	Predictor (at baseline)	R Square	F(df)	Coefficient (Beta)	t-value
Anxiety Baseline	Illness Perceptions	.171	63.220*** (1, 307)	.208	7.951***
	Uncertainty	.179	67.071*** (1, 307)	.137	8.190***
	Self-compassion	.178	66.573*** (1, 307)	-3.510	-8.159***
	Social support	.052	16.889*** (1, 307)	-.527	-4.110***
	Relationship	.120	41.763*** (1, 307)	-.826	-6.462***
	Sleep	.055	17.979*** (1, 307)	.649	4.240***
	Feeding satisfaction	.127	44.478*** (1, 307)	-.764	-6.669***
Anxiety Follow-up	Illness Perceptions	.224	29.206*** (1, 101)	.216	5.404***
	Uncertainty	.173	21.154*** (1, 101)	.124	4.599***
	Self-compassion	.258	35.190*** (1, 101)	-3.950	-5.932***
	Social support	.115	13.140*** (1, 101)	-.827	-3.625***
	Relationship	.074	8.019** (1, 101)	-.661	-2.832**
	Sleep	.019	1.914 (1, 101)	.357	1.383
	Feeding satisfaction	.107	12.097** (1, 101)	-.748	-3.478**
Depression Baseline	Illness Perceptions	.139	49.634*** (1, 307)	.194	7.045***

Outcome variable	Predictor (at baseline)	R Square	F(df)	Coefficient (Beta)	t-value
	Uncertainty	.144	51.491*** (1, 307)	.126	7.176***
	Self-compassion	.229	90.99*** (1, 307)	-4.090	-9.539***
	Social support	.070	23.283*** (1, 307)	-.631	-4.825***
	Relationship	.152	55.085*** (1, 307)	-.958	-7.422***
	Sleep	.102	34.945*** (1, 307)	.908	5.911***
	Feeding satisfaction	.079	26.357*** (1, 307)	-.621	-5.134***
Depression Follow-up	Illness Perceptions	.186	23.107*** (1, 101)	.194	4.807***
	Uncertainty	.149	17.671*** (1, 101)	.113	4.204***
	Self-compassion	.208	26.562*** (1, 101)	-3.493	-5.154***
	Social support	.059	6.305* (1, 101)	-.582	-2.511*
	Relationship	.084	10.318** (1, 101)	-.732	-3.212**
	Sleep	.113	12.902** (1, 101)	.867	3.592**
	Feeding satisfaction	.054	5.777* (1, 101)	-.542	-2.404*
Well-being Baseline	Illness Perceptions	.204	78.886*** (1, 307)	-.137	-8.882***
	Uncertainty	.223	88.104*** (1, 307)	-.092	-9.386***
	Self-compassion	.239	96.48*** (1, 307)	2.446	9.822***

Outcome variable	Predictor (at baseline)	R Square	F(df)	Coefficient (Beta)	t-value
	Social support	.095	32.281*** (1, 307)	.429	5.682***
	Relationship	.206	79.853*** (1, 307)	.653	8.936***
	Sleep	.076	25.135*** (1, 307)	-.457	-5.013***
	Feeding satisfaction	.080	26.521*** (1, 307)	.364	5.150***
Well-being Follow-up	Illness Perceptions	.243	33.809*** (1, 101)	-.170	-5.815***
	Uncertainty	.152	18.116*** (1, 101)	-.087	-4.256***
	Self-compassion	.191	23.778*** (1, 101)	2.531	4.876***
	Social support	.053	5.681* (1, 101)	.420	2.383*
	Relationship	.105	11.797** (1, 101)	.588	3.435**
	Sleep	.035	3.694 (1, 101)	-.367	-1.922
	Feeding satisfaction	.059	6.319* (1, 101)	.414	2.514*

***p<0.001; **p<0.01; *p<0.05

As can be seen from Table 5, the illness perceptions, uncertainty and self-compassion all significantly predicted anxiety, depression and well-being scores both at baseline and follow-up ($p<0.001$), in the expected directions, providing support for hypotheses 1, 2 and 3. All four control variables also significantly predicted anxiety, depression and well-being at baseline ($p<0.001$). At follow-up, baseline sleep did not significantly predict anxiety or well-being.

3.4.3. Predictors of mental health and well-being

The fourth research question aimed to explore whether parent's perceptions of their infant's GORD, experience of uncertainty and self-compassion would predict parental anxiety, depression and well-being above and beyond satisfaction with infant's feeding, sleep, partner relationship and social support (all measured at baseline). Multiple linear regressions were performed to test this and results are shown in Table 6. Control variables were entered into the first block (Model 1) and then each predictor, in turn, was added to this in the second block (Models 2a, 2b and 2c).

Table 6

Multiple Linear Regressions at Baseline.

Outcome Variable	Predictors	Unstandardized B	t-Value (df)	R squared	F (df)	R squared change	F Change (df)
GAD-7 Model 1	Social Support	-.041	-.294 (304)	.223	21.785**** (4, 304)	.223	21.785**** (4, 304)
	Relationship	-.601	-4.062**** (304)				
	Sleep	.368	2.554* (304)				
	Feeding	-.605	-5.386**** (304)				
GAD-7 Model 2a	Social Support	.025	.183 (303)	.260	21.305**** (5, 303)	.037	15.288**** (1, 303)
	Relationship	-.514	-3.513** (303)				
	Sleep	.298	2.096* (303)				
	Feeding	-.404	-3.329** (303)				
	Illness Perceptions	117	3.910** (303)				

Outcome Variable	Predictors	Unstandardized B	t-Value (df)	R squared	F (df)	R squared change	F Change (df)
GAD-7 Model 2b	Social Support	.043	.314 (303)	.288	24.570*** (5, 303)	.066	27.975*** (1, 303)
	Relationship	-.533	-3.743*** (303)				
	Sleep	.318	2.299* (303)				
	Feeding	-.411	-3.611*** (303)				
	Uncertainty	.092	5.289*** (303)				
GAD-7 Model 2c	Social Support	.030	.223 (303)	.316	28.049*** (5, 303)	.094	41.497*** (1, 303)
	Relationship	-.400	-2.807** (303)				
	Sleep	.331	2.441* (303)				
	Feeding	-.578	-5.469*** (303)				
	Self-Compassion	-2.708	-6.422*** (303)				
Well-being Model 1	Social Support	.086	1.044 (304)	.263	28.472*** (4, 304)	.273	28.472** (4, 304)
	Relationship	.503	5.837*** (304)				
	Sleep	-.272	-3.243** (304)				
	Feeding	.226	3.459** (304)				
Well-being Model 2a	Social Support	.036	.455 (303)	.329	29.737*** (5, 303)	.057	25.586*** (1, 303)

Outcome Variable	Predictors	Unstandardized B	t-Value (df)	R squared	F (df)	R squared change	F Change (df)
	Relationship	.438	5.228*** (303)				
	Sleep	-.220	-2.703** (303)				
	Feeding	.077	1.108 (303)				
	Illness Perceptions	-.087	-5.058*** (303)				
Well-being Model 2b	Social Support	.024	.317 (303)	.369	35.395*** (5, 303)	.096	46.166*** (1, 303)
	Relationship	.453	5.616*** (303)				
	Sleep	-.236	-3.006** (303)				
	Feeding	.085	1.315 (303)				
	Uncertainty	-.067	-6.795*** (303)				
Well-being Model 2c	Social Support	.038	.505 (303)	.378	38.503*** (5, 303)	.116	57.474** (1, 303)
	Relationship	.368	4.540*** (303)				
	Sleep	-.247	-3.205** (303)				
	Feeding	.208	3.459** (303)				
	Self-Compassion	1.813	7.581*** (303)				
PHQ-8 Model 1	Social Support	-.121	-.849 (304)	.244	24.580*** (4, 304)	.244	24.580*** (4, 304)
	Relationship	-.681	-4.535*** (304)				

Outcome Variable	Predictors	Unstandardized B	t-Value (df)	R squared	F (df)	R squared change	F Change (df)
	Sleep	.638	4.362*** (304)				
	Feeding	-.400	-3.509** (304)				
PHQ-8 Model 2a	Social Support	-.066	-.464 (303)	.269	22.272*** (5, 303)	.024	10.096** (1, 303)
	Relationship	-.609	-4.065*** (303)				
	Sleep	.579	3.988*** (303)				
	Feeding	-.233	-1.875 (303)				
	Illness Perceptions	.097	3.177** (303)				
PHQ-8 Model 2b	Social Support	-.048	-.344 (303)	.292	24.941*** (5, 303)	.047	20.180*** (1, 303)
	Relationship	-.622	-4.251*** (303)				
	Sleep	.594	4.182*** (303)				
	Feeding	-.231	-1.974* (303)				
	Uncertainty	.080	4.492*** (303)				
PHQ-8 Model 2c	Social Support	-.038	-.289 (303)	.366	35.023** (5, 303)	.122	58.273*** (1, 303)
	Relationship	-.445	-3.151** (303)				
	Sleep	.594	4.425*** (303)				
	Feeding	-.368	-3.516** (303)				

Outcome Variable	Predictors	Unstandardized B	t-Value (df)	R squared	F (df)	R squared change	F Change (df)
	Self-Compassion	-3.179	-7.634*** (303)				

***p<0.001; **p<0.01; *p<0.05

As can be seen in Table 6, illness perceptions, experience of uncertainty and self-compassion all significantly predicted anxiety, depression and well-being, above and beyond the control variables. This is indicated by significant 'F change' values when each predictor was added to a model containing the control variables.

Although social support was a significant predictor of outcomes on its own, when in the regression model with the other control variables it was no longer a significant predictor of any of the outcome variables.

In additional analyses where all predictors were added to the second block of the model all together, self-compassion and uncertainty were significant predictors of baseline anxiety, depression and well-being scores. Illness perceptions was no longer a significant predictor of anxiety, depression or well-being (Table 7).

Table 7

Additional Baseline Multiple Linear Regressions.

Outcome Variable (baseline)	Predictors (baseline)	Unstandardized B	t-Value (df = 301)	R squared	F (df)	R squared change	F Change (df)
GAD -7 Model 2	Social Support	.088	.673	.355	23.624*** (7,301)	.132	20.489*** (3, 301)
	Relationship	-.370	-2.642**				
	Sleep	.292	2.193*				
	Feeding	-.418	-3.671***				
	Illness Perceptions	.014	.374				
	Uncertainty	.066	2.952**				

Outcome Variable (baseline)	Predictors (baseline)	Unstandardized B	t-Value (df = 301)	R squared	F (df)	R squared change	F Change (df)
	Self-Compassion	-2.317	-5.512***				
Well-being Model 2	Social Support	-.006	-.084	.448	34.887*** (7, 301)	.175	31.875*** (3, 301)
	Relationship	.344	4.420***				
	Sleep	-.217	-2.927**				
	Feeding	.085	1.348				
	Illness Perceptions	-.014	-.659				
	Uncertainty	-.048	-3.869***				
	Self-Compassion	1.519	6.494***				
PHQ-8 Model 2	Social Support	.004	.033	.387	27.180*** (7, 301)	.143	23.401*** (3, 301)
	Relationship	-.426	-3.038**				
	Sleep	.568	4.260***				
	Feeding	-.255	-2.238*				
	Illness Perceptions	.000	-.011				
	Uncertainty	.055	2.450*				
	Self-Compassion	-2.886	-6.848***				

***p<0.001; **p<0.01; *p<0.05

3.4.4. Predictors of mental health and well-being

The fifth research question explored whether parent's perceptions of their infant's GORD, experience of uncertainty and self-compassion at baseline would predict parental anxiety, depression and well-being at follow-up above and beyond satisfaction with infant's feeding, sleep, partner relationship and social support (at baseline). Multiple linear regressions were

performed to test this and results are shown in Table 8. As above, control variables were entered into the first block (Model 1) and then each predictor, in turn, was added to this in the second block (Models 2a, 2b and 2c).

Table 8

Multiple Linear Regressions at Follow-up.

Outcome Variable Model (follow-up)	Predictors (baseline)	Unstandardized B	t-Value (df)	R squared	F (df)	R squared change	F Change (df)
GAD-7 Model 1	Social Support	-.659	-2.720** (98)	.215	6.711** (4, 98)	.215	6.711*** (4, 98)
	Relationship	-.223	-.854 (98)				
	Sleep	.147	.579 (98)				
	Feeding	-.635	-3.052** (98)				
GAD-7 Model 2a	Social Support	-.526	-2.218* (97)	.282	7.629*** (5, 97)	.067	9.089** (1, 97)
	Relationship	-.096	-.376 (97)				
	Sleep	.010	.039 (97)				
	Feeding	-.286	-1.239 (97)				
	Illness Perceptions	.151	3.015** (97)				
GAD-7 Model 2b	Social Support	-.549	-2.305* (97)	.270	7.191*** (5, 97)	.055	7.370** (1, 97)
	Relationship	-.195	-.771 (97)				
	Sleep	.122	.493 (97)				
	Feeding	-.374	-1.676 (97)				
	Uncertainty	.081	2.715** (97)				
GAD-7 Model 2c	Social Support	-.518	-2.360* (97)	.373	11.549*** (5, 97)	.158	24.475*** (1, 97)

Outcome Variable Model (follow-up)	Predictors (baseline)	Unstandardized B	t-Value (df)	R squared	F (df)	R squared change	F Change (df)
	Relationship	-.095	-.404 (97)				
	Sleep	-.022	-.097 (97)				
	Feeding	-.543	-2.890* (97)				
	Self-Compassion	-3.272	-4.947*** (97)				
Well-being Model 1	Social Support	.217	1.156 (98)	.157	4.550** (4, 98)	.157	4.550** (4, 98)
	Relationship	.387	1.917 (98)				
	Sleep	-.160	-.812 (98)				
	Feeding	.316	1.966 (98)				
Well-being Model 2a	Social Support	.084	.472 (97)	.276	7.042*** (5, 97)	.120	16.017*** (1, 97)
	Relationship	.261	1.366 (97)				
	Sleep	-.023	-.123 (97)				
	Feeding	-.031	-.177 (97)				
	Illness Perceptions	-.150	-4.002*** (97)				
Well-being Model 2b	Social Support	.125	.684 (97)	.226	5.649***	.069	8.626** (1, 97)
	Relationship	.364	1.870 (97)				
	Sleep	-.138	-.730 (97)				
	Feeding	.099	.579 (97)				
	Uncertainty	-.067	-2.937** (97)				
Well-being Model 2c	Social Support	.129	.728 (97)	.266	7.033*** (5, 97)	.109	14.463*** (1, 97)
	Relationship	.308	1.617 (97)				

Outcome Variable Model (follow-up)	Predictors (baseline)	Unstandardized B	t-Value (df)	R squared	F (df)	R squared change	F Change (df)
	Sleep	-.054	-.292 (97)				
	Feeding	.259	1.708 (97)				
	Self-Compassion	2.030	3.803*** (97)				
PHQ-8 Model 1	Social Support	-.401	-1.665 (98)	.202	6.219*** (4, 98)	.202	6.219*** (4, 98)
	Relationship	-.261	-1.006 (98)				
	Sleep	.692	2.743** (98)				
	Feeding	-.373	-1.806 (98)				
PHQ-8 Model 2a	Social Support	-.282	-1.187 (97)	.257	6.722*** (5, 97)	.055	7.166** (1, 97)
	Relationship	-.148	-.579 (97)				
	Sleep	.570	2.289* (97)				
	Feeding	-.063	-.271 (97)				
	Illness Perceptions	.135	2.677** (97)				
PHQ-8 Model 2b	Social Support	-.283	-1.205 (97)	.268	7.086*** (5, 97)	.065	8.619** (1, 97)
	Relationship	-.232	-.926 (97)				
	Sleep	.665	2.734** (97)				
	Feeding	-.095	-.430 (97)				
	Uncertainty	.086	2.936** (97)				
PHQ-8 Model 2c	Social Support	-.285	-1.259 (97)	.311	8.753*** (5, 97)	.108	15.268*** (1, 97)

Outcome Variable Model (follow-up)	Predictors (baseline)	Unstandardized B	t-Value (df)	R squared	F (df)	R squared change	F Change (df)
	Relationship	-.157	-.644 (97)				
	Sleep	.554	2.324* (97)				
	Feeding	-.298	-1.536 (97)				
	Self-Compassion	-2.669	-3.907*** (97)				

***p<0.001; **p<0.01; *p<0.05

As demonstrated in Table 8, illness perceptions, experience of uncertainty and self-compassion all significantly predicted all follow-up outcome variables, above and beyond the control variables, as indicated by significant 'F change' values when each predictor was added to a model just containing the control variables.

As with question 4, additional analyses were run in which all predictors were added to the second block of the model together. Self-compassion was the only predictor variable that remained a significant predictor of anxiety and depression scores. Illness perceptions and self-compassion were significant predictors of well-being. Illness uncertainty was no longer a significant predictor of any of the follow-up outcomes. (Table 9).

Table 9*Additional Multiple Linear Regressions at Follow-up.*

Outcome Variable (follow-up)	Predictors (baseline)	Unstandardized B	t-Value (df = 95)	R squared	F (df)	R squared change	F Change (df)
GAD -7 Follow-up Model 2	Social Support	-.430	-1.965	.408	9.357*** (7, 95)	.193	10.330*** (3, 95)
	Relationship	-.041	-.175				
	Sleep	-.076	-.328				
	Feeding	-.293	-1.373				
	Illness Perceptions	.068	1.084				
	Uncertainty	.032	.881				
Well-being Follow-up Model 2	Social Support	.033	.192	.344	7.124*** (7, 95)	.188	9.059*** (3, 95)
	Relationship	.226	1.223				
	Sleep	.030	.164				
	Feeding	-.023	-.136				
	Illness Perceptions	-.112	-2.277*				
	Uncertainty	-.011	-.383				
PHQ-8 Follow-up Model 2	Social Support	-.195	-.866	.352	7.384*** (7, 95)	.150	7.331*** (3, 95)
	Relationship	-.123	-.506				
	Sleep	.523	2.199*				
	Feeding	-.050	-.228				
	Illness Perceptions	.035	.538				

Outcome Variable (follow-up)	Predictors (baseline)	Unstandardized B	t-Value (df = 95)	R squared	F (df)	R squared change	F Change (df)
	Uncertainty	.055	1.468				
	Self-Compassion	-2.319	-3.371**				

***p<0.001; **p<0.01; *p<0.05

3.4.5. Differences between GORD and silent-reflux (Hypothesis 6).

The final hypothesis was that parents whose infants have silent reflux would have higher anxiety and depression and lower wellbeing scores compared with those whose infants have GORD that is not silent and that this relationship would be statistically mediated by illness uncertainty. Independent samples *t*-Tests were run to test this hypothesis. Levene's tests were all insignificant and so equal variance was assumed. Results are shown in Table 10.

Table 10

t-Tests Between Reflux and Silent Reflux Groups

Measure	t-value	df	Significance (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference
GAD-7	.646	287	.519	.454	.702	-.929-1.837
Warwick	-.696	287	.487	-.269	.387	-1.031-.492
PHQ-8	2.270	287	.024*	1.614	.710	.215-3.01

***p<0.001; **p<0.01; *p<0.05

T-tests show that there are no significant differences between parents of infants with GORD and those with silent reflux in measures of anxiety or well-being. A significant difference between the GORD and silent reflux groups was found in the PHQ-8, however when Bonferroni's correction was applied, this was no longer significant, suggesting no robust differences. As the hypothesised relationship was not found, the follow-up mediation analysis was not run. Additional exploratory *t*-tests were run to explore this finding further.

No significant differences were found between GORD and silent reflux groups in any of the variables tested (Table 11).

Table 11

Additional t-Tests Between GORD and Silent Reflux Groups

Measure	t-value	df	Significance (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference
Feeding Satisfaction	-.663	287	.508	-.220	.332	-.873-.433
Sleep	-.262	287	.794	-.068	.260	-.580-.444
Social Support	.185	287	.853	.056	.304	-.542-.645
Relationship Support	-.459	287	.647	-.136	.296	-.718-.447
Time taken from symptoms to diagnosis	-.513	287	.608	-.083	.162	-.402-.236
Management of symptoms	1.002	287	.317	3.240	3.234	-3.124-9.605

***p<0.001; **p<0.01; *p<0.05

3.4.6. Content Analysis (Aim 2).

Recall that participants were asked two open ended questions:

- What (if anything) about caring for an infant with reflux has the biggest impact on your well-being?
- What do you think could help improve your well-being?

Data from each question were analysed independently using content analysis (Appendices I & J). Following discussion and revision of categories and sub-categories with a second researcher, inter-rater reliability was calculated for both questions using a sample of 10% of the meaning units and achieved a substantial kappa statistic ($\kappa = 0.84-0.88$; Landis & Koch, 1977).

A summary of categories and sub-categories generated from participant responses is presented in Table 12. Strong emotive language was used in participants' responses and examples of quotes from each sub-category are also presented in Table 12.

In response to the first question participants frequently commented on the degree of impact their infant's GORD had on their overall mental health and well-being (n=119). This included comments about the perceived impact of GORD on their ability to sleep, general mental health and feelings of guilt that participants experienced. Participants also went on to talk about specific factors that they perceived impacted on their well-being. Themes derived from participant comments are captured by an additional eight categories. These were further broken down into sub-categories to offer greater depth of understanding as to issues participants reported.

The largest category was "relentlessness of caring for child with GORD" (n=124), which comprised of four subcategories: "baby crying/screaming/ infant not able to settle", "frequent/constant sickness", practical demands and impact on daily life e.g. washing, cleaning & reflux related tasks" and "unable to relax or rest/ no respite or "me time"". Another prominent category was being "unable to help child's pain" (n=110). Participants frequently referred to the impact of seeing their child in pain, feeling helpless to make it better and feeling like a failure for not being able to comfort their child.

In terms of what participants thought might help improve their mental health, six overarching categories emerged from the data. These were broken down into sub-categories to reflect and describe the data. The largest category was "feeling supported – other", (n=110). This comprised of comments reflecting that better support from family, partner, friends and generally (not specified) as well as support groups for parents of infants with GORD would help to improve participants' well-being. The second largest category was "support from medical professionals" (n=102). This consisted of comments about wanting to have better and more timely access to medical help for their infant, not feeling dismissed or invalidated and being taken seriously, and feeling generally better supported or listened to by health professionals.

Table 12*Summary of Content Analysis*

Question	Responses (N)	Meaning units (N)	Category (n=total frequency)	Sub-category	Frequency of sub-category (n)	Example comment(s)			
What (if anything) about caring for an infant with GORD had the biggest impact on your well-being?	279	552	Unable to help child's pain (110)	Seeing child in pain	35	“Watching the most important piece of your life in agony is the most horrific thing”			
				Feeling helpless	56	“Being unable to soothe them in any way. It’s physically painful.”			
				Feeling like a failure/ not able to comfort child	19	“Feeling like a failed mother who can’t provide the basics for her baby. Food, sleep and love.”			
			Relentlessness of caring for child with GORD (124)				Baby crying/screaming/ infant not able to settle	56	“You think it’ll never end. You watch your baby scream in pure agony for hours and hours and hours and hours”
							Frequent/constant sickness	10	“It is frustrating to feed them to lose it then scream for more to have the whole routine happen again and again”
							Practical demands and impact on daily life e.g. washing, cleaning & reflux related tasks	22	“Constant stripping and washing of bedsheets during the night. Constant washing from having to change baby and me”
							Unable to relax or rest/ no respite or "me time"	36	“Never stopping to think about myself or taking full care of myself”

Question	Responses (N)	Meaning units (N)	Category (n=total frequency)	Sub-category	Frequency of sub-category (n)	Example comment(s)
				Impact on bonding/relationship with infant	10	“Being stolen of having a normal baby, i lost the most precious months of his life to reflux”
			Impact on relationships (30)	Impact on relationships with other children	13	“When my baby was untreated and undiagnosed I was very emotional, felt guilty spending so much time with the baby and not my little boy. I was very emotional about the imbalance in my care towards both children. I was conscious about my eldest feeling left out and that his mummy was not available for him.”
				Impact on partner/friendship relationships	7	“Things are strained between myself and my partner because if the lack of sleep and the crippling physical and mental exhaustion.”
				Not feeling supported (41)	Health professionals not listening/ being judgemental	25
				Family/friends not understanding/ being judgemental	8	“The fact that the spectrum of reflux and how it affects a person varies so much and because of that people (non medical) think there is nothing wrong with my child e.g. they had a child with reflux but theirs was just a ‘happy spitter’ so they think thats what I’m dealing with but we actually have severe gord, feed refusal and failure to thrive”
				Not understood listened/supported to (not otherwise specified)	8	“People not understanding why I am so worried about her and being made to feel like

Question	Responses (N)	Meaning units (N)	Category (n=total frequency)	Sub-category	Frequency of sub-category (n)	Example comment(s)
						I'm over reacting or making things up about her medical care."
			Withdrawal from going out and feeling alone (41)	Isolation/ loneliness	15	"How lonely I have become."
				Practical difficulties going out due to sickness/crying	9	"Having it place restrictions on what activities we do, as it is sometimes impossible to take enough outfits/ bibs etc to make sure baby can stay dry & clean"
				Anxiety about others seeing infant screaming / not eating/ vomiting e.g. in public	17	"Embarrassment out in public when people stare if my baby projectile vomits - then having to get us both changed into new clothes Sometimes it's easier not to go out during a bad spell"
			Unpredictability and uncertainty with GORD (47)	Unpredictability of GORD symptoms	23	"The unpredictability of the illness, one day it can seem well controlled, others it flares up out of nowhere."
				Uncertainty about GORD/ future/ course of illness/ treatment	19	"Not knowing what was wrong with him in the early days (2-4 weeks)"
				Issues with medication	5	"Incorrect prescription of ranitidine (was not given adequate dosage and had to go back to GP armed with bnf)"

Question	Responses (N)	Meaning units (N)	Category (n=total frequency)	Sub-category	Frequency of sub-category (n)	Example comment(s)
			Feared consequences of GORD (27)	Impact on child's health e.g. growth and development	12	“Worrying that he isn’t eating enough to gain weight/thrive”
				Fear of baby choking/dying	15	“The fear the choking will never stop and she might die. As a result having to watch her 24hours a day.”
			Overall Mental Health and Wellbeing (119)	Impact on parent's sleep	71	“Not being able to sleep. She wakes up very often at night, I breastfeed then hold her upright for 20 minutes. She wakes an hour or so later. So I'm getting approx 0.5-1.5 hours sleep at a time then minimum 30 minutes awake time. Exhausted.”
				Impact on general mental health/ wellbeing (including worry not specified)	40	“It’s emotionally and physically draining”
				Feelings of guilt	8	“I feel a slight guilt because I have to give him this milk”
			Other (13)	Difficulties/dissatisfaction/anxiety with feeding	13	“I hate not feeding my child successfully”
What do you think could help improve your wellbeing?	279	437	Support from medical professionals (102)	Better and more timely access to appropriate medical help (including diagnosis and treatment)	23	“I think faster appointment times and quicker treatments or effective treatments first time instead of going through the structure of weak medications that didn’t work but having to give them a 6 week trial with no results or help from them. This caused a huge impact on my emotional well-being.”

Question	Responses (N)	Meaning units (N)	Category (n=total frequency)	Sub-category	Frequency of sub-category (n)	Example comment(s)
				Not feeling dismissed/invalidated and being taken seriously by professionals	28	“For weeks we just heard "it's colic". Nothing would have been done if I didn't fight for it.”
				Feeling generally better supported/listened to by professionals	51	“Health care providers who are more helpful.”
			Feeling supported - other (110)	Feeling supported/helped/understood by family & partner (including asking for/accepting help)	34	“A partner than actually helped once in a while rather than leaving it all to me because he doesn't know how to cope with a baby with severe reflux.”
				Feeling supported/helped/understood by friends (including asking for/accepting help)	19	“Friends being more compassionate, sympathetic and standing by my side”
				Support groups for parents of infants with GORD	13	“Having access to a group of mothers who are all experiencing the same issues. It's embarrassing attending baby groups when you're the only one with a little one that's constantly vomiting.”
				More support/ help/ understanding from others (not otherwise specified)	44	“More support from outside sources. I can't put baby down so it's very intense.”

Question	Responses (N)	Meaning units (N)	Category (n=total frequency)	Sub-category	Frequency of sub-category (n)	Example comment(s)
			GORD symptom reduction (76)	Cure/gone	18	“A child with no allergies or reflux”
				Medication/ treatment that works	15	“Once medicated the change was immediate and unbelievable - I had a happy relaxed baby within 48 hours”
				GORD managed better/ symptom reduction/ happier baby	43	“I think my wellbeing will be improved once my son is fully settled, I cant see anything else improving it.”
			Greater knowledge about GORD (51)	Having a definitive diagnosis/ treatment plan	16	“A definite diagnosis of what he is allergic to and consistent advice about feeding”
				Self & Medical professionals being more informed/ having more knowledge about GORD	35	“If I could understand what is happening with my child if she is in pain or if she is just grumpy if she is teething or reflux if she is reacting to a food or just fussy. Answers would help improve EVERYTHING.”
			Overall Mental Health & Wellbeing (90)	Being able to have a break/ some "me time"	24	“Having some time out to recharge”
				Putting focus on own physical/mental health	22	“Try to remember that I am important and deserve time as well”
				Having better sleep	44	“Sleep!”
			Other (8)	Don't know	8	“I genuinely have no idea.”

4. Discussion

4.1. Prevalence of Mental Health Difficulties

Results highlighted that participants in this study experienced significantly elevated rates of anxiety and depression than would be expected in either the general population (Lowe et al., 2008; Kroenke et al., 2009) or in an overall perinatal sample (Heron et al., 2004).

Consistent with this, the powerful quotes in the content analysis offered qualitative support for the impact of infant GORD on parental mental health.

“No time, to think, to rest. Baby's constant screaming has made me question everything and feel deep guilt for doing so. It's blown my marriage apart neither of us can relax or rest. Family not understanding what it's like and the constant torture of seeing your baby in so much pain. Feeling like a failure. The negative impact on my mental health has been huge”.

This suggests that infant GORD is a risk factor for poorer mental health and is consistent with a wealth of child illness literature that demonstrates that carers of children with a chronic illness experience significantly higher stress levels and poorer well-being than caregivers of healthy children (Cousino & Hazen, 2013).

This finding was true at baseline and follow-up, although there was a significant improvement in anxiety and depression scores between the two time-points. Perceived symptom management also significantly improved between time-points. This is in line with current guidelines stating that symptoms usually become less severe over time (NICE, 2015). An interpretation of this is that parental mental health may be tied to one's experience of their infant's symptoms, consistent with the hypothesis that infant GORD is a risk factor for poorer parental mental health. This is further supported by the content analysis where parents' descriptions of the relentlessness of caring for an infant with GORD was a strong theme that emerged from the data. Additionally, the higher prevalence of mental health difficulties in

this population may not be surprising when considering the role of sleep. A large theme in the content analysis was the perceived impact of GORD on parental sleep. This is in line with the current literature on parent sleep in child illness (Meltzer & Moore, 2008) highlighting the prevalence of sleep disturbance in this population and the relationship between sleep and mental health. Whilst sleep in this study significantly improved at follow-up, caution should be taken in interpreting this as a clinically meaningful change as the overall change in sleep score was minimal between time points. It is possible that the significant difference found in sleep may be a result of a large sample size producing a Type I error.

4.2. Predictors of Parent Mental Health

Illness perceptions, uncertainty and self-compassion all independently predicted depression, anxiety and well-being scores at baseline and at follow-up, including when the control variables were added, offering support for Hypotheses 1-3 and insight into Research Questions 4 and 5. Interestingly when all predictor variables were added to the regression model together, illness perceptions did not remain a significant predictor of any of the outcomes at baseline. Only self-compassion remained a significant predictor of anxiety and depression at follow-up.

The endurance of self-compassion as a significant predictor is in line with previous research that consistently links a person's ability to be self-compassionate in the face of difficulties with better psychological health (Neff et al., 2007; Neff, 2003). Terry and Leary (2010) outline links between self-compassion and a range of adaptive coping strategies, suggesting that those with higher levels of self-compassion are likely to be less impacted by illness. In line with this, one theory as to why self-compassion, may have remained a significant predictor beyond illness perceptions (baseline and follow-up) and uncertainty (follow-up) is that self-compassion may moderate the relationship between illness appraisals and stress (e.g. Gillanders et al., 2015). Although it cannot be concluded from this study that

low self-compassion leads directly to poorer mental health, considering these findings alongside the current literature it is certainly plausible that self-compassion could impact on parental mental health in the context of infant GORD. Self-compassion has not received much attention in the childhood illness literature to date and future research would benefit from exploring this further.

Illness uncertainty was also a significant predictor of outcomes at baseline, but not follow-up, when added into the model with all predictor variables. Looking to the literature, Kerr and Haas (2014) note how transitions are often a period where illness uncertainty is heightened. It is plausible that this may be exaggerated in this population due to parents experiencing not only the transition to living with their infant's GORD, but also, for many, the transition into parenthood. Additionally, parents may experience difficulties accessing appropriate support due to not having a clear diagnosis (Yanes et al., 2016). This experience of uncertainty and lack of support is confirmed in this sample through participants' responses to the open-ended questions:

“For weeks we just heard "it's colic"; and “If I could understand what is happening with my child if she is in pain or if she is just grumpy if she is teething or reflux if she is reacting to a food or just fussy. Answers would help improve EVERYTHING”.

There is little current longitudinal research on paediatric illness uncertainty (Szulczewski et al., 2017), however a few studies do demonstrate that psychological interventions can effectively modify uncertainty suggesting that it is not a static concept (e.g. Mullins et al., 2012). Additionally, some studies in adult illness populations show that appraisals of illness uncertainty become more positive over time (Wright et al., 2009). Considering that reflux symptoms appear to improve over time (NICE, 2015), it is possible that perceptions of uncertainty reduced between the two time points. This may offer a tentative explanation as to why uncertainty measured at baseline no longer predicts outcomes at follow-up. It may be

beneficial for future research to measure uncertainty at multiple time-points to ascertain the extent to which it changes over time or alongside the illness or symptomology.

4.3. Differences in Silent Reflux

Contrary to anecdotal reports, the hypothesis that parents whose infants had silent reflux would have higher anxiety and depression and lower well-being scores was not supported. Additional analyses were run to explore this finding and revealed no significant differences between groups on any of the variables. Anecdotally, parents whose infants have silent reflux experience greater uncertainty due to symptoms being “less obvious”, making it more difficult to identify the cause of their distress and making diagnosis more difficult (Blanch & RISA, 2010). However, this observation was not upheld in this study and there were no significant differences between groups in terms of time taken to diagnosis (of GORD or silent reflux). Furthermore, in the content analysis parents of infants with silent reflux and GORD both described experiencing uncertainty:

“Very much a guessing game and trial and error. This week saw doctor who simply said come back in 6 months!!!” -GORD parent.

“Not knowing what was wrong with him in the early days (2-4 weeks), seeing him in pain, the crying! Being a first-time mum, this was hard to deal with”. -Silent reflux parent.

This may in part explain the insignificant differences in uncertainty scores and subsequently in measures of anxiety, depression and well-being. This is the first known study to explore differences in parental experience between these two groups and further research should test the replicability of these findings.

4.4. Limitations

The largely correlational nature of the results means that caution should be taken in drawing any causal conclusions as to relationships between variables. However, the longitudinal component strengthened the study’s ability to establish risk factors for future

mental health difficulties in this population. This study's large baseline sample size was a strength. However, due to high levels of participant attrition, the sample size for the longitudinal element was smaller than was hoped for and it would be beneficial to ascertain whether the findings replicate in a larger sample. Nevertheless, the sample did appear to be large enough to detect significant effects in the regression analyses.

This study's sample comprised primarily of UK-based Caucasian women (mothers) who were well-educated and either married or co-habiting. The study does not adequately address the impact of GORD on fathers' mental health, nor on racial differences that may exist in this population, limiting the generalisability of the findings. Future research should seek to explore the experience of such underrepresented groups. Additionally, using social media to recruit participants may increase the risk of sampling bias, further limiting the generalisability of findings (Ruths & Pfeffer, 2014). It is possible that posting the survey in support groups for parents of infants with reflux, would have attracted participants who were struggling more. It may be beneficial for future research to recruit through more diverse channels to capture a wider range of participants. Given the lack of literature focusing on parental mental health when an infant has GORD, it was not possible to accurately determine how representative this sample was in this regard. However, the findings of this study align with the findings from the RISA (2017) survey which demonstrated elevated rates of mental health difficulties in this population. In terms of GORD characteristics, this study's sample appears to be reasonably comparative to others (e.g. NHS, 2019a; Dahlen et al., 2018).

Although choice of predictor and control variables was based on existing literature and their links to symptoms of infant GORD, there are likely to be a large range of potential confounding variables that may have influenced results. Whilst all predictor variables significantly predicted outcomes, it should be noted that there was still a large amount of variance unaccounted for.

4.5. Clinical Implications

The large baseline response rate, high proportion of participants scoring clinically on measures of anxiety and depression, and the emerged categories from the content analysis all indicate that this is a population in which there is a high demand for better support to be put in place for parents.

Whilst the findings suggest that parent mental health improves over time, as do symptoms of GORD, this study offers support for the need for psychological interventions to support parents during this period. The finding that parent self-compassion was a predictor of mental health and well-being at both baseline and follow-up could be used to design such interventions. A recent meta-analysis (Kirby et al., 2017) has highlighted the effectiveness of interventions to improve self-compassion, making this a promising avenue to pursue clinically. Considering the role of illness uncertainty, health professionals could also benefit from additional training to support parents by providing more appropriate advice, information and support early on with the aim of preventing or reducing uncertainty and distress. Looking more broadly at clinical intervention literature, cognitive behavioural models of generalised anxiety highlight the contributing role of intolerance of uncertainty in maintaining distress (e.g. Dugas et al., 1998). Given that some level of uncertainty is inherent and likely unavoidable in this population, psychological interventions to increase tolerance of uncertainty in the context of infant GORD may be beneficial in reducing distress.

Sharing these findings could alert health professionals to this “at risk” group of parents. It is important that health professionals have an awareness of parents’ experiences (as identified in the content analysis) of not feeling listened to in the context of also experiencing the unrelenting symptoms of their infants’ GORD and feelings of helplessness. This understanding could inform training for health professionals.

4.6. Research Implications

This study offers the first empirical test of factors associated with parental well-being in the context of caring for an infant with GORD. Whilst all variables significantly predicted outcomes, there was still a large amount of variance that was not accounted for. The content analysis, whilst exploratory, could offer a direction for future research to explore predictive power of concepts identified through participants comments such as feeling listened to or supported by health professionals.

A key theme arising in the content analysis was participants' desire for greater support. Further research could utilise this study's findings of significant predictors of well-being to design and evaluate interventions for this population. Future research could also explore participants' experiences of accessing support and components of acceptable support in this context.

Future research would benefit from accessing a more diverse sample (e.g. more representation from ethnic minority groups and from fathers) and employing a comparison group (e.g. of parents of similarly aged healthy infants accessing online support forums). Without such a comparison group, it could be argued that factors other than the infant's GORD may have impacted on parents' mental health (e.g. accessing support group online).

Finally, it would be interesting to test for stability of predictor variables over time to ascertain for example whether illness uncertainty changes alongside infant GORD symptoms as well as stability of variables in response to intervention.

5. Conclusion

Participants in this study reported significantly higher rates of anxiety and depression than would be expected in a perinatal or general population sample. This was in line with the RISA (2017) study which also found elevated rates of mental health difficulties in this population. To the author's knowledge, this was the first study to explore predictors of

parental mental health in the context of infant GORD. Overall results provided support for the predictive power of self-compassion, illness perceptions and illness uncertainty, above and beyond parent satisfaction with sleep, social and relationship support and infant feeding. Interestingly and contrary to the hypothesis, no relationship was found between GORD type and experience of uncertainty. This study provides evidence that this is a population in which there is a need for research with the aim of better supporting parents. Future research and interventions should address ways to better support parents of infants with GORD in the context of uncertainty around the diagnosis and the distressing nature of symptoms.

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Major Research Project (MRP) Section C: Appendices

Appendix A

Quality Appraisal using the Mixed Methods Appraisal Tool (MMAT)

Study Design	MMAT Quality Appraisal Criteria
Screening questions for all studies	S1. Are there clear research questions? S2. Do the collected data allow to address the research questions?
1. Qualitative Studies	1.1. Is the qualitative approach appropriate to answer the research question? 1.2. Are the qualitative data collection methods adequate to address the research question? 1.3. Are the findings adequately derived from the data? 1.4. Is the interpretation of results sufficiently substantiated by data? 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
2. Quantitative Randomised Control Trials. (E.g. A clinical study in which individual participants are allocated to intervention or control groups by randomization).	2.1. Is randomization appropriately performed? 2.2. Are the groups comparable at baseline? 2.3. Are there complete outcome data? 2.4. Are outcome assessors blinded to the intervention provided? 2.5. Did the participants adhere to the assigned intervention?
3. Quantitative Non-randomised. (E.g. an intervention or studying other exposures that do not use randomization to allocate units to comparison groups (Higgins and Green, 2008).	3.1. Are the participants representative of the target population? 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? 3.3. Are there complete outcome data? 3.4. Are the confounders accounted for in the design and analysis? 3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
4. Quantitative Descriptive. Common designs include the following: single-group studies, Incidence or prevalence study without comparison group, survey designs, case series and case report (CASP, 2018).	4.1. Is the sampling strategy relevant to address the research question? 4.2. Is the sample representative of the target population? 4.3. Are the measurements appropriate? 4.4. Is the risk of nonresponse bias low? 4.5. Is the statistical analysis appropriate to answer the research question?
5. Mixed Methods – study includes both qualitative and quantitative methodology.	5.1. Is there an adequate rationale for using a mixed methods design to address the research question? 5.2. Are the different components of the study effectively integrated to answer the research question?

Study	Design	Quality appraisal of studies in this review using the above checklist Quality Appraisal	Score (0-5)
1. Ramirez et al. (2019)	Quantitative non-randomised. Longitudinal, population-based birth cohort study with longitudinal and cross-sectional analysis.	<p>5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?</p> <p>5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?</p> <p>5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?</p> <p>S1- YES: Objective to compare sleep disturbances between mothers of children with and without topic dermatitis (AD) and to test association with the AD severity and child's sleep disturbances.</p> <p>S2 – YES: Study used data from 11 649 mother-child pairs who had data on AD and sleep outcomes at a minimum of one time point.</p> <p>3.1- Study benefits from a large population sample and natural control group. However, 97% of participants identified as white and therefore the sample may not be generalisable to the wider population. Additionally, there is a possibility of selection bias due to large amounts of missing data and attrition in the study. (N)</p> <p>3.2- Researchers collected demographic data and used a standardized questionnaire to assess presence and severity of AD symptoms (self-reported by mothers). No data is presented on reliability or validity. Five maternal sleep outcomes were collected; however, no data is presented on reliability or validity of these. (N)</p> <p>3.3- The study reports large amounts of missing data. Researchers used 50 imputed data sets to repeat primary analysis, with consistent results. (Y)</p> <p>3.4- The researchers identify and measure multiple potential confounders based on similar research. (Y)</p> <p>3.5- Yes, the primary exposure was the presence and severity of AD and was measures at varying time points. The researchers were able to compare between AD severity levels and also controls with no AD present. (Y)</p>	3
2) Reilly et al. (2018)	Quantitative non-randomised. Population case-control study	S1 – YES: The study's objective was to determine the prevalence of parent-reported sleep problems in children with epilepsy and their parents,	3

		<p>to compare findings with those with a non-epilepsy neuro-disability and to consider possible contributing factors to sleep difficulties.</p> <p>S2- YES: Parents completed self-report measures of child and parent sleep and parent fatigue as well as parent mental health, child emotional and behavioural difficulties and demographic data.</p> <p>3.1- All children born between 2008-2014 and living in a particular UK geographic region and diagnosed with epilepsy were eligible. Children were identified by paediatricians and parents were contacted in person and letter with details. 48 took part. Children without epilepsy were matched based on age, gender, and estimated developmental level) and identified through attending other clinics in the study area. 81% of epilepsy group and 98% of non-epilepsy group identified as white, limiting the generalisability of findings to the wider population. The small sample size and limited age range (1-7years old) further limits the ability to generalise findings. (N)</p> <p>3.2- The study uses measures and presents evidence of acceptable reliability and validity data of these. (Y)</p> <p>3.3- 47/48 (98%) mothers and 39/48 (81%) fathers completed full set of outcome measures. (Y)</p> <p>3.4- This study benefits from a control group, which addresses a number of potential confounding variables. However, the control group is another illness population, meaning that possible confounding factors associated with illness were not controlled for. (N)</p> <p>3.5 - Yes, the primary exposure was the presence of epilepsy versus the presence of another non-epilepsy neuro-disability. Between and within groups analyses were conducted. (Y)</p>	
3. Wright, 2011	Mixed methods: Cross sectional survey & Qualitative	<p>S1- YES: The aim was to describe sleep characteristics of children receiving treatment for cancer and their caregivers.</p> <p>S2- YES: The researcher developed a questionnaire to collect data on parent and child sleep patterns and experience. Face-to-face semi-structured interviews were also conducted with a sub-sample of caregivers.</p> <p>5.1- The rationale given is that the researcher aimed to collect numerical and narrative information on sleep. Interviews were conducted to gain in-depth information and further validation of questionnaire content. The</p>	2

author states that mixed methodology in this field “offers an effective tool to understand multifactorial and complex biological, behavioral, and social phenomena”. (Y)

5.2- Quantitative and qualitative findings were merged using a matrix used in other similar designs in sleep field. (Y)

5.3- Yes, qualitative data was quantified to ascertain a sense of frequency of sleep disturbance and potential causes. Comments were used to illustrate themes that arose in both quantitative and qualitative questions. (Y)

5.4- The author notes that the agreement between quantitative and qualitative findings provides validation for both. Discrepancies not discussed. (Y)

5.5- Quantitative non-randomised: 3.1: 35 caregivers of children with cancer and 64 healthy controls. Identified at a paediatric oncology clinic and 74% had diagnosis of ALL. Small sample size and majority having one diagnosis and therefore following a particular treatment may mean not representative of children with different types of cancer. No demographic information reported and no information on recruitment of healthy control group makes it unclear whether sample is representative. (N)

3.2- Survey measures were developed and validated in a previous study to investigate sleep issues in children with physical disabilities and their families. No validity or reliability data presented. (N)

3.3 – Yes- All but one parent participants provided data on their sleep. (Y)

3.4- Some potential confounding variables such as type of treatment and pain are considered in discussion, however it is not clear how these and other confounders are addressed within the methodology. (N)

3.5- Yes exposure is group- cancer treatment versus health control (Y)

5.5 Qualitative: 1.1: Yes content analysis used to add greater depth to understanding of complex phenomena and to provide further validation of survey content. (Y)

1.2: Yes- open ended questions in survey to allow participants to share their thoughts and experience. Built upon through interviews with a sub-group of participants.(Y)

		<p>1.3: Themes in qualitative data were quantified to provide frequency data which are presented in tables. No consideration given to the role of researchers and their influence on the findings. (Y)</p> <p>1.4: Yes- quotes from participants are displayed alongside themes and frequency data to aid interpretation of findings. (Y)</p> <p>1.5: Qualitative and quantitative data were merged through comparison of data sets meaning that links between the source of data and results is not clear. (N)</p>	
4) Safer et al. (2016).	Quantitative non-randomised: Cross sectional and longitudinal intervention study.	<p>S1: Yes -To investigate the effects of the BoNT-A injection on sleep quality and depression in mothers.</p> <p>S2: Yes – data collected on child and mother sleep and mothers’ depression at various time points pre- and post-intervention.</p> <p>3.1: Small sample size of 24 participants with a range of different types and severity of cerebral palsy. Data on ethnicity, socioeconomic status etc. not presented. Authors do not comment on whether sample is representative. (N)</p> <p>3.2: Yes – measures used were established measures with data provided on reliability and validity. (Y)</p> <p>3.3: 30 participants initially recruited, but six dropped out leaving 24 which were included in analysis. Authors do not comment on missing data however frequency data provided suggests that data is complete. (Y)</p> <p>3.4: Confounders such as clinical history, severity, and marital status were accounted for, however control group not implemented limiting ability to draw firm conclusions from data (N).</p> <p>3.5: Yes – intervention is exposure to the BoNT-A injection (Y)</p>	3
5) Neu, 2014.	Qualitative: Thematic Analysis	<p>S1: Yes- the aim was to explore sleep-wake experiences of mothers of children undergoing maintenance treatment for ALL.</p> <p>S2: Yes- interviews were conducted with 20 participants using open-ended, semi-structured questions.</p> <p>1.1: Yes- thematic analysis used to explore mothers’ experiences of sleep and to analyse and report on patterns in the data. (Y)</p> <p>1.2: Yes- face-to-face in-depth interviews used to collect data on mothers’ experience of sleep. (Y)</p>	5

		<p>1.3: Researchers coded interviews manually and inductively, with codes being derived from the data. Researchers focused on data related to mothers' experiences of sleep. Researchers were careful to maintain rigour in analysis and methods to ensure this are described. (Y)</p> <p>1.4: Two themes emerged, each with subthemes. These are described in the results and participant quotes are used frequently to illustrate the theme. (Y)</p> <p>1.5: Yes- there is a clear link between the participants, data source, collection method analysis and interpretation. (Y)</p>	
6) Stremmer et al. (2010).	Qualitative: Qualitative descriptive methodology	<p>S1: Yes: to describe factors affecting the sleep of parents of critically ill children.</p> <p>S2: Yes- parents provided written answers to a range of questions about their sleep when their child was in hospital.</p> <p>1.1: Yes- researchers note that this approach is most appropriate given limited literature in the area (Y)</p> <p>1.2: Participants were sourced from convenience sample of parents with a child admitted to PICU hospital ward. Participants asked to provide written answers to four open ended questions about their experience of sleep. 114 parents were included who provided a response to at least one open ended question. (Y)</p> <p>1.3: Researchers independently coded interviews manually and inductively, with codes being derived from key concepts in the data. Codes were then organised by researchers into broader themes and descriptions of the data. A third researcher checked a portion of the data for validity prior to final agreement of codes and themes. No consideration given to the role of researchers and their influence on the findings. (Y)</p> <p>1.4: Themes are clearly presented with quotes to illustrate and justify. (Y)</p> <p>1.5: Yes- there is a clear narrative describing the link between participant selection, data collection, analysis and interpretation of data (Y)</p>	5
7) Edell-Gustafsson et al. (2014).	Qualitative: Qualitative phenomenographic study with an inductive and exploratory design	<p>S1: Yes: To explore and describe how parents of preterm and/or sick infants in neonatal care perceive their sleep.</p> <p>S2: Yes: parents participated in semi-structured interviews comprising of questions about their sleep as well as general questions about themselves and their infant. Results from this study cannot be generalised to other populations.</p>	3

		<p>1.1: Yes – an inductive and exploratory design was used to explore parents’ differing perspectives on their sleep. This was appropriate to answer the research question. (Y)</p> <p>1.2: 12 participants (8 mothers and 4 fathers) were recruited from convenience sample of parents staying in the NICU with their infants. Semi-structured interviews used to elicit data. Demographic data not reported on and no discussion on how such characteristics (e.g. income, ethnicity etc.) may influence findings. (N)</p> <p>1.3: Researchers describe and follow steps for phenomenographic analysis. Data was reviewed following the same steps and an accurate description of the analysis and interview guide is presented in the paper. No consideration given to the role of researchers and their influence on the findings. No information given on how disagreements in coding were resolved. (N)</p> <p>1.4: Four descriptive categories are presented with quotes used to illustrate parents’ perceptions (Y)</p> <p>1.5: Yes- there is a clear narrative describing the link between participant selection, data collection, analysis and interpretation of data (Y)</p>
8) Vardar-Yagli et al. (2017).	Quantitative non-randomised: Cross-sectional survey design	<p>S1: Yes- the aim of the study was to compare physical activity, sleep, anxiety and depression in mothers of hospitalised cystic fibrosis (CF) patients.</p> <p>S2: Yes- data were collected using validated measures which were appropriate in addressing the research question.</p> <p>3.1: Participants were recruited using opportunity sampling. Hospitalised patients were approached when in hospital for CF related problem. Control groups included CF patients attending an outpatient clinic and healthy controls. Inclusion criteria clearly defined, however demographic data on ethnicity and SES not reported on, meaning it is not clear how representative each group is. (Y)</p> <p>3.2: Data showing good reliability and validity of measures is included. Such data specifically for the sample in this population is not shown. (N)</p> <p>3.3: Each group had a different number of participants: hospitalised group: N=23; outpatient group N=38; health control N=37). No details provided on incomplete data however frequency data presented in results not suggestive of missing data. (N)</p>

		<p>3.4: The authors acknowledge that confounding variables were not identified or controlled for. However, the presence of two control groups strengthens the ability of the researchers to make between-groups comparisons. Despite this, the cross-sectional design means it is not possible to draw firm conclusions regarding direction of relationship or causal factors involved. (N)</p> <p>3.5: Yes, the primary exposure was the group: hospitalised, outpatient or healthy control. (Y)</p>	
9) Larson et al. (2012).	<p>Quantitative non-randomised: Cross-sectional survey design</p>	<p>S1: Yes- The aim was to explore the effect of paediatric epilepsy on parental sleep and fatigue.</p> <p>S2: Yes- data were collected using validated measures which were appropriate in addressing the aim of the study.</p> <p>3.1: Participants were caregivers (majority mothers) from 105 children with epilepsy and 79 healthy controls. It is clear where both groups were recruited from and exclusion criteria are defined. Although the sample size is acceptable, the study response rate was 18.7%, which may have introduced selection bias. No data is available on differences between responders and non-responders. Demographic data on ethnicity and socio-economic status is not presented. Only parents of children aged 2-10 included meaning the study may not generalise to older children with epilepsy and their parents. (N)</p> <p>3.2: Established measures with existing data on reliability and validity were used however reliability and validity data were not presented. Cronbach's alpha not calculated for the study's sample. (N)</p> <p>3.3: Survey's that were returned with less than 2/3 completed data were excluded. Researchers state how missing data was handled – through use of total score calculations defined by measures. Sub-scales with two or more missing items were removed from analysis. Data on number of missing items not presented. (Y)</p> <p>3.4: This study benefits from the presence of a control group, enabling researchers to compare between groups. However, the authors note that results may have been confounded due to a high rate of developmental delay and autism spectrum disorders in the in the sample as well as additional confounding genetic variables that were not taken into account. (N)</p>	1

10) McLoone et al. (2013).	Mixed methods: Cross-sectional survey design & thematic analysis	<p>3.5: Exposure was group (epilepsy versus non epilepsy) however confounding variables discussed above must be considered. (N)</p> <p>S1: Yes- the aim was to provide prevalence estimates of self-reported sleep quantity and quality among parents on paediatric oncology ward; and to compare this with age matched healthy controls. The second aim was to identify predictors of poor sleep in this group</p> <p>S2: Yes- data were collected using validated measures which were appropriate in addressing the aim of the study.</p> <p>5.1: Yes- a clear and adequate rationale for using a mixed methods design is laid out. (Y)</p> <p>5.2: The different components of the study are presented separately in the results section; however, the findings are integrated in the discussion where qualitative findings are considered as predictors of poor sleep. (Y)</p> <p>5.3: The overall findings of the study appear to benefit from the use of a mixed methods approach as the qualitative findings add additional information on predictors of poor sleep on top of the quantitative findings. (Y)</p> <p>5.4: Discrepancies between quantitative and qualitative data re not discussed. (N)</p> <p>Quantitative non-randomised: 3.1: Inclusion and exclusion criteria clearly defined. An opportunity sample of parents was identified on the oncology ward. Controls were parents of age-matched children attending an outpatient immunization clinic. Participants included 52 parents of children with cancer (response rate of 71%) and 62 controls (75% response rate). Demographic data revealed no significant differences between groups, however data on ethnicity not collected. (Y)</p> <p>3.2: The study used a validated measure of sleep developed specifically for use in the hospital setting and a validated measure of anxiety and depression. Open ended questions were used to allow parents to describe reasons for their poor sleep. Data on reliability and validity not presented for this sample. (N).</p> <p>3.3: No missing data reported. No description of how missing data may have been handled was reported. Not clear whether data set was therefore complete or not. (N)</p>	2
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		<p>3.4: This study benefits from the presence of a control group, enabling researchers to compare between groups however the cross-sectional nature means it is no possible to determine a direction in the relationship between sleep and anxiety for example (N)</p> <p>3.5: Exposure was group (cancer or healthy control) (Y)</p> <p>Qualitative: 1.1: In part – qualitative questions were included to enable parents to define reasons for their poor sleep (Y)</p> <p>1.2: Data collected through open ended questions added to largely quantitative questionnaire. Appropriate means of data collection as in-depth data not required in terms of answering research question. (Y)</p> <p>1.3: Thematic analysis was used and researchers followed an existing conceptual framework to guide this process. Themes were quantified to provide an estimate of number of families experiencing a particular issue. (Y)</p> <p>1.4: Table of themes with examples of quotes is provided in the results. (Y)</p> <p>1.5: There is a clear rationale for asking open ended questions as part of a largely quantitative study. The data source and method of collection and analysis are clear, although researchers do not acknowledge their own role/ impact in terms of interpreting results. (Y)</p>
11) Bishop et al. (2019).	<p>Quantitative descriptive study: Cross-sectional survey design</p>	<p>S1: Yes- the aim was to examine the associations of parenting stress, sleep and psychological adjustment in parents of infants and toddlers with CHD.</p> <p>S2: Yes – the data collected were appropriate to address the aim of the study. Enough participants were recruited to achieve sufficient power.</p> <p>4.1: Participants were a convenience sample of 69 parents of infants diagnosed with Congenital heart disease (CHD). Participants were recruited from a hospital clinic for CHD. Whilst this may have introduced self-selection bias, given the nature of the study it is likely that this was the most appropriate sampling methodology. (Y)</p> <p>4.2: Demographic data collected showed participants to be representative of a larger population of CHD patients seen in the hospital’s clinic which was based in a large urban US city. (Y)</p>

		<p>4.3: Yes- existing validated measures were used to collect data in this study. Cronbach's alpha was calculated for each measure in this study's population and ranged from good to excellent ($\alpha=0.69-0.97$) (Y)</p> <p>4.4: Data on participation rate was not provided meaning it is not possible to determine level of risk of non-response bias. 3.9% of items were missing from the dataset and these were determined to be missing at random. Single imputation was used to provide unbiased estimates of missing data and to improve the statistical power of analysis. (Y)</p> <p>4.5: The data analysis plan appears suitable in addressing the research questions. A range of potential confounders were included as covariates in the analysis. Mediation analysis explored the relationship between variables and effect sizes were calculated. The cross-sectional nature of the study limits the researchers' ability to make claims of causality and directionality of relationship between variables. (Y)</p>	
12) Nassery & Landgren (2019).	Qualitative: Content Analysis	<p>S1: Yes – the aim of the study was to explore parents' experiences of sleep when admitted to hospital with their ill child.</p> <p>S2: Yes - Nine individual semi-structured interviews and four couples interviews were performed to collect data to adequately address the study's aim.</p> <p>1.1: This was an exploratory study and methodology is appropriate for investigating participants' experiences. (Y)</p> <p>1.2: Data were collected using semi-structured interviews which is appropriate to address the research question (Y)</p> <p>1.3: Interviews were analysed using latent content analysis. Text was broken down into meaning units before being labelled into codes which were based upon the data. No information is provided on how discrepancies between researchers were resolved, nor on the impact of the researchers on interpretation of the data. (N)</p> <p>1.4: Results are presented as themes which are supported by quotes provided in the text. (Y)</p> <p>1.5: A clear narrative is presented outlining the links between the research aims, participants and analysis. No information provided regarding child diagnosis, nor demographic data is presented making it difficult to situate the sample. (N)</p>	3

13) Shaki et al. (2011).	Quantitative non-randomised: Cohort design	<p>S1: Yes- the aim of the study was to evaluate the effects of paediatric epilepsy on sleep in parents of epileptic children and compare this to a non-epileptic control group.</p> <p>S2: Data collected were suitable to answer the research question</p> <p>3.1: Participant's were Hebrew speaking parents of epileptic and non-epileptic children. Parents were contacted from a list of 37 children who had been hospitalised with epilepsy. Of these, 39 parents (mothers and fathers) enrolled. The comparison group sample was collected from parents waiting in the paediatric emergency room and a total of 42 parents (mothers and fathers) enrolled. Whilst no significant differences in demographic variables were found between the two groups, it is not clear how representative this population is of the wider population. Inclusion and exclusion criteria are defined and enough participants were recruited to each group to achieve sufficient power for analysis. (Y)</p> <p>3.2: Researchers used an existing reliable and valid measure of parent sleep which has been translated to Hebrew and previously validated. Data is not presented on validity/reliability in this sample. (Y)</p> <p>3.3: No information is provided on levels of missing data nor on how missing data was handled (N)</p> <p>3.4: The presence of a control group strengthened the findings of this study as it enabled comparisons in sleep to be made across different groups. However, the cross-sectional design means it is not possible to draw conclusions as to causation, only correlation between factors. The researchers claim that the control group, being comprised of parents recruited from the emergency ward adds strength to the findings as it is likely that the control parents would experience greater sleep disturbance than healthy controls, however this is not tested. Confounding variables such as child sleep quality were not measured. (N)</p> <p>3.5: Yes- exposure was group (epilepsy versus non-epilepsy). However, presence of possible confounding variables may have impacted on interpretation of findings. (Y)</p>	3
14) Ridolo et al. (2014)	Quantitative non-randomised: Cross-sectional survey design	<p>S1: Yes – the aim was to evaluate the presence of disturbed sleep in parents of children with atopic disorders, and its relationship with clinical features and the presence of sleep disturbance in children.</p> <p>S2: Data collected were suitable to address the research question</p>	2

		<p>3.1: 92 participants were recruited from an Italian outpatient allergy clinic. Inclusion criteria are clearly defined. Basic demographic information is presented including age, marital status and gender however there is no discussion on whether the sample is representative of the target population. (N)</p> <p>3.2: The study used an established measure of sleep that had previously been validated on the Italian population. No data is presented on validity in the study's sample. (N)</p> <p>3.3: Of the 92 participants who filled out the questionnaires, only 90 were included in analysis which all had been more than 95% completed. (Y)</p> <p>3.4: This study uses a cross sectional correlational design meaning that it is not possible to draw causal inferences of the determinants of parent well-being. The authors acknowledge in the discussion that they were unable to control for confounders such as the effect of treatment on parent and child sleep. (N)</p> <p>3.5: The exposure is the presence, severity and type of allergic disease in the child. However as in 3.4, the presence of confounding variables must be considered when interpreting findings. (Y)</p>	
15) Adiga et al. (2014).	<p>Quantitative descriptive study: Cross-sectional observational and survey design</p>	<p>S1: Yes- the aim was to observe the prevalence of sleep disturbance in children with CP and its correlation with sleep disturbance in primary caregivers.</p> <p>S2: Yes – the data collected were appropriate to address the aim of the study.</p> <p>4.1: Participants were a convenience sample of 50 children with cerebral palsy (CP) and their mothers. Whilst this may increase risk of self-selection bias, given the aims of the study it is likely that this was the most appropriate means of sampling in this target population. (Y)</p> <p>4.2: Due to the relatively small sample size and lack of information on participant demographic data it is not clear whether the sample is representative. A range of illness types and severities were recorded. (N)</p> <p>4.3: The study used an established measure of sleep however does not present any data on validity or reliability. (N)</p> <p>4.4: No data is provided on the participation rate in this study therefore it is not possible to ascertain risk of non-response bias. Furthermore, no information is provided on levels of missing data, nor on how such</p>	1

		<p>missing data was handled therefore it is not clear how complete outcome data were. Frequency data provided in tables suggested that data from all 50 mothers were included in analysis. (N)</p> <p>4.5: Descriptive statistics and correlational analyses were used to describe and explore relationships between variables which is appropriate in addressing the aims of the study. However, it should be noted that confounders were not obviously considered or addressed and the cross-sectional-design means that it is not possible to draw causal inferences from results. The authors note that variables such as intelligence may confound results, but do not elaborate on this. (N)</p>	
16) Macaulay et al. (2019).	<p>Qualitative: Thematic Analysis (with descriptive statistics included using PSQI scores).</p>	<p>S1: Yes- the aim was to explore diabetes-related factors affecting parent sleep</p> <p>S2: Yes- the study used semi-structured interviews and thematic analysis, collecting adequate data to address the research aim.</p> <p>1.1: Yes- thematic analysis was chosen to explore and describe parents' experiences. (Y).</p> <p>1.2: Yes- semi structured interviews were conducted with 18 participants via videoconferencing. Sample size was determined by data saturation. (Y)</p> <p>1.3: The authors describe the process of transcribing and coding data and searching for common themes that emerged. Responses for each theme were quantified to aid determination of thematic saturation and to enhance the clarity of the meaning behind themes. Inter-coder agreement was assessed by the principle researchers who compared codes to reach an agreement. (Y)</p> <p>1.4: The authors provide a table of themes and sub-themes with examples of quotes from participants to substantiate this. (Y)</p> <p>1.5: A clear narrative is presented outlining the links between the research aims, participants and analysis. Key demographic and illness related data is presented which helps to situate the sample. (Y)</p>	5
17) Monaghan et al. (2012).	<p>Quantitative descriptive study: Cross-sectional survey design (as part of a larger RCT design)</p>	<p>S1: Yes – the aims of the study were to evaluate sleep characteristics among young children with type 1 diabetes and associations with parent sleep, emotional functioning and diabetes care.</p>	2

		<p>S2: Yes/maybe- data presented are sufficient to answer the research question, however should be interpreted with caution due to small, relatively homogenous sample size.</p> <p>4.1: Participants were a convenience sample of 24 parents of children (aged 2-5years) with type 1 diabetes. Of 33 parents who were identified as eligible for the study, these 24 (73%) participated. This represents a reasonably high participation rate reducing the chance of response bias. (Y)</p> <p>4.2: Participants were primarily female (88%, Caucasian (75%) and married (92%). Due to small, relatively homogenous size caution should be taken in generalising the findings beyond this study. (N)</p> <p>4.3: The study adapted an existing measure of child sleep for use with parents, following procedures used by another paper. Whilst the measure had no existing data on reliability/ validity, the sample in this survey demonstrated acceptable internal consistency ($\alpha=.76$). Other measures used were also well established in the literature and achieved excellent internal consistency in this sample ($\alpha=.92-.96$). (Y)</p> <p>4.4: No information is provided on levels of missing data, nor on how such missing data was handled therefore it is not clear how complete outcome data were. No data is provided on potential differences between participants and those who chose not to participate; however, 72% of those approached participated, which minimises bias introduced through non-response. (N)</p> <p>4.5: This study uses a cross sectional correlational design meaning that it is not possible to draw causal inferences. Authors note that glycaemic control may not have been controlled for sufficiently in this study as the majority of children had good glycaemic control. However, the data analysis plan appears to be appropriate in answering the research questions. Descriptive statistics and correlational analyses were used to describe and explore relationships between variables. ANCOVA and t-tests were used to further explore relationships between variables. (Y)</p>	
18) Coleman et al. (2018).	Quantitative descriptive study: Cross-sectional survey design	S1: Yes – the aim of the study was to evaluate sleep in parents/ caregivers of children undergoing hematopoietic stem cell transplant	1

		<p>S2: Yes/maybe- data presented are sufficient to answer the research question, however should be interpreted with caution due to small sample size.</p> <p>4.1: Participants were a small convenience sample 17 parents of children undergoing stem cell treatment. Whilst this may increase risk of self-selection bias, given the likely limited number in the target population and the scope of the study it is likely that this was the most appropriate means of sampling. (Y)</p> <p>4.2: The small sample size and lack of demographic information presented in the paper make it difficult to ascertain how representative the sample is of the target population. (N)</p> <p>4.3: The study used an existing measure of sleep however no data is presented on reliability or validity of this measure. The researchers also developed a questionnaire to collect demographic information and information on variables associated with parents disrupted sleep. No data on reliability/ validity is presented. (N)</p> <p>4.4: It is not clear how many potential participants were approached, nor the response rate. No information is provided on levels of missing data, nor on how such missing data was handled therefore it is not clear how complete outcome data were. (N)</p> <p>4.5: This study uses a cross sectional correlational design meaning that it is not possible to draw causal inferences. There is no discussion around additional potential confounding variables and findings are only presented as descriptive statistics. (N)</p>	
19) Meltzer & Booster, 2016	Quantitative non-randomised: Cross-sectional survey design	<p>S1: Yes- the aim of the study was to examine sleep patterns and sleep disturbances in caregivers of children with chronic illness.</p> <p>S2: Yes – the data collected were appropriate to address the aim of the study.</p> <p>3.1: Participants were caregivers of children with atopic dermatitis (AD, n=35), asthma (AS, n=27), AD and AS (n=57), ventilator assisted (VENT, n=61) and healthy controls (HEALTHY, n=63). Exclusion and inclusion criteria are clearly defined. Demographic data is presented for each group. The majority of participants were White, Married and Female and therefore may not be generalizable to a wider group of caregivers (Y).</p>	3

		<p>3.2: The study used existing, validated measures of sleep. Additional questions were added to one of the measures to further explore reasons for sleep disruptions. These were not included in the total score of the measure. No data on this sample is presented. (N)</p> <p>3.3: No information is provided on levels of missing data, nor on how such missing data was handled therefore it is not clear how complete outcome data were. (N)</p> <p>3.4: This study uses a cross sectional correlational design meaning that it is not possible to draw causal inferences. The authors note that the use of self-report measures of sleep may introduce bias, and that researchers did not control for sleep disturbances prior to the onset of the child's illness. However, the presence of four groups strengthens this study as it allows tentative comparisons to be drawn between group differences. (Y)</p> <p>3.5: Exposure was "group". The presence of a variety of illness groups as well as healthy control strengthens confidence in conclusions drawn. The authors note that despite the limitations (described in the above points) the study adds to the literature and provides evidence for sleep disturbance in caregivers of children with illness. (Y)</p>	
20) Feeley et al. (2018).	<p>Quantitative descriptive study: Non-experimental descriptive study with content analysis.</p>	<p>S1: Yes- the aim of the study was to explore caregivers' descriptions of their experience of night-time sleep</p> <p>S2: Yes/maybe- data presented are sufficient to answer the exploratory research question, however should be interpreted with caution due to small sample size and lack of use of validated measures.</p> <p>4.1: A convenience sample of 22 caregivers of children with type 1 diabetes were recruited for this study while children were attending a 1-week camp for children with diabetes. (N)</p> <p>4.2: This was a small, self-selected sample size and no data is presented on demographics making it difficult to ascertain how representative the sample is of the target population. (N)</p> <p>4.3: Researchers designed questionnaires for use in this study. No data is presented on reliability or validity, although the questions are detailed in the publication. (N)</p> <p>4.4: No data is provided on the number of parents who were approached, but declined to participate, nor on overall numbers of children attending</p>	1

		<p>the camp, nor on potential differences between respondents and non-respondents (N)</p> <p>4.5: Descriptive statistics were used to describe sleep disruption in caregivers. Open ended questions were analysed qualitatively (content analysis?) although it is not completely clear what methodology was chosen. Respondents answers to open ended questions were grouped into two themes reflecting difficulties to do with their sleep. Such methods may be appropriate for the exploratory nature of the study; however, the lack of rigour should be noted. (Y)</p>
<p>21) Jaser et al. (2016).</p>	<p>Quantitative Descriptive Study: Cross-sectional survey</p>	<p>S1: Yes- the aims of the study were to: characterise sleep in children with T1D and their parents, to examine associations between child sleep, glycemic control and adherence, parent sleep and wellbeing, parent fear of hypoglycaemia and nocturnal caregiving.</p> <p>S2: Yes – the data collected were appropriate to address the aim of the study</p> <p>4.1: Participants were a large convenience sample of 515 self-selecting parents of children with diabetes who were enrolled in a type 1 diabetes exchange clinic. (Y)</p> <p>4.2: Whilst this study benefits from a large sample size, this represented 22% of the overall population of parents in the clinic. Demographic data shows the majority of the participants identified as Caucasian. Parents education level was varied. (N)</p> <p>4.3: The study used existing measures of sleep however no data is presented on reliability or validity (N)</p> <p>4.4: Parent sleep data is analysed for 501 of the 515 parents, suggesting a reasonably high level of completeness. However, this is not discussed and it is not clear how researchers handled missing or incomplete data. The large sample size reduces risk of non-response bias; however, this still only represents a small percentage of the overall target population. (Y)</p> <p>4.5: The statistical analysis appears to be appropriate to answer the research questions. This study uses a cross sectional correlational design meaning that it is not possible to draw causal inferences. Researchers account for various potential confounding variables and assessed a range of co-variates for association with each outcome through univariate</p>

		analysis: race/ethnicity, age, sex, age at diagnosis, insurance status, insulin modality (Y)	
22) Matthews et al. (2014).	Quantitative non-randomised: Cross-sectional survey design	<p>S1: Yes- the study aimed to compare the sleep of children with ALL during maintenance treatment with controls and to measure the effect on maternal sleep.</p> <p>S2: Yes – the data collected were appropriate to address the exploratory aim of the study however the small sample size limits generalisability of findings and cross-sectional design means that causation cannot be assumed.</p> <p>3.1: Participants were 26 dyads of mothers and their children with ALL and age and gender matched healthy controls. Inclusion and exclusion criteria are clearly stated and justified. Demographic and ethnicity data are presented. The Majority of participants (77%) were Caucasian. Power calculations revealed a sample size of 50 was a minimum number to achieve adequate power. (Y)</p> <p>3.2: Researchers used a combination of validated self-report measures of parent and child sleep, sleep diaries and objective measures (actigraphy). (Y)</p> <p>3.3: Missing data was imputed using multiple imputation. The percentage of missing data on all measures ranged from 12-19%, which authors note is well within the range for using multiple imputation without introducing bias (Y).</p> <p>3.4: A range of possible confounders that may affect sleep such as age, income, number of children, employment etc. were identified and accounted for in analysis. Whilst this is a cross sectional survey making it difficult to draw conclusions regarding causality, this study benefits from the presence of a control group which enabled comparisons to be made between groups. (Y)</p> <p>3.5: The exposure was group – “ALL” versus “healthy control”. A range of possible confounding variables are considered and controlled for (Y)</p>	5
23) Feeley et al. (2019).	Quantitative Descriptive Study: Cross-sectional descriptive pilot study	<p>S1: Yes- the study aimed to examine to correlations in sleep between caregivers and young children with type 1 diabetes.</p> <p>S2: Yes – the data collected were appropriate to address the exploratory aim of the study however the small sample size limits generalisability of</p>	2

		<p>findings and cross-sectional design means that causation cannot be assumed.</p> <p>4.1: A convenience sample of 18 parent-child dyads from an outpatient paediatric endocrinology centre were recruited. This is a small sample size and may be influenced by selection bias (N)</p> <p>4.2: All participants were Caucasian, with the majority being mothers and married meaning there was a lack of diversity in the sample which may not represent the target population. (N).</p> <p>4.3: Measures used were appropriate – the researchers used combination of validated self-report measures of parent and child sleep, sleep diaries and objective measures (actigraphy). (Y)</p> <p>4.4: No data is presented on response/participation rate, nor on possible differences between those who chose to participate and those who did not. (N)</p> <p>4.5: Data analysis was appropriate in addressing the study’s exploratory questions. Researchers used descriptive statistics and correlational analyses to explore relationships between variables. Researchers acknowledge that due to the cross-sectional design causality cannot be assessed. (Y)</p>	
24) Meltzer & Pugliese, 2017.	<p>Quantitative non-randomised: Cross-sectional survey design</p>	<p>S1: Yes- the study aimed to characterise sleep in young children with and without asthma and their parents</p> <p>S2: Yes – the data collected were appropriate to address the aim of the study.</p> <p>3.1: Participants were 364 parents of children (aged 1-4 years) who completed an online survey through a national online research panel. Demographic data was collected and shows that this study involved participants from a range of geographical regions, ethnicities and age groups. Inclusion criteria are clearly defined. (Y)</p> <p>3.2: The study used a range of existing self-report measures of sleep however no data is presented on reliability or validity. Additional items were also added in to gain further insight into parents’ reasons for their sleep disturbance. (N)</p> <p>3.3: No information is provided on levels of missing data, nor on how such missing data was handled therefore it is not clear how complete outcome data were. (N).</p>	1

		<p>3.4: Researchers do not appear to consider potential confounding variables although they do acknowledge that a limitation of this study is its cross-sectional design which limits the ability to draw conclusions about the direction of the relationship between asthma and sleep. (N)</p> <p>3.5: The exposure is group: this study benefits from a “healthy” control group enabling tentative comparisons to be made between groups. However potential confounders are not discussed meaning it is not clear if the exposure occurred as intended. (N)</p>	
25) Meltzer et al. (2015).	<p>Quantitative non-randomised: Cross-sectional survey design</p>	<p>S1: Yes- the studies aimed to compare the sleep patterns of parents of ventilator assisted children and healthy controls and to examine the relationship between sleep variability and health related quality of life. S2: Yes – the data collected were appropriate to address the aim of the study.</p> <p>3.1: Participants were 42 families with a ventilator assisted child and 40 families with a healthy child. This represented approximately 40% participation rate. Participants were recruited from a variety of sources however the majority were Caucasian and married. Inclusion and exclusion criteria are clearly defined and a priori power analysis indicated that 35 participants per group would be sufficient to detect a difference in total sleep time. (Y)</p> <p>3.2: An objective measure of sleep was used (actigraphy) and a well-established measure of health related-quality of life was used. No data is presented on reliability or validity. (Y)</p> <p>3.3: The researchers note that 9% of nights where actigraphy was used to measure sleep were not scored due to participants not wearing the device. It is not clear how missing data was managed in the analysis. (N)</p> <p>3.4: Some demographic characteristics e.g. gender, were considered in the analysis as confounding variables, however the researchers were unable to control for other factors such as child age or medical diagnosis due to the heterogeneous sample.</p> <p>3.4: The exposure was group – “ventilator assisted” versus “healthy control”. However, a range of potential confounders are not considered in the analysis meaning it is not clear if the exposure occurred as intended. (N).</p>	2

26) Wayte et al. (2012).	Quantitative non-randomised: Cross-sectional survey design	<p>S1: Yes – the study aimed to compare sleep problems in children with cerebral palsy (CP) to typically developing children. And to study the relationship between sleep problems in children with CP and maternal sleep quality and depression.</p> <p>S2: Yes – the data collected were appropriate to address the aim of the study.</p> <p>3.1: Participants were mothers of 40 children with cerebral palsy (a recruitment rate of 70%). Control group data was available from children only of health controls from a white European background. Minimal parent demographic data is presented in the publication making it difficult to judge how representative the sample is of the target population. (N)</p> <p>3.2: The study used a range of existing self-report measures of sleep however minimal data is presented on reliability or validity. (N)</p> <p>3.3: No information is provided on levels of missing data, nor on how such missing data was handled therefore it is not clear how complete outcome data were. (N).</p> <p>3.4: A range of potential confounding variables were identified and controlled for in the analysis (employment status, severity of child’s visual disturbance, presence or absence of epilepsy and cognitive ability). (Y)</p> <p>3.5: The exposure in this study is the presence and severity of cerebral palsy. A range of potential confounding variables are accounted for. The authors acknowledge the limitations of a cross-sectional design in impairing the ability to draw causal inferences on the nature of the relationship. This study also benefits from a control group; however, the control group is only available for child data, not mothers (Y)</p>	2
27) Stremmer et al. (2013).	Quantitative Descriptive Study: Prospective cross-sectional observational & survey design	<p>S1: Yes, the aim was to describe sleep quantity, patterns, fatigue and sleepiness of parents of critically ill hospitalised children.</p> <p>S2: Yes – the data collected were appropriate to address the aim of the study.</p> <p>4.1: A large convenience sample of 118 parents (44 fathers and 74 mothers) of children admitted to the PICU were enrolled to the study. (Y)</p> <p>4.2: Demographic data are presented in the text. Participants were majority Caucasian (69%) and married (92%). They had a range of educational backgrounds; employment statuses, and children were admitted to the PICU with a range of illnesses. (Y)</p>	5

		<p>4.3: The study used a range of self-report and objective measures of sleep (questionnaire, sleep diary and actigraphy). It is not clear whether all additional measures had been validated, although the measure of social support used had good internal consistency ($\alpha=.88$). (Y)</p> <p>4.4: Data on response/participation rate is not provided however this is a reasonably large sample size, reducing the likelihood of non-response bias. In terms of missing data, sleep data was recorded for 87% of participants. In 13 cases where actigraphy data was not available, sleep diary data was used as a substitution. (Y)</p> <p>4.5: The analysis appears appropriate to address the research aims. Descriptive statistics and correlational analyses were used to describe and explore data. A wide range of variables were considered and factored into the analysis (e.g. gender, age of child, marital status, number of siblings, type of admission, sleep location and more.). (Y)</p>
28) Paddeu et al. (2014).	<p>Quantitative non-randomised: Cross-sectional survey design</p>	<p>S1: Yes – the aim was to investigate how congenital central hypoventilation syndrome (CCHS) affects mothers and fathers by producing poor sleep quality, sleepiness, anxiety and depression.</p> <p>S2: S2: Yes – the data collected were appropriate to address the aims of the study however the small sample size limits generalisability of findings and cross-sectional design means that causation cannot be assumed.</p> <p>3.1: Participants were parents of 23 children with CCHS and 23 age matched healthy subjects. The authors note that this is a small sample size due to the low incidence of CCHS. Demographic data is presented in the text; however, it is not clear how representative this sample is of the overall population (N)</p> <p>3.2: This study used a range of validated self-report measures and presents data on internal consistency of each of these which is good ($\alpha=0.80-0.89$). No objective measures were used. (Y)</p> <p>3.3: No information is provided on levels of missing data nor on how any missing data was handled. (N)</p> <p>3.4: This study benefits from a control group which allows tentative comparisons to be made between groups. Potential confounders are not discussed in the analysis or results however the authors note in the discussion that poor sleep quality in the CCHS group may also be due to absence of night nursing support. (N)</p>

		3.5: The intended exposure is group – CCHS versus healthy control. The cross-sectional nature of the study and the lack of acknowledgement of confounding variables in the analysis mean it is not completely clear whether the exposure occurred as planned or not. (N)	
29) Al Maghaireh et al. (2017).	Quantitative Descriptive Study: Cross-sectional survey design	S1: Yes- the study aimed to investigate stressors and stress levels among Jordanian parents of infants in the NICU and their relationship to anxiety, depression and sleep disturbance S2: Yes- the data collected were appropriate to address the aim of the study. 4.1: Participants were a convenience sample of 310 parents of infants in the NICU in two different Jordanian hospitals. Whilst use of convenience sample may have increased bias given the specific population targeted and the nature of the research it is likely that this was an appropriate means of sampling (Y). 4.2: Researchers achieved the required sample size for the study based upon the overall population size. A wide range of demographic variables were considered and participants included parents with diverse socioeconomic status, education and infant health status, however, it should be noted that the majority of participants came from high income families and identified as muslim. (Y) 4.3: The study used a range of valid and reliable self-report measures. Cronbach's alpha was calculated for all measures used with this sample and all were found to be acceptable ($\alpha=0.72-0.96$). (Y) 4.4: No information is provided on levels of missing data nor on how any missing data was handled. No information is provided on potential differences between completers and non-completers however the large population sample does reduce the risk of non-response bias. (N) 4.5: Yes, the statistical analyses appear appropriate in answering the research question. A wide range of demographic and illness history data was collected to account for possible confounding variables. Descriptive statistics, correlational analyses and t-tests were used to explore and describe relationships between variables (Y).	4

30) Daniel et al. (2018).	Quantitative Descriptive Study: Cross-sectional survey design	<p>S1: Yes – the study aimed to describe sleep quality and disturbance among caregivers of children in the maintenance phase of acute lymphoblastic leukaemia (ALL) and to examine the rel. between sleep quality, child sleep disturbance, and caregiver guilt and worry.</p> <p>S2: Yes- the data collected were appropriate to address the aim of the study.</p> <p>4.1: Participants were 68 caregivers of children with ALL aged 3-12 years old. 81 potential participants were identified through a cancer registry at a hospital, meaning the participation rate was 84%. (Y)</p> <p>4.2: The authors note that the sample lacks diversity and was made up primarily of Caucasian mothers. (N)</p> <p>4.3: The study used a range of established self-report measures of sleep and stress/well-being. Researchers calculated reliability which was acceptable for all measures used in the study ($\alpha=.78-.87$). Two additional questions were added to the parent sleep questionnaire to assess how caregiving impacts their sleep. (Y)</p> <p>4.4: No information is provided on levels of missing data nor on how any missing data was handled. No data is provided on potential differences between participants and those who chose not to participate (N)</p> <p>4.5: The statistical analyses and rationale are explained and appear to be appropriate for answering the research questions. A range of possible confounding variables are considered and accounted for (e.g. child age at diagnosis) such factors were accounted for by entering them as covariates in the first step of the regression model. However, the authors note that a limitation of the study is that data on caregiver sleep disorders were not collected which may have confounded results. (Y)</p>	3
31) Meltzer et al. (2010).	Quantitative Descriptive Study: Cross-sectional descriptive design	<p>S1: Yes- the study aimed to examine the relationship between home-care nursing support, sleep and daytime functioning in caregivers of ventilator assisted children (VAS)</p> <p>S2: Yes- the data collected were appropriate to address the exploratory aims of the study.</p> <p>4.1: Families with VAS children were identified by a home care program. Inclusion and exclusion criteria are clearly defined and a self-selecting sample of 27 (out of 40 approached) enrolled in the study. Such selection strategy may have introduced bias through self-selection however given</p>	2

		<p>the relatively small overall population size and nature of the study it is likely that this was the most appropriate method to recruit participants. (Y)</p> <p>4.2: Participants were primarily Caucasian mothers and there was a range of health conditions of the VAS child, however it is unclear how representative the sample is of the target population. (N).</p> <p>4.3: This study used a range of well-established self-report measures. The paper presents reliability data for each measure however not specifically for this sample. (N)</p> <p>4.4: This study may have been subject to non-response bias as only 68% of those approached with information about the study chose to participate. (N)</p> <p>4.5: Yes – although the authors note that the study lacks power, the statistical methods employed are suitable for addressing the research questions. Researchers use descriptive statistics to analyse nursing coverage and sleep patterns, correlational analysis to explore relationships between variables and T-tests and ANOVA to explore differences between groups. (Y)</p>
32) Angelhoff et al. (2018b).	<p>Qualitative: Phenomenographic study</p>	<p>S1: Yes- the study aimed to explore and describe perceptions of sleep in parents of children under 2 years old with Atopic Dermatitis (AD) and to explore consequences of parental sleep loss.</p> <p>S2: Yes- the data collected were appropriate to address the exploratory aims of the study.</p> <p>1.1: Yes- the phenomenographic approach of this study appears to suitably address the aims to explore parents' perceptions of their sleep. (Y).</p> <p>1.2: Purposive sampling was used and parents who had experience of AD were invited to participate in semi-structured interviews. Data from 12 interviews was included in the analysis. (Y).</p> <p>1.3: The authors describe following seven steps of phenomenographic analysis. They reflect on the process of this and note how three authors discussed the material substantially before coming to conclusions. (Y).</p> <p>1.4: The paper presents a range of quotes from different participants to demonstrate the quality of the data and to substantiate their interpretations. (Y).</p> <p>1.5: A clear narrative is presented outlining the links between the research aims, participants and analysis. The authors also acknowledge the</p>

		potential impact of their own background and experience in analysing and interpreting the data (Y).	
33) Ledet et al. (2015).	Quantitative Descriptive Study: Intervention pilot study with pre and post measures of parent sleep,	<p>S1: Yes- the study aim was to assess the impact of screening and teaching interventions for sleep-wake disturbance in parents of children with epilepsy</p> <p>S2: Yes/maybe- the data collected were appropriate to address the exploratory aims of the study however the small sample size greatly limits the ability to draw firm conclusions or generalise to a wider population.</p> <p>4.1: Participants were a convenience sample of 12 self-selecting parents of children with epilepsy. This may have introduced bias through self-selection however given the nature of the study it is likely that this was the most appropriate method to recruit participants. (Y)</p> <p>4.2: Demographic data is not presented and due to the small sample size, it is unlikely that participants are representative of the wider target population. (N)</p> <p>4.3: The study uses established self-report measures of parent sleep, and data from previous research is presented on reliability or validity. Such data does not appear to have been calculated for this study's sample. (N)</p> <p>4.4: There is significant risk of non-response bias due to the small sample size. No data is provided on the number of eligible participants approached versus those recruited. (N)</p> <p>4.5: The statistical methods appear appropriate to answer the research questions. The researchers use descriptive statistics to explore sleep scores pre and post intervention, and T-tests to compare differences pre- and - post. (Y)</p>	2
34) Angelhoff et al. (2018a).	Quantitative Descriptive Study: Prospective descriptive study with a cross-sectional survey design	<p>S1: Yes, the study's primary aim was to describe sleep quality and mood in parents accommodated with their sick child in a family centred paediatric ward.</p> <p>S2: Yes- the data collected were appropriate to address the exploratory aims of the study.</p> <p>4.1: A convenience sample of parents from six paediatric wards for children were selected. Whilst the self-selecting nature of this mode of recruitment may have introduced bias, given the nature of the study it is likely that this was the most appropriate method to recruit participants. (Y)</p>	4

		<p>4.2: The final sample comprised of 82 parents, well above the 35 the researchers required to achieve sufficient power for analysis. A range of parent and child demographic data was collected however it is not clear how representative this sample was of the target population. However, the authors note that a strength of the study is that parents were included from six different wards, increasing the heterogeneity of the sample. (Y)</p> <p>4.3: This study used a variety of validated measures and present good reliability data in this sample ($\alpha=0.73-0.90$). (Y)</p> <p>4.4: Single items of missing data were replaced by the mean; however, no information is provided on levels of missing data, nor on potential differences between completers and non-completers. (N).</p> <p>4.5: The statistical analysis is clearly defined and justified in the text and appears appropriate in answering the research questions. (Y)</p>	
35) Albayrak et al. (2019).	<p>Quantitative non-randomised: Cross-sectional survey design with control group</p>	<p>S1: Yes, the aims were to evaluate pain, care burden, depression level, sleep quality, fatigue and quality of life (QoL) among a group of mothers of children with cerebral palsy (CP) and to compare these with healthy controls.</p> <p>S2:</p> <p>3.1: Participants were 101 mothers who had children with CP and 67 mothers who had a healthy child. Inclusion and exclusion criteria are clearly defined. Demographic and clinical data was collected and is presented in the findings; however, it is not clear how representative the sample is and authors note that due to being conducted in a single centre, results cannot be generalised to the whole target population. (N)</p> <p>3.2: This study uses a range of established valid and reliable measures; however, no data is presented on reliability in this sample nor in previous research (N).</p> <p>3.3: No information is given on levels of missing data, nor on how this was handled in the analyses (N).</p> <p>3.4: Researchers take into account a range of possible confounding variables including severity of CP and socio demographic and illness related factors. However, it is not clear how this was managed in the analysis which was purely correlational. (N)</p>	1

		3.5: The exposure was group – CP or healthy control. Whilst there is no information on how confounding variables may have intervened, the presence of the control group does enable tentative comparisons to be made between groups, lending strength to conclusions of difference between CP parents and controls (Y).	
36) Safa et al. (2012).	Quantitative Descriptive Study: Descriptive study with a cross-sectional survey design	<p>S1: Yes, the study’s primary aim was to explore the correlation between depression and anxiety and sleep quality in mothers of children suffering from cystic fibrosis and asthma who were staying in hospital.</p> <p>S2: Yes- the data collected were appropriate to address the exploratory aims of the study.</p> <p>4.1: No information is given on how the sample of 148 mothers was recruited. Authors note that acceptance rate of the questionnaire was 99%, which may suggest little bias introduced through self-selection, however this cannot be determined as it is not clear who researchers approached. (N).</p> <p>4.2: The sample was a good size; however, no information is provided on how representative this sample is of the overall target population. No information provided regarding power calculations. Limited demographic information presented; however, the authors do note how participants with a variety of academic backgrounds were able to participate as a they state that a researcher completed questionnaires of those who were “not literate”. (N).</p> <p>4.3: This study used two validated measures translated to Persian; however, data for this sample is not provided. (N).</p> <p>4.4: no information is provided on levels of missing data nor on how this was handled in the analysis. (N)</p> <p>4.5: The statistical analysis, whilst limited, is defined in the text and appears appropriate in answering the research questions. (Y).</p>	1

Appendix B: Information sheet for Facebook group administrators



Paediatric Gastroesophageal Reflux Disease and Parental Mental Health: Prevalence and Predictors.

What is the aim of this research?

- To investigate how common mental health difficulties are among primary caregivers of infants with reflux (including silent reflux).
- To investigate psychological factors that might predict parental well-being.
- To hear parents' and primary caregivers' views on what has the biggest impact on their wellbeing.

Why this research is important

There is lots of anecdotal evidence suggesting that caring for an infant with reflux may impact on parental wellbeing. However, there is no scientific research that has looked at this. This research is therefore important because the findings may be used to inform interventions aimed at improving wellbeing in families who have infants with reflux.

What are the possible benefits of taking part?

- The main benefit is that we will gain greater understanding of the impact that reflux has on parents and primary caregivers' mental health and well-being. This will help families both now and in the future.
- After completing the questionnaire, participants will be invited to take part in a prize draw for a chance to win one of four £25 Amazon or Love to Shop vouchers.

Who can participate?

Parents and primary caregivers who currently have a child aged 3-12 months old who has a diagnosis of reflux **and** is receiving prescribed treatment for their reflux.

What does taking part involve?

- Participants will be asked to complete an online survey about their experiences of caring for an infant with reflux, as well as their mental health and well-being.
- The survey will take approximately 20-30 minutes to complete.
- It is possible that answering some questions might raise some difficult emotions. Participants can choose to not answer and can stop the survey at any time. An example of a question is *"How much does your child's illness affect you emotionally (e.g. does it make you angry, scared, upset or depressed)?"*
- At the end of the survey, participants will be given the option to provide an email address. Participants can choose to be entered into a prize draw where there will be an opportunity to win one of four £25 Amazon or Love to Shop vouchers.

- They will also have the option to choose whether to be sent a second survey in two months' time. The aim of this is to gain a greater understanding of well-being over time when caring for an infant with reflux. Please note that participants do not need to take part in this second stage should they not wish to.
- Participants who take part in the second survey will be entered into the prize draw twice.

Will taking part in the study be kept confidential?

All the information recorded will be strictly confidential. Data will be stored securely on a password-protected computer that is only used by researchers working on the project.

What will happen to the results of the Study?

Once the study is completed, we intend to publish the results. This is in order to help other families who have an infant with reflux. Participants will not be named and any information that might identify participants will be removed. Participants will be asked if they wish to receive a summary of the results.

Any questions?

If you have any questions, you can contact the Project Lead – Lizzi Aizlewood, Trainee Clinical Psychologist at Salomons Canterbury Christ Church University

Email: [REDACTED]

You can also contact the project supervisors:

Dr Rachel Whatmough, Clinical Psychologist and Clinical Academic Tutor at Salomons Canterbury Christ Church University. Email: [REDACTED]

Dr Fergal Jones, Clinical Psychologist and Reader in Clinical Psychology at Salomons, Canterbury Christ Church University. Email: [REDACTED]

Appendix C: Social Media (Facebook) Post



Invitation to take part in research.

Hi all, I'm a mum of a 2-year-old with reflux and I'm also a Clinical Psychologist.

I'm supervising a research study looking into how reflux impacts on Parental Mental Health. If you would like to take part it's an online survey that will take about 20-30 minutes. There is a chance to win a £25 voucher (your choice of Amazon or Love to Shop) if you would like to be entered into the prize draw. There is no obligation to take part but if you would like to find out more click the following link to get involved! (Admin has approved this post)

https://cccsocialsciences.az1.qualtrics.com/jfe/form/SV_cNFMIPVYz4yNsTH

Appendix D: Qualtrics Baseline Survey

This has been removed from the electronic copy

Appendix E: Email to Participants

Infant Reflux & Parental Wellbeing

Hello,

Thank you for your participation in my research looking at infant reflux and parental mental health and wellbeing.

I am emailing you because you indicated on the survey you completed that you would be happy for me to send you a second, shorter survey as part of this research. Please see the link below which will take you to the second survey.

link

I have included an information sheet at the beginning of the survey and you will be asked to provide your email address again. Please ensure you enter the same email address that you entered on the first survey (i.e. the email address at which you are receiving this email).

This is so that I can connect up your information from surveys one and two. Once I have done that, your email address will be removed, and your privacy will be protected from there on.

You will also be asked again at the end of the survey if you would like to be entered into the prize draw for a second time.

Thank you again for being part of this research. Your participation is greatly appreciated, and the findings of this research could be used to inform interventions to improve quality of life in families of infants with reflux.

Wishing you all the best

Lizzi
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Appendix F: *Qualtrics Follow-up survey*

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Appendix G: Salomons Ethics Approval for Research

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Appendix H: *t-Tests exploring baseline differences between participants who did and did not complete the follow-up survey.*

		Independent Samples Test					t-test for Equality of Means	
		Levene's Test for Equality of Variances		t	df	Sig. (2-tailed)	Mean Difference	Std. Error
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Difference between groups
Age	Equal variances assumed	2.987	.085	.321	304	.748	.185	
	Equal variances not assumed			.334	227.825	.739	.185	
NumberChildren	Equal variances assumed	.962	.327	.141	307	.888	.015	
	Equal variances not assumed			.145	220.347	.885	.015	
NumberReflux	Equal variances assumed	.359	.549	-.236	307	.814	-.015	
	Equal variances not assumed			-.246	228.777	.806	-.015	
InfantAgeMonths	Equal variances assumed	1.167	.281	-1.292	307	.197	-.451	
	Equal variances not assumed			-1.327	219.467	.186	-.451	
AgeSymptoms	Equal variances assumed	1.893	.170	.577	307	.564	.044	
	Equal variances not assumed			.556	184.853	.579	.044	
AgeDiagnosis	Equal variances assumed	.004	.947	.078	307	.937	.015	
	Equal variances not assumed			.080	215.209	.936	.015	
TimeToDiagnosisMonths	Equal variances assumed	.004	.952	-.179	307	.858	-.029	
	Equal variances not assumed			-.185	220.657	.854	-.029	

Appendix H continued.

		Independent Samples Test				t-test for Equality of Means		
		Levene's Test for Equality of Variances						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Difference
FeedingSatisfaction	Equal variances assumed	4.472	.035	1.655	307	.099	.558	
	Equal variances not assumed			1.740	233.428	.083	.558	
SatisfiedFriends	Equal variances assumed	6.306	.013	-.154	307	.878	-.049	
	Equal variances not assumed			-.162	232.419	.872	-.049	
SatisfiedRelationships	Equal variances assumed	2.378	.124	1.375	307	.170	.417	
	Equal variances not assumed			1.419	222.227	.157	.417	
SleepQuality	Equal variances assumed	.195	.659	-.055	307	.956	-.015	
	Equal variances not assumed			-.055	202.499	.956	-.015	
TotalIPQScoreMissingData	Equal variances assumed	.828	.364	-1.691	307	.092	-2.427	
	Equal variances not assumed			-1.641	188.692	.103	-2.427	
PPUSTotalScoreMissingData	Equal variances assumed	.705	.402	-1.607	307	.109	-3.592	
	Equal variances not assumed			-1.575	193.488	.117	-3.592	
SCSTotalScore	Equal variances assumed	.251	.617	-.495	307	.621	-.04328	
	Equal variances not assumed			-.490	198.542	.625	-.04328	
PHQTotalScore	Equal variances assumed	1.104	.294	-.558	307	.577	-.417	
	Equal variances not assumed			-.544	190.984	.587	-.417	
WMWBSTotalTransformed	Equal variances assumed	2.522	.113	.300	307	.764	.13126	
	Equal variances not assumed			.279	169.464	.781	.13126	
GADTotalScore	Equal variances assumed	6.633	.010	-1.392	307	.165	-1.010	
	Equal variances not assumed			-1.338	184.156	.182	-1.010	

Appendix I: *Content analysis sample of coding frame and inter-rater reliability for Q1.*

Question 1: What (if anything) about caring for an infant with reflux has the biggest impact on your mental health?

Coding frame:

Categories	Sub-Category Title	Sub-Category Number
Unable to help child's pain	Seeing child in pain	1
	Feeling helpless	3
	Feeling like a failure/ not able to comfort child	22
Relentlessness of caring for child with reflux	Baby crying/screaming/ infant not able to settle	10
	Frequent/constant sickness	23
	Practical demands and impact on daily life e.g. washing, cleaning & reflux related tasks	14
	Unable to relax or rest/ no respite or "me time"	21
Impact on relationships	Impact on bonding/relationship with infant	11
	Impact on relationships with other children	12
	Impact on partner/friendship relationships	13
Not feeling supported	Health professionals not listening/ being judgemental	4
	Family/friends not understanding/ being judgemental	5
	Not understood listened/supported to NoS	25
Withdrawal from going out and feeling alone	Isolation/ loneliness	15
	Practical difficulties going out due to sickness/crying	24
	Anxiety about others seeing infant screaming / not eating/ vomiting e.g. in public	6
Unpredictability and uncertainty with reflux	Unpredictability of reflux symptoms	17
	Uncertainty about reflux/ future/ course of illness/ treatment	18
	Issues with medication	19
Feared consequences of reflux	Impact on child's health e.g. growth and development	7
	Fear of baby choking/dying	8
Overall Mental Health and Wellbeing	Impact on parent's sleep	9
	Impact on general mental health/ wellbeing (including worry not specified)	16
	Feelings of guilt	20
Other	Difficulties/dissatisfaction/anxiety with feeding	2

Sample of comments and inter-rater reliability check:

Question 1 Participant Comment	Coder 1	Coder 2
The medical professionals make you feel like you're an over anxious mother.	4	4
The screaming and crying	10	10
The lack of sleep	9	9
Not being believed by GP/ Just told by HV that she was high needs	4	4
Lack of understanding from family and friends.	5	5
Sleep deprivation.	9	9
Not being believed by the doctors that something was wrong	4	4
The fact that my son has reflux related apnea (or we think that's what it is.) he is now in medication but I live in constant fear of him stopping breathing.	8	8
The crying & clingyness	10	10
The inability to make it better.	3	3
The unpredictability of the illness, one day it can seem well controlled, others it flares up out of nowhere.	17	18
Having to see him in pain and discomfort constantly.	1	1
The constant crying and fussiness	10	10
makes me feel like I'm failing as a parent.	22	22
He requires so much attention that I cannot put him down so my daughter doesn't get the attention she deserves.	12	12
Then it's making sure they are getting all the medication at the right time	19	14
The bad days makes me feel like I'm failing at protecting her and keeping her safe.	22	22
especially getting out and about and doing housework,	14	21
The constant crying	10	10
The uncertainty of the long term impact the medication will have on her.	7	7
the constant heartache of seeing your baby in pain	1	1
not being able to help.	3	3
Stress and worry of not knowing what is wrong	18	18
to be made to feel like I'm crazy and making it up about my child from health professionals.	4	4
Being stolen of having a normal baby, i lost the most precious months of his life to reflux.	11	11
Having it place restrictions on what activities we do, as it is sometimes impossible to take enough outfits/ bibs etc to make sure baby can stay dry & clean	24	24
Increased already chronic anxiety	16	16
In the early months, never being able to put him down to sleep. This impacted hugely on my mental health.	9	10

Appendix J: Content analysis sample of coding frame and inter-rater reliability for Q2.

Question 2: What do you think could help improve your well-being?

Coding Frame:

Category	Sub-category	Sub-category number
Support from medical professionals	Better and more timely access to appropriate medical help (including diagnosis and treatment)	1
	Feeling dismissed, invalidated or not taken seriously by professionals	2
	Feeling generally better supported/listened to by professionals	3
Feeling supported (other)	Feeling supported/helped/understood by family & partner (including asking for/accepting help)	4
	Feeling supported/helped/understood by friends (including asking for/accepting help)	5
	Support groups for parents of infants with reflux	6
	More support/ help/ understanding from others (Not otherwise specified)	7
Reflux symptom reduction	Cure/gone	8
	Medication/ treatment that works	9
	Reflux managed better/ symptom reduction/ happier baby	10
Greater knowledge about reflux	Having a definitive diagnosis/ treatment plan	12
	Self & Medical professionals being more informed/ having more knowledge about reflux	13
Overall Mental Health & Wellbeing	Being able to have a break/ some "me time"	14
	Putting focus on own physical/mental health	15
	Having better sleep	16
Other	Don't know	17

Sample of comments and inter-rater reliability check:

Question 2 Participant Comment	Coder 1	Coder 2
Much needed sleep	16	16
not having to constantly worry if she's gonna spit up and get upset	10	10
Being listened to by doctors	2	2
Help from others.	7	7
Time for myself.	14	14
Better support especially from healthcare professionals who were more worried about their budget than my son's wellbeing	3	3
Proper sleep	16	16
Lucky I have family to help but if you were doing this on your own it'd be impossible."	4	7
I can actually wash more than once a week, brush my teeth every day and not feel so stressed and on edge all of the time.	15	14
More answers on how to help my child.	13	13
Having help with looking after her	7	7
Knowing I'm not alone with this	7	7
Being respected by professionals.	2	3
Having a definite answer, so that I know the pain, failure to thrive and feeding aversion is definitely caused by silent reflux.	12	12
And help and support from friends	5	5
[help and support] from family	4	4
More information to GPS	13	13
For weeks we just heard "it's colic". Nothing would have been done if I didn't fight for it.	2	2
More help from partner and family	4	4
Having access to a group of mothers who are all experiencing the same issues. It's embarrassing attending baby groups when you're the only one with a little one that's constantly vomiting.	6	6
Professionals who trust and listen to my concerns.	2	2
Sleep!!!	16	16
Support!!	7	7
More support from outside sources. I can't put baby down so it's very intense.	7	7
My baby not projectile vomiting.	10	10
My family taking it more seriously	4	4
Speaking to other parents in a similar position to me	6	6

Appendix K: Summary of study and results for participants



Infant Reflux and Parental Well-being: Summary of Results

Dear Participant,

Thank you for taking part in my research study looking at parent mental health when an infant has reflux. I am writing to give you a summary of the project and to share the results.

Aims

- To investigate how common mental health difficulties are among parents and primary caregivers of infants with reflux (including 'silent reflux' i.e. reflux without vomiting).
- To investigate factors that might predict parental well-being.
- To explore differences between reflux and silent reflux.
- To hear parents' views on what has the biggest impact on their wellbeing.

Methods

Participants were invited to take part in an online survey which was shared on Facebook support groups for parents who have an infant with reflux. The survey included questions about participants' experiences of caring for an infant with reflux and about participants' mental health and well-being. Participants were invited to take part in a follow-up survey 8 weeks after the initial survey.

Results

- There was a large response, with 309 participants completing the initial survey and 103 participants completing the follow-up survey.
- The analysis showed that a higher proportion of participants scored above "clinical cut-off" in measures of anxiety and depression than would typically be found in a post-natal population.
- The proportion of participants scoring above the cut-off dropped significantly in the follow-up survey.
- Self-compassion refers to a person's ability to be kind to oneself in times of difficulty. Participants with higher self-compassion scores had overall lower anxiety and depression scores at both the initial survey and at follow-up.
- Illness uncertainty refers to feelings of uncertainty a parent might have about their child's illness. Participants who experienced more uncertainty about their infant's reflux when completing the initial survey had overall higher levels of anxiety and depression scores in the initial survey. However, uncertainty scores in the initial survey did not predict anxiety or depression scores in the follow-up survey.
- No differences were found in any of the measures between participants whose infants had reflux (with vomiting/regurgitation) versus those whose infants had silent reflux.
- Several themes emerged from participants responses to open-ended questions and these are summarised in the table below.

Question	Theme	Sub-themes
What (if anything) about caring for an infant with reflux had the biggest impact on your well-being?	Unable to help child's pain	Seeing child in pain Feeling helpless Feeling like a failure/ not able to comfort child
	Relentlessness of caring for child with reflux	Baby crying/screaming/ infant not able to settle Frequent/constant sickness Practical demands and impact on daily life (e.g. washing, cleaning & reflux related tasks) Unable to relax or rest/ no respite or "me time"
	Impact on relationships	Impact on bonding/relationship with infant Impact on relationships with other children Impact on partner/friendship relationships
	Not feeling supported	Health professionals not listening/ being judgemental Family/friends not understanding/ being judgemental Not understood listened/supported to (not otherwise specified)
	Withdrawal from going out and feeling alone	Isolation/ loneliness Practical difficulties going out due to sickness/crying Anxiety about others seeing infant screaming / not eating/ vomiting e.g. in public
	Unpredictability and uncertainty with reflux	Unpredictability of reflux symptoms Uncertainty about future/ course of illness/ treatment Issues with medication
	Fear of consequences of reflux	Impact on child's health e.g. growth and development Fear of baby choking/dying
	Overall Mental Health and Wellbeing	Impact on parent's sleep Impact on general mental health/ wellbeing (including worry not specified) Feelings of guilt
	Other	Difficulties/dissatisfaction/anxiety with feeding
What do you think could help improve your wellbeing?	Support from medical professionals	Better and more timely access to appropriate medical help (including diagnosis and treatment) Not feeling dismissed/invalidated and being taken seriously by professionals Feeling generally better supported/listened to by professionals
	Feeling supported - other	Feeling supported/helped/understood by family & partner (including asking for/accepting help) Feeling supported/helped/ understood by friends (including asking for/accepting help) Support groups for parents of infants with reflux More support/ help/ understanding from others (not otherwise specified)
	Reflux symptom reduction	Cure/gone Medication/ treatment that works reflux managed better/ symptom reduction/ happier baby
	Greater knowledge about reflux	Having a definitive diagnosis/ treatment plan Self & medical professionals being more informed/ having more knowledge about reflux
	Overall Mental Health & Wellbeing	Being able to have a break/ some "me time" Putting focus on own physical/mental health Having better sleep

Conclusions

The results of this study suggest that infant reflux is a risk factor for mental health difficulties in parents. Results also suggest that parental mental health improves over time. Participants comments to open ended questions demonstrate the significant emotional and practical challenges faced by parents. Self-compassion appears to predict well-being over time, as participants who scored highly in self-compassion at the initial survey reported better mental health at the initial survey and at follow-up. Future research should explore this further and investigate whether interventions to improve parents' self-compassion results in improvements in mental health. Participant's experience of uncertainty predicted mental health scores at the initial survey, and participants reported high levels of uncertainty in their responses to open ended questions. This finding may also help to guide future research and interventions with the aim of improving parents experience, mental health and well-being when caring for an infant with reflux.

Thank you again for participating in my research. I really appreciate the time you gave and the openness in your responses.

If you have any questions about my research please contact me using the details below.

Best wishes,

Lizzi Aizlewood

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Appendix L: *Feedback to Ethics Panel*

Paediatric Gastroesophageal Reflux Disease and Parental Mental Health: Feedback to Ethics Panel

Aims

- To investigate how common mental health difficulties are among parents and primary caregivers of infants with reflux (including 'silent reflux' i.e. reflux without vomiting).
- To investigate factors that might predict parental well-being.
- To explore differences between reflux and silent reflux.
- To hear parents' views on what impacts on their well-being.

Methods

Participants took part in an online survey which was shared on Facebook support groups for parents who have an infant with reflux. The survey included questions about participants' experiences of caring for an infant with reflux and about participants' mental health and well-being. Participants were invited to take part in a shorter survey at eight-week follow-up. Descriptive statistics and confidence intervals were used for prevalence data. Simple linear regressions were calculated to explore the relationship between all predictor (and control) variables and outcomes at baseline and follow-up. Paired sample t-tests tested for difference between reflux and silent-reflux groups. Content analysis was used to identify themes in the qualitative data.

Results

- There was a large response, with 309 participants completing the initial survey and 103 participants completing the follow-up survey. The majority of participants were mothers from the United Kingdom and identified as being white British.
- The analysis showed that a higher proportion of participants scored above "clinical cut-off" in measures of anxiety (66%) and depression (63%) than would typically be found in a post-natal population (10-20%).
- The proportion of participants scoring above the cut-off dropped significantly in the follow-up survey (anxiety = 40%, depression = 49%). Perceived management of reflux symptoms also improved over time as did participant reported satisfaction with sleep and feeding.
- Self-compassion predicted anxiety, depression and well-being at baseline and follow-up. Self-compassion also remained a significant predictor when added to the regression model with all other control and predictor variables.
- Illness uncertainty predicted outcomes at baseline when in the regression model with all other variables, however it did not remain a significant predictor at follow-up.
- Illness perceptions was not a significant predictor of outcomes when in the regression model with all other variables.
- No differences were found in any of the measures between participants whose infants had reflux versus those with silent reflux.

- Several themes emerged from participants responses to open-ended questions and are summarised in Table 1 (overleaf).

Conclusions

The results of this study suggest that infant reflux is a risk factor for mental health difficulties in parents. Results also suggest that parental mental health improves over time. Participants responses to open-ended questions demonstrated the significant emotional and practical challenges faced by parents. Self-compassion predicted well-being at baseline and follow-up. Future research should explore this further and investigate whether interventions to improve parents' self-compassion result in improvements in mental health. Participant's experience of uncertainty predicted mental health scores at the initial survey. Participants also reported high levels of uncertainty in their responses to open-ended questions. This finding may help to guide future research and interventions with the aim of improving parents experience, mental health and well-being when caring for an infant with reflux.

Table 1: Categories and sub-categories from content analysis

Question	Category	Sub-category
What (if anything) about caring for an infant with reflux had the biggest impact on your well-being?	Unable to help child's pain	Seeing child in pain Feeling helpless Feeling like a failure/ not able to comfort child
	Relentlessness of caring for child with reflux	Baby crying/screaming/ infant not able to settle Frequent/constant sickness Practical demands and impact on daily life (e.g. washing, cleaning & reflux related tasks) Unable to relax or rest/ no respite or "me time"
	Impact on relationships	Impact on bonding/relationship with infant Impact on relationships with other children Impact on partner/friendship relationships
	Not feeling supported	Health professionals not listening/ being judgemental Family/friends not understanding/ being judgemental Not understood listened/supported to (not otherwise specified)
	Withdrawal from going out and feeling alone	Isolation/ loneliness Practical difficulties going out due to sickness/crying Anxiety about others seeing infant screaming / not eating/ vomiting e.g. in public
	Unpredictability and uncertainty with reflux	Unpredictability of reflux symptoms Uncertainty about future/ course of illness/ treatment Issues with medication
	Fear of consequences of reflux	Impact on child's health e.g. growth and development Fear of baby choking/dying
	Overall Mental Health and Wellbeing	Impact on parent's sleep Impact on general mental health/ wellbeing (including worry not specified) Feelings of guilt
	Other	Difficulties/dissatisfaction/anxiety with feeding
What do you think could help improve your wellbeing?	Support from medical professionals	Better and more timely access to appropriate medical help (including diagnosis and treatment) Not feeling dismissed/invalidated and being taken seriously by professionals Feeling generally better supported/listened to by professionals
	Feeling supported - other	Feeling supported/helped/understood by family & partner (including asking for/accepting help) Feeling supported/helped/ understood by friends (including asking for/accepting help) Support groups for parents of infants with reflux More support/ help/ understanding from others (not otherwise specified)
	Reflux symptom reduction	Cure/gone Medication/ treatment that works reflux managed better/ symptom reduction/ happier baby
	Greater knowledge about reflux	Having a definitive diagnosis/ treatment plan Self & medical professionals being more informed/ having more knowledge about reflux
	Overall Mental Health & Wellbeing	Being able to have a break/ some "me time" Putting focus on own physical/mental health Having better sleep

Appendix M: *Author Guideline Notes for Submission to the Journal of Pediatric Psychology***Instructions to Authors**

The Journal of Pediatric Psychology publishes articles related to theory, research, and professional practice in pediatric psychology.

Original research articles should not exceed 25 pages, in total, including title page, references, figures, tables, etc. This paper will be edited to meet these criteria.

Further information can be found at: https://academic.oup.com/jpepsy/pages/author_instructions