Parents' views on their children's sleep difficulties and their approach to help seeking: An exploratory study

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A thesis submitted for the degree of Professional Doctorate in Child, Community and Educational Psychology

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Date of submission for examination: September 2023

Abstract

Background

The impact of sleep on physical and mental health is significant. This is evidenced through a wide range of literature (Williamson et al., 2020). This includes educational and personal outcomes for young people (Konen et al, 2015). The patterns and habits that children form in early life can support them to develop positive sleep habits and routines into adulthood (Sutton et al., 2019). Research has shown that parents can be reluctant to seek support for children's sleep difficulties (Cook et al., 2020). In a longitudinal study by Williamson et al. (2020), 5107 children were recruited at birth and monitored for sleep difficulties up to the age of 11; almost half the children had some form of reported sleep difficulty. This high prevalence provides further rationale for the current exploratory study. Despite how well-established the importance of sleep is, there is little research into what specifically parents would seek or use in terms of support.

Aims and objectives

This research aimed to establish what support parents would like or have sought for sleep difficulties of children aged 3-11 in mainstream primary schools in England. Further aims were to find out what parents consider when deciding whether to seek such help.

Methods

The study used a mixed-methods design. Data was collected using an online questionnaire for parents to explore help desired and sought. Semi-structured interviews were used to explore parents' views, experiences and considerations on their help-seeking journeys. The questionnaire data was analysed using descriptive statistics and content analysis; and the interview data was analysed using reflexive thematic analysis (RTA).

Results and Conclusions

Analysis of quantitative data is presented alongside key themes identified from qualitative data: Losing Sleep; Weighing it Up; Experiences of Support; Family Matters; What about me? The findings are reviewed in relation to existing literature and implications for educational psychology (EP) practice are highlighted. The strengths and limitations of the study are discussed alongside recommendations for future research. The main implications are the consideration, going forward of the unique position of EPs and how they could be utilised to best support families in which children struggle with the important area of a human’s existence, sleep.

Acknowledgements

I could not have completed this research without the unending support of so many. My supervisors: Jude Mortell who started me off with strength on my journey: Then Katy Cole who carried me through to the finish line with unfailing encouragement, enthusiasm and kindness.

Barney Wade, my placement supervisor was my rock throughout the process. Janchai King, my personal supervisor held a strong faith in my ability to succeed whenever I was low on hope. All of my incredible friends, family and fellow Tavi trainees have fueled me with encouragement, love and cake throughout the entire process.

My two greatest cheerleaders have always been my Mum, Ruth and my Dad, Colin. Thank you for everything.

My proof readers helped me on the home stretch and particularly my Dad, who read the entire thesis (more than once through).

Finally, and most importantly, thank you to the parents who graciously gave their time and thoughts for this research to support the knowledge base and help others to seek the help they most wholeheartedly deserve. Thank you.

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Chapter 1: Introduction

1.1 Chapter Overview

This chapter will present an overview of the issue of sleep difficulties in children and provide a rationale for research into this area. It will cover the core definitions used throughout the study and discuss what sleep is, why it is important and what it means to seek help for sleep difficulties. The prevalence of sleep difficulties in the UK and government policies around sleep health will be considered.

The researcher's local context will be explored including what support is available for children's sleep difficulties. It will finish by outlining the aims and purpose of this study, the rationale for the specific research questions and the researcher's positionality.

1.2 The Science of Sleep

1.2.1 What is Sleep?

Sleep is an active state of unconsciousness produced by the body where the brain is in a relative state of rest and is reactive primarily to internal stimulus (Brinkman et al., 2023). It is defined by the Oxford English Dictionary as "the natural state of rest in which your eyes are closed, your body is not active, and your mind is not conscious" (Oxford English Dictionary, n.d.).

The exact purpose of sleep has not been fully elucidated, however there are several theories that attempt to explain it (Colten & Altevogt, 2006).

1.2.2 Why is Sleep Important?

Sleep is a universal need of all mammals including humans, and its purpose is still being studied. Studies so far have shown the following to be key areas in which sleep crucially impacts health and development (Anderson & Tyldesley, 2019):

- Cognition and brain development
- Learning and memory
- Physical growth and development

These are all areas relevant to the practice of Educational Psychologists (EPs).

Sleep Architecture

The human body cycles through two phases of sleep: rapid eye movement (REM) and non-rapid eye movement (NREM) sleep, which is further divided into three stages (N1-N3) (Patel et al., 2022). Each phase and stage of sleep includes variations in muscle tone, brain wave patterns, and eye movements. The body cycles through all of these stages approximately 4-6 times each night, averaging 90 minutes for each cycle (Colten & Altevogt, 2006). The stages of sleep are as follows:

- Stage 1 (N1) – this first stage of NREM lasts less than 10 minutes and is marked by a slowing heartbeat, breathing and eye movements. Muscles relax and brain waves begin to slow when entering this stage of light sleep.
- Stage 2 (N2) – this period of light sleep before you enter deeper sleep lasts around 20 minutes. The heartbeat and breathing both slow further in this stage and the brain begins to produces bursts of rapid, rhythmic brain wave activity known as sleep spindles.

- Stage 3 (N3) – the final stage of NREM sleep is the deepest period of sleep and lasts for 20-40 minutes. Breathing and heartrate slow even further and your muscles become so relaxed that it may be hard to be roused from sleep.
- REM sleep – finally the REM sleep stage is entered which initially may only last a few minutes, but lengthens with each new cycle of sleep and may last for up to an hour. This is typically the stage of sleep in which dreaming occurs but it can also occur in NREM sleep. Eyes will make rapid movements under the eyelids at this time and breathing and heartrate will quicken.

When we sleep, our brain undergoes a series of changes that are vital to our overall health (Suni & Callender, 2022). During N3 sleep, delta waves are generated to help restore the body and mind. The delta wave activity processes memories and experiences from the day. At the same time, the brain produces growth hormones to repair muscle tissue, regrow bone cells and strengthen the immune system.

Sleep is important to a number of brain functions, including how nerve cells communicate with each other. Four key occurrences taking place in the brain during sleep are laid out below (Nunez & Lamoreux, 2023):

1. Brain waves – There is a high rate of change in brain waves in each different stage of sleep. Studies have shown that brain waves slow during the early part of sleep and then there are a number of quick bursts of brain activity during later, deeper sleep.
2. Waste removal – Recent findings suggest that sleep plays a housekeeping role that removes toxins in the brain that build up while you are awake. The glymphatic system clears out waste from the central nervous system.

3. Memory consolidation – Sleep is important for memory consolidation, which is the process of converting short-term memories into long-term ones. During sleep, the brain stores new information and gets rid of toxic waste, which supports healthy brain function.
4. Brain plasticity – Sleep is required for brain function, allowing neurons to reorganise. When we sleep, our brain's glymphatic system removes toxic byproducts from our brain, which build up throughout the day. This allows our brain to work well when we wake up.

Maslow's (1943) hierarchy of needs shows sleep on the base layer as a core requirement for human functioning. It may come as no surprise therefore that humans need to sleep for a multitude of reasons. According to 'Mental Health UK' a registered charity, almost 1 in 5 people are not getting enough sleep (cited at https://mentalhealth-uk.org/help-and-information/sleep/). "The World Health Organisation (WHO) has declared a sleep loss epidemic throughout industrialized nations." (Walker, 2018, p. 4)

How much sleep is needed?

There is no absolute certainty around the optimum hours of sleep. However, the National Health Service (NHS) in the UK has issued some guidance for the recommended number of hours people should sleep at different ages, (NHS, n.d.). It states that a healthy adult usually needs between 7 and 9 hours of sleep, depending on age, health and personal circumstances. Teenagers, children and babies require more sleep because they are still growing. This will also be variable and typically falls between 8 and 16 hours a night. The following table gives further detail as advised by the United States national public health agency, the Centers for Disease Control and Prevention (CDC, 2015).

Table 1: Amount of Sleep Recommended by CDC by Age, (CDC, 2015)

Age	Amount of sleep recommended
birth to 3 months	14 to 17 hours
4 to 12 months	12 to 16 hours per 24 hours, including naps
1 to 2 years	11 to 14 hours per 24 hours, including naps
3 to 5 years	10 to 13 hours per 24 hours, including naps
6 to 12 years	9 to 12 hours
13 to 18 years	8 to 10 hours
18 to 60 years	7 or more hours
61 to 64 years	7 to 9 hours
65 years and older	7 to 8 hours

1.2.3 Sleep and Children

Sleep is important for a child’s development of their mental health, physical health, social-emotional wellbeing, behaviour and cognitive functioning (Lewien et al., 2021). If sleep health is not supported at this early stage of life, difficult habits or issues related to sleep may arise that are problematic for the duration of the child’s life and into adulthood (Konen et al., 2015; Luo et al., 2019; Pike et al., 2019). Early development is also a determining factor for many outcomes of an adults’ life.

Pacheco and Vyas (2023) discuss benefits of sleep and dangers of lack of sleep for children in a number of areas of their development (Pacheco & Vyas, 2023; Table 2). Their article is presented on the Sleep Foundation Organisation website (cited at www.sleepfoundation.org/children-and-sleep) which explains that articles it uses are evaluated by medical experts to ensure the information is factual, up-to-date, and free of bias. The Sleep Foundation presents its fact-checking guidelines within the Website. However, as the article was not found from a data-base utilised in the literature review, it is important to view these points with some caution and consider that there may be more in-depth, thorough or up-to-date information from alternative sources.

Table 2: Benefits of Sleep and Impact of Lack of Sleep for Children.

Area of Development	Benefits of Sleep	Impacts of Lack of Sleep
Cognitive Functioning	Improved attention, behaviour, learning, memory and overall IQ scores.	Reduced attention span, difficulty concentrating, poor memory and lower IQ scores.
Physical Health	Promotes healthy growth and development, increases muscle mass, regulates puberty and fertility and repairs cells and tissues.	Increased risk of obesity, diabetes and cardiovascular disease.
Mental Health	Improves mood, resiliency and vocabulary acquisition.	Increased risk of anxiety, depression and suicidal thoughts.
Behaviour	Promotes better overall behaviour.	Increased risk of hyperactivity, impulsivity and aggression.

All of these areas can also have an impact on one another and so cannot be viewed in isolation (Ramar et al., 2021). Therefore, it is important to understand children's sleep needs and promote healthy sleep habits to ensure their optimal development and well-being.

Walker (2018) explains that a lack of sleep is often confused with a diagnosis of Attention Deficit Hyperactivity Disorder ADHD. He posits that 50% of children diagnosed with ADHD likely have an undetected sleep disorder. Walker feels that a government policy uninfluenced by ADHD medication is needed to support the disparity between sleep and ADHD.

1.2.4 Sleep and Families

When a child has trouble sleeping, the impact can spread to all members of the family or household in which they live. This can lead to a multitude of other problems which the family may then have a further reduced chance of managing. Sviggum et al. (2018) discuss how supporting a child’s sleep issues has an important role in safeguarding the wellbeing of the entire family. Associations have been made in research between family structure and sleep patterns. Nilsen et al. (2022) performed a study to explore these associations and found them to be inextricably linked. They commented that other research had also documented the association between family structure and adolescent sleep (Delaruelle et al., 2021; Schmeer et al., 2019; Troxel et al., 2014). Adolescents in single or Stepparent families may have a higher likelihood of experiencing later bedtimes, short sleep duration, and sleep problems compared to those in nuclear families. This is based on several studies that have looked at the relationship between family structure and sleep patterns in adolescents (Lewien et al., 2021; Mancini et al., 2020; Rydzkowski et al., 2016). These studies suggest that family environments can influence adolescents' sleep patterns, and that disadvantaged family contexts may contribute to sleep problems among adolescents, which can have implications for their health and well-being.

1.2.5 What is a sleep difficulty?

This study focuses on sleep difficulties or issues in children aged 3-11, therefore definitions will focus on this population. Terms used to describe problems with sleep in this study include: sleep disorder, sleep deprivation, sleep issues and sleep difficulty. These terms will be interchangeably referred to as the terms are often used interchangeably in existing literature, and the nuanced differences in meaning may suit some contexts better than others. Each term is defined below.

Sleep Disorders

Defined by the DSM-5 as ‘difficulty initiating sleep’ and in children, they can manifest as difficulty initiating sleep without caregiver intervention, difficulty maintaining sleep, characterised by frequent awakenings or problems returning to sleep after awakening, or early-morning awakening with inability to return to sleep (DSM-5, n.d.). According to the United States National Institute of Health (NIH), 20-30% of young people suffer from ‘sleep disorders’.

Sleep Deprivation

Sleep deprivation is a condition that occurs when an individual does not get enough sleep or their sleep quality is poor. It can be a short-term issue affecting one or a few nights, or it can be a chronic concern that lasts weeks or even months. Sleep deprivation can be caused by various factors, including voluntary or involuntary sleeplessness, circadian rhythm sleep disorders, and certain health conditions.

Sleep Issue and Sleep Difficulty

For the purposes of this study, the researcher has defined a *sleep issue* or *sleep difficulty* as anything regarding their children's sleep for which parents sought additional support.

1.3 Help-seeking

1.3.1 What is Help-seeking?

In the context of this study, help-seeking is taking specific, measured steps to solve a perceived problem by the help-seeker. To 'help-seek' parents would have had to make a conscious decision to change something about how they were managing their situation. This could be wide ranging and span from asking friends or family for support through to making a specific medical or professional request. Ultimately, the researcher wanted participants in the study to state whether they felt that they had engaged in specific 'help-seeking' behaviours.

1.3.2 When is Help Sought?

Sleep difficulties are normal and expected in most children, so when does it become a difficulty that requires help? When does it become atypical and what is the threshold for it tipping into a situation where a parent may actively seek out support?

Research shows that it can take a long time for parents to seek out support for their children's sleep issues (Hargadon & Downes, 2019; Cook et al., 2020). Many parents do not seek support at all for these difficulties (Cook et al., 2020). Cook et al (2020) reported the following as barriers to parents seeking support:

- Parents perceived health care professionals (HCP) to have a lack of knowledge or training around the topic of children’s sleep
- They felt that advice would be limited in terms of breadth of information or management options that would be offered
- Parents were concerned about wasting their own or HCP’s time
- They perceived a lack of continuity in the information they received
- There was a concern about possible negative consequences for their family if they shared details about any child sleep difficulties

Further research shows that parents will often only seek help for sleep issues when the difficulty has become so extreme that there is a significantly detrimental impact on the child’s physical or mental health or the family as a whole (Kitsaras et al., 2021). A Norwegian study (Sviggum et al., 2018) found that parents will develop coping strategies rather than seek external help. Studies such as this one supported development of an idea of what might be appropriate or suitable support to provide. Acknowledging difficulties, defining self-understanding, putting change into action, and ensuring the welfare of one’s family were all examples of coping mechanisms. These coping mechanisms led to the main subject of “health-promoting regulation of interactions, including parents’ strengthening of sleep regulation in their young children and the safeguarding of well-being in the family” (page 3) as a result of these coping mechanisms. The authors came to the conclusion that for parents to find ways to deal with such difficulties early, individually tailored assistance for parents with a focus on disclosing and admitting their experiences with sleep disorders in children is one of the determining factors in help-seeking. Setting appropriate goals appears to be crucial for them to be successful in improving their children’s sleep regulation in a more sustainable way.

Whilst barriers persist in parental help-seeking behaviours for children’s sleep difficulties, children and young people may continue to spend longer periods of time without the support they require to manage their difficulties with sleep. This delay in support for such a key element of children’s development is one of the core reasons for initiating this research.

1.4 National and Local Context

1.4.1 National Context

According to an NHS digital survey in 2022, 34% of CYP are experiencing sleep difficulties at least 3 times per week. Anderson and Tyldesley (2019) report that The World Health Organisation (WHO; 2004) highlighted the importance of the identification of sleep deprivation in children and young people (CYP) because of its adverse impact upon health and behaviour problems. Educational efforts were reported to be required in order to help CYP become familiar with healthy sleep hygiene, which can be described as the helpful practices that promote falling and staying asleep, including regular sleep and wake times in order to encourage an efficient sleep-wake cycle (WHO, 2004).

Amongst government health policy, there is little that is specifically directed at sleep and how to maintain a heathy sleep routine. It has only been in the last 5 years that sleep has been on the agenda of government priorities and policy advice. In July 2019, The Guardian posted an article about a leaked draft of a public health green paper that was to review evidence on sleep and health. (The Guardian, 2019), however, it would appear that this policy was never published. There is also an evidence review of sleep and health from 2020 that outlines the government's views around the topic area, (UK health security agency, 2020). Finally, a Parliamentary Office of Science and Technology (POST) Notes from the Houses of Parliament (2018) outlines the essential nature of sleep and the impact of lack of sleep, (Parliamentary Office of Science and Technology, 2018).

Another Guardian article from February 2019 about sleep explains that medical admissions of those aged 16 and under with a primary diagnosis of sleep disorder rose from 6,520 in 2012/13 to 9,429 in 2018, (The Guardian, 2019). The same article states that there is also a crisis around sleeplessness, with hospital admissions for young people lacking sleep said to have risen sharply in the past six years.

For those who require support for their children's sleep difficulties in the UK, expensive private clinics, local GP surgeries or general literature appear to be the main sources of help. A general search by the author did find an NHS initiative; 'Sleep Station' that provides some online therapeutic support. It is not aimed at any particular age group, but is said to be clinically validated and designed by experts. This is freely available nationwide and provided the author with a glimmer of hope to what may lie ahead in terms of UK based sleep support programmes.

1.4.2 Local Context

Sleep difficulties are mentioned a number of times within Education, Health and Care Needs Assessments (EHCNAs) for the population of CYP aged 0-25 produced by the local authority (LA) where the researcher carried out this study. However, very little information is provided within the advice around support available for parents.

The local offer in this LA includes support for children with disabilities who are experiencing sleep difficulties from the disability charity SCOPE. Although supportive, a referral is needed and this is not for neurotypical children. There has also been discussion in educational psychology service (EPS) team meetings regarding the high prevalence of sleep difficulties being discussed during consultation. The awareness being raised in this context shows the need for support in this area of health. Within a final search, the author found that a local hospital in the LA supports sleep difficulties using an online cognitive behavioural therapy (CBT) based programme.

1.4.3 The Impact of COVID-19 on Children's Sleep

Paiva et al. (2021) explain that sleep becomes particularly relevant and important when humans face stressful situations such as a global pandemic. Young people are listed as one of the groups more affected by the pandemic in terms of decreased sleep quality. The study concluded that quality of sleep during highly stressful life events such as COVID-19 is impacted not only by the time spent sleeping, but daytime effect of mood control, level of positive attitudes and behaviours, physical exercise, nutrition intake and dependence on technology. The impact of the pandemic therefore was to exacerbate the number of factors having an effect on the ability for people to sleep well and thus live well in their waking lives.

1.5 Sleep and the Role of the Educational Psychologist (EP)

Educational Psychologists (EP) work with children with a wide range of needs and difficulties. They see CYP in their homes, schools and community contexts which opportunely places them to monitor, explore and discuss the complicated area of sleep.

Sleep difficulties are often comorbid with other conditions, which can make sleep difficult to pinpoint as an area to manage within EP work. Trainee EPs (TEPs) are required to gather evidence to show they are meeting the British Psychological Society (BPS) proficiencies (2019) and Health and Care Professions Council (HCPC) competencies (2015). Sleep issues amongst CYP do not specifically arise within these, which may be because sleep is rarely isolated as a specific health concern. *Table 3* below shows competencies that are associated with but not directly related to sleep health.

Table 3: BPS Competencies Associated with Sleep Health.

BPS competency	**Area associated with sleep health**
BPS 1.1.5 PDE	Understand individual differences in developmental progression by demonstrating knowledge of theories of psychology relevant to: Physical and sensory development
BPS 1.4 PDE	Demonstrate knowledge of biological, cultural, and social influences on learning, cognitive, and developmental processes, and application of evidence-informed curriculum and instructional strategies.

	Demonstration of understanding of biological influences on learning, cognitive and developmental processes. (This is the author's interpretation)
BPS 6.2 PIE	Synthesise, use and share assessment information to negotiate and develop action plans to address learning, social, physical and mental health outcomes for children and young adults with diverse abilities and needs.
BPS 6.3 PIE	Demonstrate the ability to identify and plan suitable evidence-based interventions, drawing on relevant assessment information and formulation.
BPS 7.6 SDOC	Work effectively with a range of professionals from health and social care backgrounds (e.g., speech and language therapists, occupational therapists, Child and Adolescent Mental Health Service (CAMHS) staff, social workers) and have an understanding of their knowledge base so that collaborative working is enhanced by identification of distinctive and complementary areas of practice
BPS 8.2 TD	Develop 'bespoke' training with clear, defensible, psychological foundations to address training needs of service users and commissioners.

Considering the number of health and wellbeing factors that are impacted by poor or inadequate sleep as mentioned earlier in this chapter, it is curious that sleep difficulties are not recognised under the umbrella of special educational needs and disabilities (SEND). Support being readily available for sleep difficulties would fall in line with recommended early intervention from the 'Children and Families Act' (2014).

Anderson & Tyldesley (2019) explored what new competencies would be required for TEPs to be trained to support children presenting with sleep deprivation. They found from their Delphi study that EPs are indeed well-situated to support CYP with improving sleep. There is still a concern amongst researchers that sleep issues are not identified enough and so not treated enough. This causal effect of identification and treatment could be part of the reason for the lack of training in psychological professions. There is a lack of specialists in sleep medicine and very few training pathways for a direct focus on sleep. Sleep is often labelled as ‘cross-disciplinary’ which could be a significant factor in its absence from the EP doctoral or other psychology training courses. Sleep does not sit neatly in any particular area of the training, but providing trainees with increased knowledge and support for CYP with sleep difficulties could place the role of the EP in a particularly unique and accessible position to contribute to the improvement of outcomes for CYP who present with sleep deprivation. EPs can use information in relation to the quantity, quality and timing of sleep to understand the factors that may be impacting upon the development of CYP.

Rydzkowski et al. (2016) argue that sleep difficulty is about more than simply physical health implication and impact. Sleep is affected by a wide-ranging number of areas and thus cannot be isolated and managed by a single professional authority but needs to be considered in context among many other aspects of a CYP’s life. EPs work within many systems around a child, and so are ideally placed to support the complexity of cause and impact around sleep difficulties. Rydzkowski et al. (2016) posit that the most successful outcomes may arise from approaches tailored to specific needs. This may allow CYP to develop their emotional regulation and self-efficacy within the context of support from their family and peers. EPs are placed in an ideal position to support with this kind of input. An example of this put into practice is De’Cage (2018) a TEP who designed and implemented an intervention called ‘Sleep Club’ as part of her doctoral research, which provided positive outcomes for the CYP involved.

1.6 Researcher Reflexivity

It is essential within research, to state, explore and question one’s assumptions and biases as a researcher (Finlay, 2002). The following section will take the reader through the researcher’s experiences that may have influenced the study, and thought processes when designing the study to ensure transparency to the process.

Throughout this research, if first person is used by the researcher, italic font will be used to identify the change of writing style.

As a Psychology Assistant, before I began the doctoral training course, I found that a CYP’s sleep would be discussed frequently in encounters with families or schools. The CYP my colleagues and I were supporting often had some trouble with their sleep, but it was quickly surpassed in conversation and never, in my experience so far, focused on or discussed in more detail. This confused me as it is such a core and fundamental part of the CYP’s life; why was there not more curiosity around their sleep? In conversation with EPs I have worked with, I found that most had the sense that they did not feel qualified enough to adequately tackle the issue, so they referred to more specific health specialists or sometimes provided light-touch and generic advice such as key points around sleep hygiene. Moving into the doctoral programme, I have found a continuation of regular mention of sleep issues amongst the population I worked with as a TEP. Within the area of sensory and physical health, I and my colleagues would often query the CYP’s sleep health, and it was often poor. Yet, again, there was very little to guide us to what we would discuss next, other than to signpost or offer the same support that can be easily found online. It is of note that in my role as a TEP, I was working in an inner London borough *which was a very different cultural area to the Southeast England Local Authority in which I was a Psychology Assistant. This span of locations has shown me that these difficulties are not isolated to one area, but permeate more than one geographical location.*

I also have personal experience of difficulties with sleep. These have impacted my life in complex ways, and medical advice did not help me to manage the issues I was experiencing. Symptoms of chronic fatigue impacted my professional and personal life in frightening ways. Due to difficulties with sleep as a teacher, daytime fatigue would leave me unable to keep my eyes open and safely manage children in the classroom or on school trips. I was also unable to safely drive at times which impacted my ability to attend social or leisure activities. GPs were able to offer tests to search for deficiencies in blood levels. However, when they were returned as normal, I was left with no further solution. The frustration and fear that I have encountered as an adult managing these issues, has led to my determination to consider what may be possible within role as an EP to support at the earliest stages of life with this essential element of human existence, sleep.

It is important for me to consider the potential biases I may be holding whilst carrying out this research. My experience is one in isolation. It is important that I remain aware of this and do not allow myself to make generalisations or conclusions without due consideration of a wider population. The following section will cover my approach to the analysis of this study and my positionality as a researcher.

1.7 This Research

1.7.1 Aims and Purpose of the Research

The overarching aim of this research was to explore parents' help-seeking for their children's difficulties with sleep. The purpose of this study was to inform support arrangements for parents.

1.7.2 Research Questions

The research questions addressed through this study were:

- *What support do parents want and what support have parents sought for their children's sleep difficulties?*
- *What do parents consider when deciding whether to seek support for their children's sleep difficulties?*

1.7.3 Rationale: The Unique Contribution of this Research

There is limited research around parental support seeking for children's sleep difficulties. The contribution of the present research study is the specific question asked by the researcher around what parents hold in mind when deciding whether to seek help for their children's sleep difficulties, and what can help them, how that help can be accessed.

In the next chapter, literature will be systematically reviewed to provide a clearer picture of what has already been researched in the area of children's sleep and parents' help-seeking. Themes will be drawn and gaps in the literature will be discussed with an increasingly clear view and rationale for this study.

Chapter 2: Literature Review

2.1 Chapter Overview

The researcher systematically searched the current literature about parents' views on help-seeking for their children's sleep difficulties. With this chapter, a review and synthesis are presented of the current literature base. It is important to review the current literature to draw robust conclusions, pull ideas together and present knowledge of what already exists in response to the area of research enquiry (Siddaway et al., 2019). It helps to highlight gaps between what is known and what needs further research. This literature review is systematic, exploratory and aims to identify what is known about the literature review question (LRQ) below helps to pinpoint the focus of the research.

LRQ: What are the views of parents on seeking or accessing support for sleep difficulties?

With the current review, the author was trying to find out what is known about parent views on:

- The extent to which parents seek help for their children's sleep difficulties
- Why they are or are not seeking help
- What might aid parents to seek help
- What hinders parents in seeking help

2.2 Search Strategy

2.2.1 Databases

The following databases were chosen to be sure to explore research in a variety of different fields of interest to the research and research topic. The chosen databases were:

- APA PsychInfo
- APA PsycArticles
- Education Source
- ERIC
- MEDLINE

2.2.2 Search Terms

The literature was systematically searched on 2nd August 2023. Initial scoping searches were carried out to determine the most suitable terms. The terms chosen in the final searches run are shown in Table 4 below. Three searches (S1, S2 and S3) were conducted and then combined in S4. Figure 1 shows the PRISMA chart demonstrating the literature found from the search. A further scoping search was conducted on 20th August 2023 to ensure there was no further literature added to the databases relevant to the present study.

Table 4: Search Terms and Boolean Phrases

Search Number	Search Terms and Boolean Phrases	Area of Article Searched	Hits
S1	sleep difficulties OR sleep issues OR sleep problems	AB Abstract	3,297
S2	support OR help OR advice	AB Abstract	555,310
S3	parents OR carers OR guardians	AB Abstract	103,691
S4	S1 AND S2 AND S3	AB Abstract	147

The titles of the 147 studies were then screened using the following inclusion and exclusion criteria (Table 5). This supported the researcher to determine which articles to select for the final review.

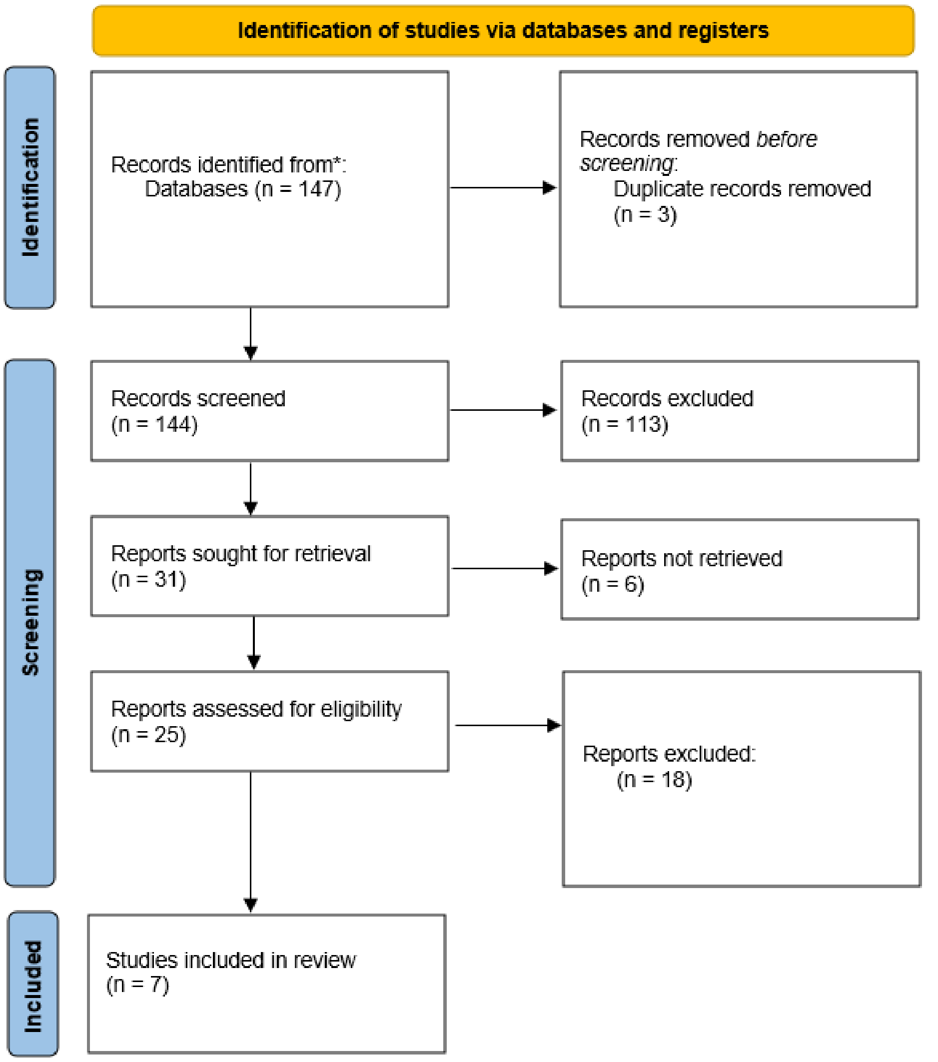
Table 5: Inclusion and Exclusion Criteria

Inclusion	Exclusion	Rationale
Sleep difficulties in children	Sleep difficulties in adults	Research question refers to sleep difficulties in children and there could be some overlap within the literature; this needs to be filtered out.
Parent views around seeking support	Views of non-parents (e.g., professionals) Parent views on sleep difficulties that are not to do with seeking support Impact of sleep difficulties (when not presented through parent views)	To ensure the focus of the research was on parental views

Studies between 2013 and 2023	Studies earlier than 2013	Views and advice around sleep will be changeable over time, consequently the researcher was looking at research from the last ten years
Peer reviewed paper	Non-peer reviewed paper	While researcher autonomy is a fundamental component of the empirical study process, peer evaluation is a crucial part of any reliable contribution to the body of knowledge.
Studies written in English	Studies written in languages other than English	Studies could be read and critiqued by the researcher
Linked full text	No linked text available	To allow access to the studies
Studies in which data is sufficiently distinguishable to the literature review question.	Studies in which data is not sufficiently distinguishable to answer the literature review question around the sleep help seeking. i.e., Reliant on interpretative measures of the author.	To support the answering of the literature review question.

The abstracts of the resulting 25 articles were then screened to determine suitability for inclusion in the literature review.

Figure 1: PRISMA Chart



2.3 Overview and Critical Appraisal of the Literature

Seven papers were selected to be reviewed, which consisted of 5 qualitative studies (interview, focus group and questionnaire) and 2 quantitative survey studies. These papers have been critically appraised by the author using tools appropriate for their methodologies. The following tools were used:

- Critical Appraisal Skills Programme (CASP) - Qualitative Studies Checklist – used to review the 5 qualitative studies

- Critical Appraisal of a Survey – Center for Evidence-Based Management (CEBMa) – used to review the 2 quantitative studies

Appendix 1 presents the results of the CASP for critical appraisal. Appendix 2 presents the results of the use of the CEBMa critical appraisal tool used for the quantitative studies. Throughout this review, the author has commented on the critical appraisal of each article. Table 6 below shows some information about the included literature and an overview of details of each study.

Table 6: Overview of the Included Literature

Number	Reference	Aims	Methodology	Findings	Strengths and Limitations
1	Cook, G., Appleton, J. V. & Wiggs, L. (2020). Parentally reported barriers to seeking help and advice for child sleep from healthcare professionals. *Child: Care, Health and Development, 46,* 513-521.	To understand the barriers reported by parents to consulting HCPs about child sleep.	Qualitative: Online questionnaire with open questions about help-seeking behaviours related to child sleep. Thematic analysis	Five themes as barriers to parents accessing support: professionals perceived to lack knowledge about sleep, professionals lack of flexibility, concerns about wasting time, concerns about negative consequences, lack of continuity or conflicting information from professionals.	Limitations: sample bias due to majority white female participants. No standardised questionnaire for researching this area exists so one was made for this study which may not capture the subtleties of parental barriers
2	Cook, G., Gringras, P., Hiscock, H., Pal, D. K. & Wiggs, L. (2021). A Qualitative Investigation Into What Parents Want From an	To identify from parents if there were special considerations for the content	Qualitative: Semi-structured interviews.	Themes identified in answer to the research question: Other parents views and	Small sample size due to challenge of recruitment.

	Online Behavioural Sleep Intervention for Children With Epilepsy. *Frontiers in Psychology, 12,*(628605), 1-12.	and delivery of an online Behavioural Sleep Intervention (BSI) for parents of children with epilepsy (CWE)	This study had intended to use focus groups but had logistical issues in bringing participants together at the same time.	experiences, change over time, range of management options, personalisation of information, child anxiety around sleep, practical sleep intervention suggestions, general sleep information, parental anxieties and concerns, help, support and reassurance around sleep, include child in intervention.	
3	Hatton, R. E. M. & Gardani, M. (2018). Maternal perceptions of advice on sleep in young children: How, what, and when? *British Journal of Health and Psychology, 23,* 476-495.	Understand how parental knowledge of sleep for children can be improved.	Qualitative Interviews Constructivist grounded theory	Themes relating to how UK mothers wish advice on sleep to be formulated, what they believe it should include and when they would like to receive it, were identified from the data.	This study may not represent the views and experiences of parents from deprived areas in the UK. Fathers are also underrepresented.

4	McLay, L., Hansen, S. G., Carnett, A., France, K. G. & Blampied, N. (2020). Attributions, causal beliefs, and help-seeking behavior of parents of children with autism spectrum disorder and sleep problems. *Autism, 24*(7), 1829-1840.	To gather information about parents' attributions about children's sleep problems and beliefs about causes and on sources of information about and decisions regarding help-seeking.	Quantitative. Online survey.	Parents commonly view sleep problems as a consequence of their child's autism and unlikely to change over time **and** located within the child, stable and difficult to treat. Despite this, parents also viewed sleep issues as important.	Respondents were a largely homogenous group with a lack of variability in demographics.
5	Newton, A. T., Corkum, P. V., Blunden, S. & Reid, G. J. (2021). Influences on help-seeking decisions for behavioral child sleep problems: Why parents do and do not seek help. *Clinical Child Psychology, 26*(1), 207-221.	To identify predictors for sleep problem perception and help-seeking **and** reasons why parents did not seek professional help for children's sleep problems.	Quantitative Online study Nested-logit regression Chi-square	Greater parental socioemotional problems significantly predicted professional help-seeking. Logistical barriers or a sense of not needing help were perceived as the greatest barriers.	The study did not utilise objective measures of child sleep. Participants were self-selecting.

6	Petersen, S., Reddihough, D. S., Lima, S., Harvey, A. & Newall, F. (2021). Barriers and Facilitators to Seeking Sleep Solutions for Children With Cerebral Palsy: A Qualitative Study. *Frontiers in Psychiatry, 12*(729386), 1-9.	The aim of this study was to explore the experience and impact of sleep disturbance and seeking of sleep solutions for parents of school aged children with cerebral palsy (CP).	Qualitative Thematic analysis	Seven themes were identified: My child doesn't fit into the box; A mother's ears are always on; Sleep disturbance is like water torture; sleep is one of many spot fires, I put it on the backburner; luck, money or jumping up and down; there is never one silver bullet; help: the earlier the better. Key finding: Parents of CYP with CP often described their child's needs being distinct from what is provided by systems and services.	Health care system varies from state to state in Australia and so results may not be generalisable. Demographics were also parents from higher than average education and socioeconomic status.

7	Sutton, J. E., Huws, J. C. & Burton, C. R. (2019). Experiences of sleep hygiene education as an intervention for sleep problems in children with developmental disabilities: Findings from an exploratory study. *British Journal of Learning Disabilities, 47,* 165-173.	This exploratory study aimed to enhance qualitative understanding and explore stakeholder perceptions about experience, current practice and ideas around the implementation of Sleep Hygiene Education.	Qualitative: Semi-structured interviews and focus groups Thematic analysis	Four parent themes: beliefs about sleep problems, getting professional help, ways of knowing about sleep, visions of sleep support. Two practitioner themes: sleep serviced accessibility and inconsistent sleep support.	Strengths: broad range of experiences captured including varied representation of sleep consultation, signposting, social care, health and voluntary organisations. Limitation: views of fathers has not been explored.

One paper (Petersen et al., 2021) was part of a longer, three-part study that utilised mixed-methods overall. However, as the part of the study that related to parent views was qualitative, it has been assessed, analysed and critiqued as such. It was a follow-up qualitative phase to a previously published quantitative phase on the experience and impact of sleep problems for children with cerebral palsy (CP). As explained, this has been viewed as an isolated qualitative study because the aforementioned quantitative phase is not being considered within this review.

All articles were empirical. Four out of the 5 qualitative studies were conducted in the UK and 1 in Australia. Both quantitative studies were comprised of populations from Australia, USA and New Zealand or Canada.

The seven articles identified from the literature search were sorted into four groups as shown in Table 7 below. The author organised the studies into those that focused on children with diagnoses and those that focused on children without diagnoses due to how a diagnosis can specifically impact help seeking of parents. Newton et al. (2021) and Sutton et al. (2018) make clear that comorbidities alter the attributions that parents will make to the sleep difficulty. For example, they will often see it as “part and parcel” (page 169, Sutton et al., 2018) of their child’s other difficulties or that the sleep issue is “too interwoven with other problems to be addressed by professionals’ interventions,” (page 217, Newton et al., 2021).

Table 7: Grouping of Studies Included for Review

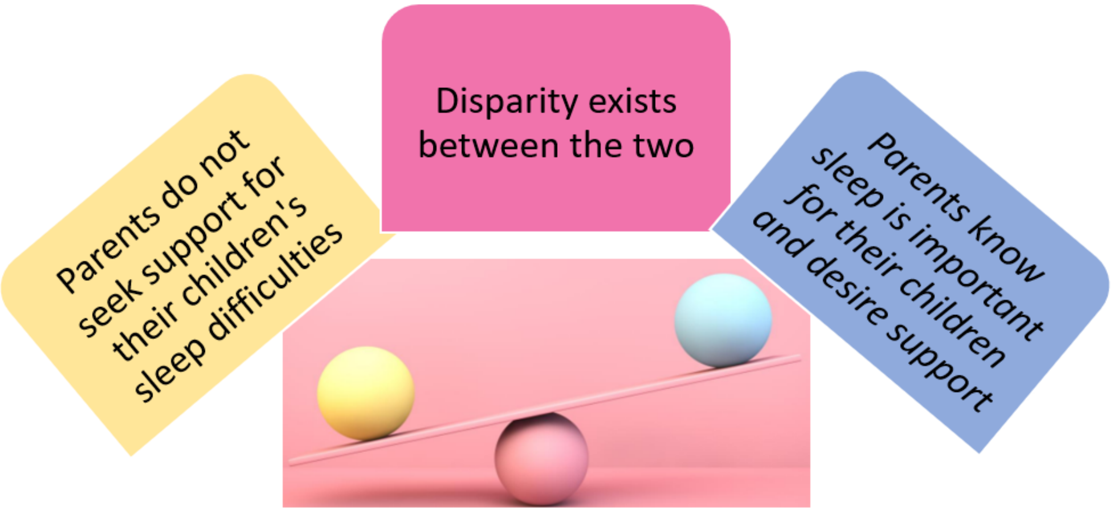
	CYP with no specific diagnoses	**CYP with specific diagnoses**
Quantitative	Newton et al. (2021) – survey	McLay et al. (2020) – survey
Qualitative	Cook et al. (2020) – questionnaire Hatton & Gardani (2018) – interviews	Cook et al. (2021) – interviews Sutton et al. (2019) – Interviews and Focus groups Petersen et al. (2021) – interviews

The studies following a quantitative methodology often had quite a narrow focus, analysing data using statistical methods. In comparison, those with qualitative methodology developed broad themes in response to their focus question. Later in this chapter, a synthesis will be provided of themes across the studies, in order to effectively answer the LRQ.

It is worth noting that EPs are not mentioned in any of the articles discussed. This is curious, particularly in the cases of CYP with specific diagnoses as the difficulties mentioned are those which EPs would typically be supportive of. It is also noteworthy that fathers are significantly under-represented across the data set and are mostly mentioned in relation to the importance of inclusion in future research.

The majority of articles stated their main rationale being that there is little known about why many parents do not seek support for their children's sleep difficulties (Cook et al., 2020), as discussed in Chapter 1, Introduction. A common rationale presented in the literature was the disparity between parents seeing sleep as important and wanting support for this, but not seeking this support (McLay et al., 2020; Cook et al., 2020). Figure 2 below shows a visual representation of the disparity that exists between parental desire for help around children's sleep issues and parental seeking of this support.

Figure 2: Image Depicting a Disparity Displayed across the Literature



No studies commented specifically on the sex of the child in terms of findings. In two studies, the demographics sections show the number of male children, but it is seemingly assumed that the remaining percentage is female, with no consideration given to children who may be transgender or non-binary. The author of the present study is aware that as the children are very young, this is not very likely to be a factor requiring consideration, however it is worth noting the curiosity that male and not female children are mentioned in the statistics.

Sutton et al. (2019) was the only article that sought views of professionals as well as parents. This goes beyond the scope of the LRQ for the present study, but is helpful to gain a more holistic picture of the reasons behind help-seeking behaviours.

A commonly presented limitation of studies was the lack of representation of certain populations and small sample sizes. Qualitative sample sizes ranged from 9 to 19 participants. Quantitative sample sizes ranged from 244 to 407 participants. The self-selection of participants was seen as another potential limitation as those who did not have time or inclination to volunteer to be part of such studies may ironically be those most relevant to include as they may be less likely to seek help.

A notable aspect of this review is the limited available literature, which offers an insight into gaps in research that are further explored later in this chapter. In consideration of future research, McLay et al. (2020) and Newton et al. (2021) explore the idea of longitudinal designs being useful in the future to assess how the changes would provide real support in identifying how the ideas developed may be used and tested to support parents with their help-seeking for their children’s sleep-difficulties.

2.5 Summary of Excluded Literature

A full list of and rationale for excluded literature can be found in Appendix 3. Although unsuitable for inclusion in this systematic review, excluded studies provide some helpful information regarding children's sleep difficulties and the support available for families.

Decisions for exclusion were made based on the inclusion and exclusion criteria (Table 5). The majority of the excluded research focused on the effectiveness of sleep interventions. Some explored the emotional distress around sleep issues and the lack of sleep rather than the support for the difficulties. Other areas explored by the excluded studies were tools to measure sleep difficulties, changes in sleep during COVID-19, association between sleep duration and executive functioning, a comparison of government health-care services for children with sleep problems and the effect of parental separation and socioeconomic status on child sleep quality.

An interesting focus of one study (Lang et al., 2021) was on the caregiver's sleep quality alongside the child's sleep. This is a very interesting consideration that the present study does not focus on in detail, but that is heavily relevant in terms of the potential impact on their views. So, by association, this could be seen as relevant to the LRQ. It was difficult to decide whether this particular study should be included in the review, however it was felt that the author was using too much of their own interpretation on Lang et al.'s (2021) study for it to be directly answering the LRQ. McQuillan et al. (2019) focused their study on parent sleep, associated stress and parenting style, which again could in some ways be supportive of answering the LRQ for the present study. However, within this paper, the parents' sleep issues were so interwoven with the child’s sleep issues that you could not separate the child’s sleep issues and hold them in isolation sufficiently to answer the literature review question.

2.6 Synthesis of the Literature

This review will provide a synthesis of what the included studies present in answer to the LRQ: *What are the views of parents on seeking or accessing support for sleep difficulties?*

2.6.1 Findings from Quantitative Studies

This section will discuss and synthesise the two articles shown in *green* within Table 7 above.

Newton et al. (2021) conducted a quantitative study using an online questionnaire in which parents indicated whether their child had no sleep problem, a mild problem or a moderate-to-severe problem. They completed additional questionnaires on parent and child functioning. Their main findings concluded that around 5% of parents sought professional help for their child's sleep problem. Parents who perceived a sleep problem in their child were more likely to seek professional help if the problem was severe and if they had greater socioemotional problems. Parents who perceived no problem or a mild sleep problem reported not needing professional help as the main reason for not seeking help. Parents who perceived a moderate-to-severe problem reported logistic barriers most often, such as treatment unavailability and cost. The study suggested that parental problem perception around sleep, and help-seeking predictors somewhat reflected their child's general mental health. For example, barriers were often based on problem severity. This may suggest that a range of help-seeking interventions are needed, such as education of what help is available and how to access that help.

Within McLay et al.’s (2020) quantitative study, sleep problems were found to be common among children with autism spectrum disorder (ASD), and without effective intervention, they were unlikely to resolve. A survey was conducted to gather information about how parents made sense of their children's sleep problems, beliefs about their causes, sources of information, and help-seeking behaviour. The analysis of responses from 244 parents revealed that parents commonly viewed sleep problems as a consequence of their child's ASD and unlikely to change over time, and as located within the child, stable over time, and difficult to treat. Despite this, parents also rated sleep problems as being important to treat. 82% of parents surveyed reported seeking some kind of help for their child's sleep disturbance, and the average parent had tried six different treatment strategies, most commonly medical approaches (e.g., melatonin). The alignment between parents' treatment choices and those strategies that are supported by research was poor, but belief in the effectiveness of treatments was closely related to how often the treatment was used. These findings have important implications for parental education and clinical practice in the treatment of sleep problems in children with ASD.

It is interesting that these two studies found substantially different results for the percentage of parents who sought help for their children’s sleep difficulties. This may be influenced by the fact that one study is based on parents of children with a specific diagnosis and one is not. As discussed later in this chapter, a gap in the research is the difference between help-seeking behaviours for children with and without specific diagnoses.

From the use of the quantitative critical analysis tool (appendix 2), it can be seen that methodologically, the study by Newton et al. (2021) can be held in slightly higher confidence. It meets almost all of the criteria set out on the checklist. In contrast, McLay et al. (2020) either did not meet or it was difficult to tell whether the criteria had been met. Considerations for the quantitative methodology were shown to have been made more thoroughly by Newton et al. (2021).

The two quantitative studies support the understanding of the nature of sleep problems, parental beliefs, help seeking behaviours, barriers and treatment approaches. In synthesis of the two studies, the nature of sleep problems is perceived to be intrinsically linked to comorbidity. In the case of these two studies with autism or with socioemotional problems. Parental beliefs about the sleep problem and the likelihood of whether it would change over time was found to impact their help seeking behaviours. If they perceived it as less likely to change over time, this was often a barrier to help seeking. Treatment options taken up were often linked to treatment being sought for the other diagnoses or difficulties that their child was facing. The sleep issue was often seen as a secondary issue, or parental perception of the sleep difficulty was impacted by their perception of the child’s other difficulties or diagnoses.

2.6.2 Key Themes developed from the Qualitative Literature

This section will discuss articles shown in pink within Table 7 above.

Figures 3, 4 and 5 below is used to support explanation of how the author of the current study developed their literature review themes. It depicts the themes or findings that the reviewed studies developed. They are then colour coded to show how the author developed the themes presented in this section to support answer to the LRQ.

Colour coding from the key indicates which themes from the literature helped to develop the themes in the current literature review. It is of note that the colour attached to the themes from the literature does not always directly relate to that theme specifically. It may be a loose connection but has helped to *develop* that theme.

Figure 3: Colour Key for Figures 4 and 5 below

	Key
Colour	**Literature review theme**
🟪	*A range of options*
🟦	*Individualised assessment of sleep difficulties*
🟩	*Knowledge about sleep and sleep difficulties.*
🟨	*What will they think of me?*
⬜	*Specific needs or diagnoses*

Figure 4: Themes or Main Findings from the Literature Linked to Literature Review Themes (Quantitative Studies)

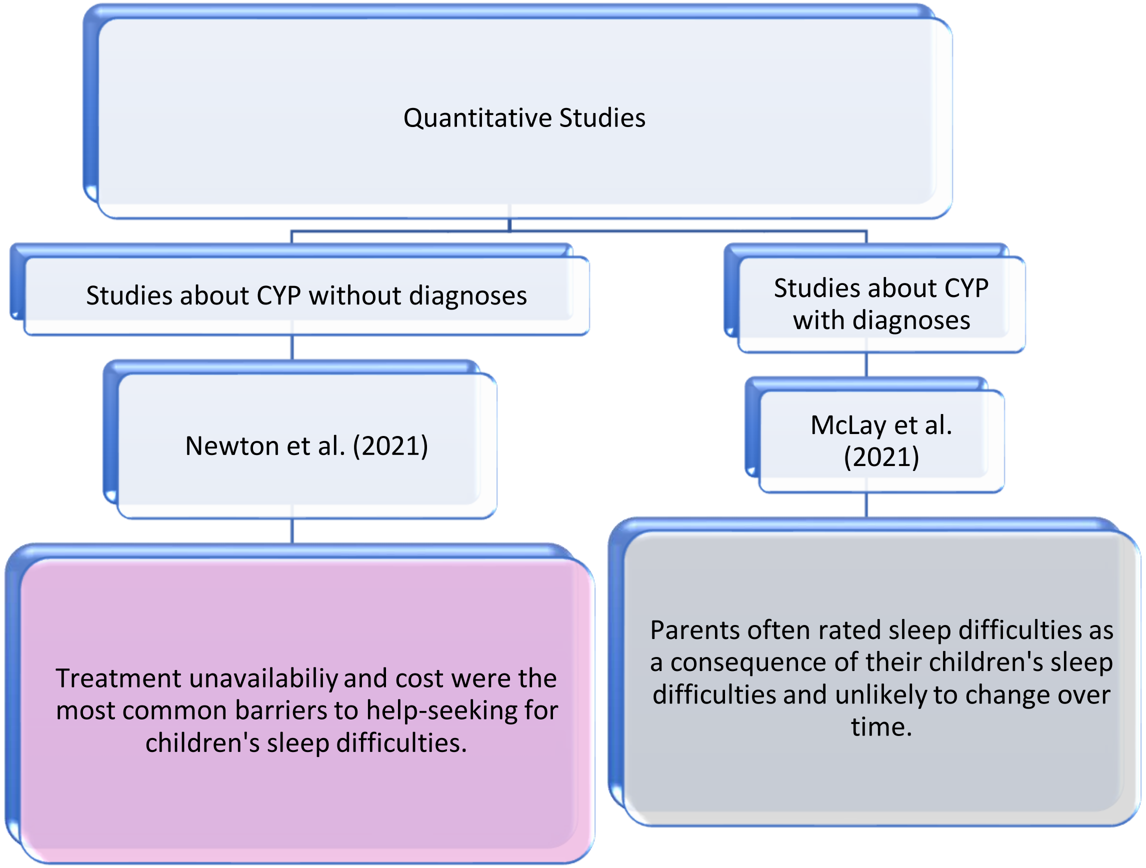
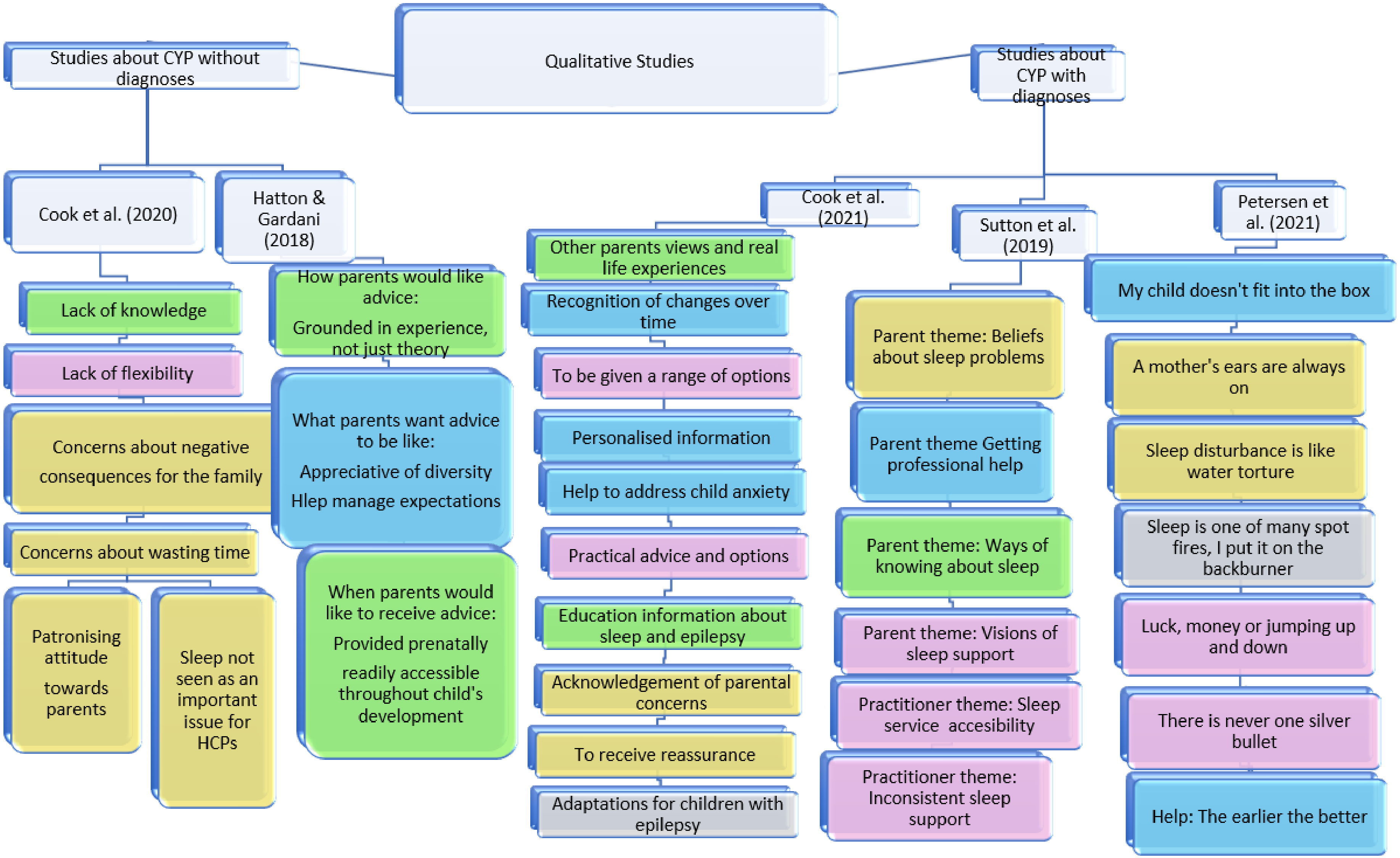


Figure 5: Themes or Main Findings from the Literature Linked to Literature Review Themes (Qualitative Studies)


Qualitative Studies
Studies about CYP without diagnoses
Cook et al. (2020)
Lack of knowledge
Lack of flexibility
Concerns about negative consequences for the family
Concerns about wasting time
Patronising attitude towards parents
Sleep not seen as an important issue for HCPs
Hatton & Gardani (2018)
How parents would like advice: Grounded in experience, not just theory
What parents want advice to be like: Appreciative of diversity Hlep manage expectations
When parents would like to receive advice: Provided prenatally readily accessible throughout child's development
Studies about CYP with diagnoses
Cook et al. (2021)
Other parents views and real life experiences
Recognition of changes over time
To be given a range of options
Personalised information
Help to address child anxiety
Practical advice and options
Education information about sleep and epilepsy
Acknowledgement of parental concerns
To receive reassurance
Adaptations for children with epilepsy
Sutton et al. (2019)
Parent theme: Beliefs about sleep problems
Parent theme Getting professional help
Parent theme: Ways of knowing about sleep
Parent theme: Visions of sleep support
Practitioner theme: Sleep service accesibility
Practitioner theme: Inconsistent sleep support
Petersen et al. (2021)
My child doesn't fit into the box
A mother's ears are always on
Sleep disturbance is like water torture
Sleep is one of many spot fires, I put it on the backburner
Luck, money or jumping up and down
There is never one silver bullet
Help: The earlier the better

Of the five qualitative studies, one used a questionnaire (Cook et al., 2020), four used individual interviews only (Hatton & Gardani, 2018; Cook et al., 2021; Petersen et al., 2021) and one used interviews and focus groups (Sutton et al., 2019).

There is a section later on in this chapter that focuses specifically on studies about children with diagnoses, however the findings from these studies are relevant to the themes presented here in the synthesis, so they are also referred to throughout this section.

A limitation important to mention is that Cook et al. (2020) and Cook et al. (2021) expressed a ‘hope’ that the findings they elicited will support professionals to alter intervention for parents based on what they have found with regards to what parents want. However, they do not describe how they intend to distribute their findings to lead to this desired impact. This requires changes to occur outside of the control of the research. The reader is left wondering how they will follow up or know that what they have found from their study will reach the required people. In both of these studies, author positionality is also not considered.

2.7.1 A range of options

Cook et al. (2021) and Hatton and Gardani (2018) found that parents preferred to have a diverse range of options available, including practical suggestions. This led to them being more likely to seek support for their children’s sleep difficulties. McLay et al. (2020) with their survey analysis also found that having a choice of treatment options suited parents and made it more likely that they would feel positive about sourcing help. Petersen et al. (2021) discussed a core theme that parents feel there really is “never a silver bullet [one solution] to fix things [sleep problems]” (p. 5). They found that parents favoured an individualised approach to supporting their children’s sleep issues.

Newton et al. (2021) gathered the views of parents of children aged 2-10 years around the level of sleep difficulty their child(ren) had. They found that parents often felt that the logistics were not considered when suggestions were made by professionals which often led to difficulties with implementation. This affected attitudes to help-seeking and likelihood of support having a positive or helpful impact. Sutton et al. (2019) within their exploratory study, used focus groups and interviews and drew a theme that parents were influenced by the location in which support was offered. The logistics of attending a clinical setting compared with a home visit in the child’s naturalistic environment was felt to be inappropriate by some parents and impacted ease of access in terms of transportation and time. In their qualitative interview-based study on barriers and facilitators to seeking support for sleep difficulties in children with CP, Petersen et al. (2021) found that a lack of time often led to a necessity for something that will fit in with the time parents had available. They had conducted 19 interviews with parents of children with CP aged 6-12 years. The key finding of this study was that parents of children with CP often described their children’s needs as being distinct from what is provided by systems and services.

Also, in consideration of time, the timing of the sleep support within a child’s development is an important consideration for parents (Hatton & Gardani, 2018). This qualitative study used a grounded theory approach and a constructionist epistemology, intending to produce a compelling and clear depiction of parental views. They drew a thread from their findings around *when* in a child's life would be best to provide support with sleep difficulties. Parents felt that it would be appropriate and supportive for help and advice to be provided prenatally and also throughout a child's life, as it is for many other health considerations. Petersen et al. (2021) also found with their thematic analysis that parents felt early intervention best suited the specific needs required for supporting an area of health most vital for a child's development (Cook et al., 2021).

Cook et al., (2021) carried out nine semi-structured interviews with mothers of children with epilepsy (CWE). Following thematic analysis of the data, a suggestion developed within their findings was for the child themselves to be included in the development of the sleep support. Parents felt that the children themselves would benefit from being a part of the solution as they were the problem-holder. However, this particular study was rated as 'can't tell' for aspects in the CASP on critical analysis as the design was not rigorous and held flaws that may impact the outcome and findings.

Finally, the sleep 'treatment' itself is explored within Sutton et al.'s (2019) study. This study explored parent views on two types of treatment option: pharmacological (medication) and behavioural. Parents often felt that medication was a 'quick-fix' for the sleep issue that professionals would reach for first, without considering the issue itself in-depth. "Parents indicated that this over-simplified children's sleep difficulties, and felt that decisions to introduce medication was rushed and inadequately informed" (p. 170). Use of the CASP found this study had a strong design and so holds gravitas in response to the LRQ around views of parents' help-seeking. This links to the next theme exploring the assessment of children's sleep.

2.7.2 Individualised assessment of sleep difficulties

Each child and their specific sleep difficulties are so different to each other, that parents expressed that it is unhelpful to be provided with generic advice, as it is unlikely to support with the nuances of their child's problems (Sutton et al., 2019; McLay et al., 2020). Sutton et al. (2019) specifically found that parents saw professionals advising or prescribing treatments (often medication) for a sleep difficulty when there had been no assessment of the actual sleep difficulty. This was noted as being unlikely to occur in other areas of health (Hatton & Gardani, 2018), where triage systems are in place to assess needs. Sutton et al. (2019) found that parents often viewed the sleep difficulty as "part and parcel" (p. 169) of the other difficulties that the child had. In the theme 'Visions of sleep support', parents described disappointment at their child's sleep difficulties not being formally assessed before treatment such as medication was offered.

Assessment of sleep difficulties was seen by Cook et al. (2020) and Petersen et al. (2021) as often becoming lost amongst other difficulties compounding at the same time; the individual assessment of sleep did not get prioritised or was not felt important enough to focus on. Petersen et al. (2021) identified a theme 'Sleep is one of many spot fires, I put it on the backburner' showing that parents have so many other things to deal with that sleep issues can often remain untreated. Although sleep issues can fill parents and children with anxiety (Cook et al., 2021) and the difficulties are described as 'torturous' (Petersen et al., 2021), Newton et al.'s (2021) quantitative study found that only around 5% of parents are likely to seek support. One reason for this was that parents considered that sleep issues are something that will in fact get better by themselves (Newton et al., 2021). Hatton & Gardani (2018) explain that it may be beneficial for practitioners to work in collaboration with parents when formulating advice to ensure it is practical based on assessment of the sleep issues.

As mentioned in the first theme, a consideration is raised by Cook et al. (2021) about whether the child themselves should be involved in an assessment of their difficulty and subsequent creation of intervention to support with sleep. The child is likely to understand their own sleep best and it was found that parental attributions to and beliefs about the sleep itself were a determining factor in their view of the support available or offered (McLay et al., 2020). From a number of these articles, it can be seen that the beliefs that parents held about sleep problems influence their likelihood of seeking support. The view they held of the knowledge that professionals would actually have about sleep in children was another very significant factor in their view of seeking and accessing support for their child’s sleep issue. This is further explored in the next theme.

2.7.3 Knowledge about sleep and sleep difficulties.

Cook et al. (2020) received 266 responses to a questionnaire from UK-based parents of children 6-36 months about help-seeking behaviours for sleep-related issues. They used thematic analysis on the data and drew out five themes that parents reported as barriers to seeking help from health care professionals (HCPs). They discuss how parental attitude towards the helper can influence their view of accessing support for sleep difficulties. Parents often wanted professionals to have knowledge about sleep and sleep difficulties to be able to help. It was often felt by parents that this would only be possible if they had direct experience of being a parent themselves and experiencing the issues firsthand.

Sutton et al. (2019) found that parents would often normalise the child’s difficulty so did not see it as something requiring professional help. “…parents commonly talked about becoming accustomed to, or “normalising,” sleep difficulties.” (p. 169). Parents considered what it meant to seek help and expressed that it can feel like a ‘clinical’ action where ‘clinical’ support is not warranted (Sutton et al., 2019). Petersen et al. (2021) also found through their thematic analysis of interviews, that navigating the systems to source the professional who is likely to have the required knowledge can be a challenge.

Sutton et al. (2019) identified that parents believed that professionals often did not know what to do to help them. Furthermore, many felt that their concerns were not taken seriously. Hatton and Gardani (2018) found that parents wanted professionals to have experience in addition to theory, to respond most impactfully and effectively to their child’s sleep issues. Cook et al. (2020) and Cook et al. (2021) drew themes that general sleep information and professional knowledge were seriously lacking in the health sector.

Cook et al. (2020) found that the perception of lack of knowledge can lead some parents to feel that professionals do not care about this area of health. Health and Care Professional (HCP) training includes little about sleep (Cook et al., 2020). If professional training in sleep improved, this may support parents towards being more able to feel confident in and manage their beliefs and attitudes towards the sleep issues (Sutton et al., 2018).

One concerning finding that arose was that parents are accessing or utilizing advice or support that is not evidence-based (McLay et al., 2020; Hatton & Gardani, 2018; Cook et al., 2020) and so may be unsafe or be causing more sleep issues. Researchers faced an ethical dilemma on uncovering this information, as their remit was not to further advise parents on ‘best practice’, but they all had to consider to what extent they would involve themselves in the safety of the children in question.

2.7.4 What will they think of me?

“Many parents felt that seeking help for child sleep would be a waste of time and that, if they raised concerns about child sleep, these would not be taken seriously by HCPs [Health Care Professionals].” (page 518, Cook et al., 2020).

This theme captures the findings of several articles around the negative view that some parents have of seeking help for their children’s sleep difficulties, based on how they think they may be viewed by other people (professionals, friends, family members or other parents), despite the importance they place on sleep. A parent likened sleep deprivation to “a form of torture” (Sutton et al., 2019, p. 169,), showing the devastation it can cause for the parent themselves when the child has trouble with sleep. Yet parents often described not feeling able to request the help they so desire, due to the view they perceive others will have of them (Sutton et al., 2019; Cook et al., 2020; Hatton & Gardani, 2018).

Parents sensed that they may be wasting their own or professionals time by seeking help (Cook et al., 2020). Hatton and Gardani (2018) provided further evidence for this finding and stated that parents often felt the need to manage their own expectations of what might be possible. This attitude and belief led many to halt their efforts of support seeking.

Hatton and Gardani's (2018) study explored parental views of what, how and when support would be helpful for sleep difficulties in children. Through interviews, this study found that parents worry that they may be judged negatively and possibly blamed for their children's sleep issues. Co-sleeping for example is thought to be largely stigmatised in the West and so parents will not talk to health visitors about it. The study explained that it may be better for professionals to teach families about safe co-sleeping rather than to encourage them not to engage in it at all.

2.7.5 Specific needs or diagnoses

Three studies focused on sleep difficulties of CYP with specific needs or diagnoses. Cook et al. (2021), McLay et al. (2020) and Petersen et al. (2021) focused respectively on children with epilepsy, autism and Cerebral Palsy (CP). Discussion of these studies has been weaved in throughout the other themes drawn from this literature review, however this section will look at what is additional to the other themes. The author felt it appropriate to focus here specifically on these three articles. Some key ideas were drawn from these studies around children with specific needs or diagnoses.

Parents in the study by Petersen et al (2021) talked about putting sleep on the 'backburner'. They found they were not placing as much priority on sleep because health difficulties for these children are multiple. In Cook et al.'s (2021) study parents wanted to know more about the relationship between sleep and epilepsy to develop their understanding of the comorbidity their child was experiencing.

Particularly for parents in these studies, generic advice was often felt to be unhelpful. For example, Petersen et al.'s (2021) theme of 'My child doesn't fit into the box' and Cook et al.'s (2021) theme of parents wanting 'personalised information and suggestions for behaviour-change options'. They found that professionals would deem a sleep issue to simply be an 'expected' comorbidity making it hard to isolate or prioritise it as an issue. Parents also found that emotional factors such as being tired, grieving or adjusting to their child's disability diagnosis were barriers to them asking for help.

Sutton et al.'s (2019) study explored parent views on sleep of children with developmental disabilities. This does not focus on children with one specific diagnosis, but the research specifies that it is about children with developmental disabilities which the author of the current study has counted as diagnoses. Their results and findings were not directly related to the developmental disabilities that their children were experiencing, but they do inform policy and practice.

2.8 Summary of the evidence base

'What are the views of parents on seeking or accessing support for sleep difficulties?' was the LRQ posed at the start of this chapter. A review of the available

literature has made it possible to consider several important elements that support the current research enquiry.

The quantitative articles indicated a lack of help-seeking for some children's sleep difficulties (Newton et al., 2021; McLay et al., 2020). However, for children with a specific diagnosis or comorbid issue (e.g., autism and socioemotional difficulties), help-seeking was represented in a higher population.

The qualitative articles showed a number of themes around what can help or hinder parents from seeking support for their children's sleep difficulties.

The groups created by the author of the current study helped to demarcate the findings into different study designs and different populations of children. Therefore it starts to represent the difference in these populations towards the research base.

The themes drawn from this literature review are below:

- A range of options
- Individualised assessment of sleep difficulties
- Knowledge about sleep and sleep difficulties
- What will they think of me?

Articles looking at children with specific diagnoses came up with additional themes including:

- Sleep was not prioritised because there were multiple difficulties
- Generic advice was often found to be unhelpful

- Professionals often deemed a sleep issue an ‘expected’ comorbidity when children had other specific diagnoses and did not isolate it as an issue to support

Selected articles were grouped according to design and inclusion of children with specific diagnoses (Table 7). From findings explored with this review, it can be seen that parents of children with specific diagnoses (notably Cerebral Palsy (CP), epilepsy and autism) find it particularly difficult to seek help due to factors including:

- Sleep issue simply being an ‘expected’ comorbidity making it hard to isolate or prioritise it as an issue
- Emotional factors such as being tired, grieving or adjusting to their child’s disability diagnosis being barriers to them asking for help

In the group of literature around children with no specific diagnoses, a negative view of help-seeking for sleep difficulties is also prevalent. Analysing literature across these two groups supports a holistic indication of a problematic situation in which caregivers need to be supported to access help for this important area of a child’s health and development.

Gaps in the Literature

One area in which there is a clear gap in the research, is what facilitates parents to seek help for their children’s sleep difficulties. The research presented here indicates a significantly negative view of help-seeking, and aims to understand reasons for this. However, there are some parents who *are* seeking support. So it may be a helpful line of future research to speak with parents who are seeking help, to attempt to understand what facilitated them to do so.

The available literature highlights a shortage of quantitative articles which indicates the qualitative nature of the topic area. Having only been able to include seven studies, most of which were conducted within a UK context, this area of research appears underrepresented.

Future research that would address gaps in the literature could include:

- A comparison of parents' views with professionals' views for more information on barriers and facilitators to parent help-seeking.
- Longitudinal designs to assess impact of suggestions to support parents' help-seeking over time.
- Inclusion of fathers and children in help-seeking for sleep difficulties.
- The difference between help-seeking behaviours for children with and without specific diagnoses.

Purpose of this research

No research has yet used a mixed-methods design to explore what parents want and what they have sought with regards to their child(ren)'s sleep difficulties (quantitative); and the considerations parents make when deciding whether to seek or access support for their children's sleep difficulties (qualitative). The aim with this research was to explore what support parents of children aged 3-11 were accessing, or wanted to access, to help with their child's sleep difficulties, alongside gaining an understanding of the facilitators and barriers to seeking help. The intention behind this research was to inform the literature base of what parents want to seek and have already sought in terms of help for their child(ren)'s sleep difficulties, and how best to provide support when it is needed, by answering the following research questions:

- *What support do parents want and what support have parents sought for their children’s sleep difficulties?*
- What do parents consider when deciding whether to seek support for their children’s sleep difficulties?

Chapter 3: Methodology

3.1 Chapter Overview

This chapter’s aim is to outline the methodology that was chosen for the research. It discusses the aims, objectives and research questions and provides the ontological and epistemological positioning of the research. It explains the design and methods of data collection, construction of research tools and data analysis. Justifications and ethical considerations are included.

3.2 Aims, Objectives, Purpose and Research Questions

This research took an exploratory approach. The researcher’s aim was to find out what form of support parents of children aged 3-11 had sought or wanted to access to help with their child’s sleep difficulties, alongside gaining an understanding of the considerations parents made when deciding whether to seeking help. The intention of this research was to address the gaps in the literature around these aims.

Chapter 2 provided discussion of a range of current literature around children’s sleep difficulties. The foci of previous research include but are not limited to:

- Understanding barriers reported by parents to consulting health care professionals (HCPs) about child sleep (Cook et al., 2020).
- Identifying whether there were special considerations for the content and delivery of online Behavioural Sleep Intervention (BSI) for parents of children with epilepsy (CWE), (Cook et al., 2021).
- Understanding how parental knowledge of sleep for children can be improved, (Hatton & Gardani, 2018).

- Gathering information about parent’s attributions about children’s sleep problems and beliefs about causes and on sources of information about and decisions regarding help-seeking, (McLay et al, 2020).
- Identifying predictors for sleep problem perception and help-seeking and reasons why parents did not seek professional help for children’s sleep problems, (Newton et al., 2021).
- Exploring experience and impact of sleep disturbance and seeking of sleep solutions for parents of school aged children with cerebral palsy (CP), (Petersen et al., 2021).
- Enhancing qualitative understanding and exploring stakeholder perceptions about experience, current practice and ideas around the implementation of Sleep Hygiene Education, (Sutton et al., 2019).

There was no specific research found about what kind of support parents feel they would like in relation to their children’s sleep difficulties. Since further investigation and data are seen to be necessary to explore the help seeking behaviours of parents for their children’s sleep difficulties, the research does not intend to offer any clear solutions. However, the research does aim to inform ideas about what may be applied practically to assist professionals working with parents whose children have sleep issues.

Chapters 1 and 2 have highlighted the importance of sleep, the positive impact that parental support has on improving the sleep of children and the challenges faced by parents accessing support. Chapter 2 also highlights the lack of information around parents’ access to support. Therefore, the research questions are:

- *What support do parents want and what support have parents sought for their children's sleep difficulties?*

- *What do parents consider when deciding whether to seek support for their children's sleep difficulties?*

It was hoped that in answering these questions, EPs as a profession would feel more informed towards supporting this important element of children's development.

The information from this study may also be supportive for parents/carers of children struggling with sleep difficulties or other professionals supporting families with children's development.

3.3 Positioning and Orientation

3.3.1 Defining Ontology

Ontology is driven by the question 'what is there to know?' (Willig, 2013, p. 61) and is concerned with what a researcher believes about the nature of reality, namely, what actually exists (Al-Saadi, 2014). When formulating a research question, there will be assumptions being made about what reality is, and this is the ontological perspective of the researcher. The research questions play a vital role in determination of the ontology being used. In the present study, the research questions are around parents' 'help-seeking' behaviours for their children's sleep difficulties. This assumes that there is such a thing as a 'sleep difficulty' and that children can have these 'sleep difficulties'.

A realist ontology determines that true knowledge is attainable and must be obtained with the research. It presumes that this truth exists independently of the researcher's or participants' views (Willig, 2013). Realism is at one end of the continuum of ontology and is sometimes seen as a naïve perspective (Willig, 2013). With realism there is deemed to be only one truth that is accessible by appropriate research techniques (Braun and Clarke, 2013). Realism often sits well with purely quantitative research.

Critical realism proposes that data obtained from research would need to be analysed before 'truth' or 'knowledge' can be extracted and presented (Willig, 2013). It would include more of a process of interpretation than with realism. Critical realism advocates that reality is socially constructed and social concepts that are created will mean different things to different people (Willig, 2013). In the present study, the children's sleep difficulties that the researcher will be talking to parents about are true for them, in their own interpretation of those difficulties. This speaks to a critical realist ontology as the knowledge is true to the participant and no-one else.

Relativism rejects the idea that there is a concept of truth or knowledge. This can be seen as quite a radical position and posits that knowledge does not exist in itself, but must be constructions of different versions of an experience that can be uncovered by the exploration undertaken during research (Willig, 2013). Braun and Clarke (2013) posit that with a relativist ontology, there are multiple realities of which all individuals have their own, and all are 'real' to the holder of that reality.

3.3.2 The Present Study: Ontology

This study adopted a critical realist ontology. With critical realism, a defined truth is not accepted, but the views of participants are collected with the understanding that they will not all align to one another. This negates the possibility of one known truth as with realism. However, it accepts that to each individual, their own truth is spoken, opposing relativism which states that there is no absolute truth. It is the researcher's view that participants will each have their own lived reality, and that reality exists, but that access to it is mediated by socio-cultural meanings and interpretations (Willig and Rogers, 2017).

3.3.3 Defining Epistemology

Epistemology addresses the question of what is possible to know (Braun & Clarke, 2013). It is concerned with what is legitimate knowledge, what counts as 'true' and 'real'. As with ontological perspectives, there is a spectrum of epistemological positions that can be taken when approaching research. A selection will be discussed here and there are further epistemologies for which discussion can be found in a vast array of literature. Epistemology is about the nature between the knower and the known (Mertens, 2020).

Positivism is the epistemology most aligned with realism. It posits that knowledge that can be obtained is limited to that which can be observed (Mertens, 2020). Positivists hold that it is the researcher's job to discover the one reality that exists (Guba & Lincoln, 1994). Early positivist thinking also saw the researcher and participants as separate entities. This sits in contrast with critical realist epistemology.

A critical realist epistemology argues that interpretation of experience is constructed rather than determined (Willig, 2013). It posits that data would need to be interpreted to determine what it is telling us rather than taken at face value. Thus, it sits well within a mixed-methods approach in which two forms of data (qualitative and quantitative) are being taken together to provide a richer assessment in answer to the research question(s) being posed.

The final epistemological positions to be discussed here, are social constructionism and social constructivism. They fit well with a relativist ontology as they determine that knowledge is found by construction of reality by either groups or individuals, respectively. Willig (2013) explains that within this positionality of how knowledge is gained, the human experience is mediated culturally, historically and linguistically. What we perceive, is only our reading of the environmental conditions. It proposes that there are multiple knowledges rather than just one knowledge.

3.3.4 The Present Study: Epistemology

A critical realist epistemology was used in line with critical realist ontology. Fletcher (2017) explains how this orientation uses existing knowledge combined with a critical engagement with participants views and knowledge. The researcher maintained an open-minded approach when meeting with parent participants for interview. It was the intention of this research that application provided interpretation, as opposed to truth. The intention was not to provide claim to a defined truth.

3.3.5 Critical Realism and the Research Questions

Phase one answered the research question:

- *What support do parents want and what support have parents sought for their children's sleep difficulties?*

and phase 2 answered the research question:

- *What do parents consider when deciding whether to seek support for their children's sleep difficulties?*

The critical realist position taken by the researcher can be justified by the consideration that it is not possible for there to be just one reality for how parents perceive their children's sleep difficulties. It has to be a construction of reality determined by the parents themselves. This will have come from a number of factors surrounding the context of the family at the time of the research project being carried out. Sleep itself is a phenomenon that all mammals, including humans need to survive, which leads the researcher away from a solely relativist ontology and social constructionist or constructivist epistemology, because the understanding that all humans need to sleep, has been biologically proven. The mixed-methods approach seeks both 'factual information' such as actual support sought as well as perceptions of support seeking (perspectives on 'reality').

3.4 Researcher Positionality

The researcher is always implicated in the research process in one way or another (Willig, 2013). It is therefore important to consider the researcher's reflections about themselves when considering the positionality of the present study. The researcher of the present study ensured they considered their own views of elements of the study before undertaking the research. These included:

- Emotional connection to thinking about the importance of sleep
- Their own experience of difficulties with sleep
- Their own current experience of sleep
- Their experiences of children who experience sleep difficulties

Within the work around researcher reflexivity in Chapter 1, the researcher has reflected on these areas and proceeded to hold these in mind for the duration of the research.

It is important for researchers to consider their own view of the world and position within the world when embarking on the analysis of others' views. Willig (2013) describes how consideration must be given to the combination of researcher analysis, positionality, research question and how they interact and impact upon each other. It is important to remember that the position of the researcher is not fixed by how they have chosen to analyse the data (Willig, 2013).

3.5 Research Design

Within this section, the author takes the reader through the detail and rationale for the research design selected for this research.

3.5.1 Design Overview

The researcher used a 'mixed-methods', concurrent, exploratory design for this study. This section will be split into two parts:

- Phase 1: Quantitative

- Phase 2: Qualitative

This is a thematic study that uses reflexive thematic analysis with the qualitative data, which makes this a big Q study as described by Braun and Clarke (2021). As defined by Creswell (2015), ‘mixed-methods’ is a research design in its own right that combines qualitative and quantitative approaches in a complimentary way to provide richer, fuller data.

3.5.2 Rationale for mixed-methods

A ‘mixed-methods’ design was used to allow a richer set of data to be gathered. With qualitative alone there would not have been a chance for such a wide sample. In addition, conducting semi-structured interviews following the questionnaire phase gave participants more time to consider the subject and express their opinions, increasing the possibility that responses would be more thoughtful as a result.

The mixing of methods in this study does not involve triangulating data or connecting the two sets of analysis. The author of the current study has asked two separate RQs with this research. The reason for this was to be able to answer a broader range of questions rather than to answer just one question in more depth.

Dawadi et al. (2021) explain that quantitative research allows a researcher to explore in great *breadth* by asking a large population; whereas qualitative allows the researcher to go into more *depth*. Using mixed-methods allows the two to work in combination to gain the most helpful aspects of both.

Mixed-methods is also helpful by adding to trustworthiness of construction of reality. Due to a wide sample, quantitative typically allows more validity, reliability and replicability whereas qualitative is more about trustworthiness of data as participants have been interacted with directly. With mixed-methods, again, both in combination create a stronger overall design. Coolican (2014) describes the qualitative-quantitative dimension as a “fundamental division within the theory of methods in contemporary psychological research” (p. 32). He explains that within mixed-methods research, the two methods are complementary rather than conflicting. It is important to ensure you are focusing on the appropriate method for the research question in mind; quantitative and qualitative will each be answering a different research question. Castro et al. (2010) explain that the purpose of using both methods together, is to define the relationships more accurately among the variables being analysed.

The author is aware of some unavoidable negatives of mixed-methods and these are presented below. It can lead to complicated data analysis and, when there are conflicting results, it can be hard to reconcile the quantitative and qualitative data. There is a need for expertise and for the researcher to be well-versed in both quantitative and qualitative research methods for mixed-methods research to be effective. The researcher also needs to know how to avoid the major challenges of the design. While mixed-methods research can provide more in-depth findings and stronger evidence, it is important to consider these potential drawbacks when deciding whether to use this approach.

3.5.3 Nested Concurrent Mixed-methods

Nested concurrent research is a mixed-methods research design that involves collecting and analysing both quantitative and qualitative data simultaneously. The term "nested" refers to the fact that one type of data is nested within the other, meaning that one type of data is collected within the context of the other. For example, semi-structured interviews may be nested within a survey or census, with respondents selected for interviews based on their responses to the survey questions, (Schatz, 2012).

Within the present study, the questionnaire issued with the first phase was used to answer a RQ, but also to gather participants for phase 2 of the study. Analysis of the first phase was however not required to inform the analysis of the second phase as they were answering different RQs. Therefore, the qualitative phase is nested within the quantitative. They are concurrent as the quantitative phase does not need to be complete before the qualitative begins. They took place at the same time and the researcher began interviews as soon as respondents volunteered to participate.

3.5.4 Phase 1: Quantitative

The first phase of this study was quantitative and was initiated with the dissemination of a questionnaire.

3.5.4.1 Research Question for Phase 1 (Quantitative)

What support do parents want and what support have parents sought for their children’s sleep difficulties?

3.5.4.2 Questionnaire Construction

Using the BRUSO model (‘brief’, ‘relevant’, ‘unambiguous’, ‘specific’ and ‘objective’ [Peterson, 2000]), the researcher developed the questionnaire. Effective survey questions are succinct and direct. Long, highly technical, or superfluous terms were avoided. As a result, the hope was that they would be simpler for respondents to comprehend and take less time to complete. The aim of the questionnaire was to gain insight into what kind of help parents would like and have sought for their children’s sleep difficulties. It was also via the questionnaire that participants could volunteer for the interview about their child’s sleep difficulties. ‘Google Forms’ was used to create the questionnaire and the link was sent to schools via email with the quantitative information sheet (Appendix 5). The length of the questionnaire needed to be taken into consideration. If it were too long, it was likely that the sample size would have been small. If it were too short, insufficient information would have been gathered.

3.5.4.3 Rationale for Online Questionnaire

The RQ that the researcher wanted to answer with the quantitative phase of the study meant that only a very few questions needed to be included. A questionnaire was therefore suitable and practical. More specifically, the use of an *online* questionnaire also allowed a wide sample to be taken in an accessible way. This supported the ethical aim of the researcher for their placement LA in which the survey was initially sent out. The LA contained a very diverse population of cultures, some of whom have English as an additional language. If the survey needed to be translated by the school disseminating it, the small number of questions would have made it more straightforward.

The researcher asked schools to consider families with English as an additional language and to translate the questionnaire in the same way they would for any other communications. Given that the questionnaire was on Google Forms, the researcher anticipated that the school would need to download the questions to send through to the families once translated into the relevant language. The questionnaire going through the school meant that parents were more likely to trust it than if it had come straight to their own email address. The reason for this is that parents are more likely to trust an organisation that they have already received communications from. In the case of schools, parents may already be receiving communications from them and have established a level of trust. Finally, online questionnaires are one of the most time efficient methods of gathering data from a large sample (Robson, 2002). This also increases the likelihood of participation. A limitation that the author is aware of is the choice not to use a range of sampling methods. The choice to send to all schools in the country was made to account for this limitation.

3.5.4.4 Participant Recruitment and Sampling

The researcher chose to ask parents of children with sleep difficulties to complete an online questionnaire and then volunteer themselves to be interviewed. Parents were originally contacted from 58 mainstream, publicly funded primary schools in the LA where the researcher was on placement. Specialist schools were omitted because the researcher did not want to increase the likelihood of comorbidity or other diagnoses. It was likely to be more possible to compare data from children within mainstream schools. Independent or privately funded schools were omitted due to consideration that they may have more access to support for sleep (and other) difficulties than publicly funded schools.

It was considered that not all potential participants may have access to the internet or a device to easily access an online questionnaire. The researcher requested schools to provide internet access to families who wished to participate but were unable to do so due to their situation. The purpose of this request was to ensure that all families had equal access to the study.

As many parents as possible were required for the questionnaire element of the design due to quantitative analysis requiring a larger sample for validity and reliability of results. Very few responses were received from the questionnaire being sent via schools in the Local Authority. In order to increase the number of survey responses, ethical approval was sought to widen the age range and geographical area for participant recruitment. An excel spreadsheet with contact emails for schools across the UK was obtained from a publicly available government website (Get Information About School services) as part of the Freedom of Information Act (2000). The author used the blind carbon copy (BCC) email function to email the survey to all schools and provided their email address for any follow up support required. This list contained email contact details for 24,869 primary schools across England which the author sent the questionnaire out to.

In the online questionnaire, participants were asked if they would be willing to consider being interviewed. If they were, they were asked to share their email address and were sent the Phase 2 information sheets (Appendix 7) and consent

form (Appendix 8). The questionnaire was completed anonymously and participants were only asked for contact details if they wanted to be interviewed.
Schools across the country did not have chance to be involved in interview.
Researcher already had enough by time this was sent out.

3.5.4.5 Data Collection

An online questionnaire was initially sent via email to SENCos and Head Teachers of all primary schools in the researcher's placement borough. An information sheet and advertising poster were sent with the link to the questionnaire. There was also the option for all schools to contact the researcher to ask any further questions. Due to the low rate of participants gathered, the questionnaire was then sent to primary schools across England. Schools were sent an email with an information sheet advertising the research to ask for the questionnaire link to be disseminated to parents. The Phase 1 consent form (Appendix 6) was incorporated into the online survey and participation in the survey was restricted to only those who consented.

3.5.4.6 Data Analysis

The data from the quantitative element of the research was analysed using descriptive statistics and content analysis. Descriptive statistics are used to summarise raw data from a sample population (Kaur et al., 2018). They are summaries of gathered data where the sample statistics usually include a measure of central tendency and a measure of dispersion (Coolican, 2014).

Kaur et al. (2018) also explain that descriptive statistical analysis is a prerequisite to using inferential statistics to draw conclusions from the data. In this study, as it is exploratory, descriptive statistics and content analysis were enough to summarise the data gathered from the quantitative element.

A summative content analysis involves counting and comparisons, usually of keywords or content, followed by the interpretation of the underlying context. The analysis is inductive, meaning the data has driven the analysis, (Hsieh & Shannon, 2005).

Relative frequency of occurrence of answers will be reported because this ensures consideration is made for the total data gathered as well as the number who represent a certain answer.

3.5.5 Phase 2: Qualitative

3.5.5.1 Research Question for Phase 2: Qualitative

What do parents consider when deciding whether to seek support for their children's sleep difficulties?

3.5.5.2 Interview schedule construction

The researcher developed the questions for the semi-structured interview guide based on advice from Adams (2015). He lays out six steps for how to draft questions in the guide. The following six points are adapted from Adams, 2015, pg. 496.

1. Ensure you have enough time to draft, edit and pre-test the guide.
2. Prioritise the issues to be discussed in the interview. Ensure questions pertaining to the highest priorities are in bold. Lower tiers of questions to be asked if time allows. Remove questions asking for simple facts that could be gathered beforehand.

3. Closed-ended questions can be ideal gateways to open-ended probing. The question of ‘why’ can always be added after asking a closed ‘yes or no’ question. With closed questions the summary analysis will have some clear quantitative points of reference.
4. In all cases, but particularly when participants have English as an additional language, use plain, jargon-free vocabulary and make adjustments to wording where necessary.
5. Consider whether draft questions may evoke pressure to give socially acceptable answers. Assurances should be given throughout to remove any stigma that participants may attribute to certain questions or answers.
6. When drafting the question order in the guide, try to consider the smoothest sequence. However, remember that it is fine if the order changes based on how the interview runs.

3.5.5.3 Rationale for semi-structured interviews

Within a semi-structured interview, the researcher has a schedule of questions that they may follow for some structure to be followed. However, the set up will take more of a conversational tone as opposed to a fully structured set up.

The researcher of the present study considered that semi-structured interviews would be the most advantageous choice of data gathering for the qualitative element of the design as they elicit significant and rich data due to a number of advantages. Coolican (2014) explains some of the reasons why this is an extremely popular form of interviewing. It retains advantages of maintaining an informal procedure as it does not ask pre-set questions in exactly the same order each time. An informal procedure is likely to allow both interviewer and interviewee to relax into the conversation allowing a more free-flowing stream of speech hopefully bringing richer data. The interviewer uses an outline of topics as a guide to obtain required information. The guide usually leaves the interviewer to decide, on the day, how to work in and phrase questions on the various topics. Coolican discusses some advantages:

- There is a relatively natural flow of talk
- The respondent has freedom to explore unpredicted avenues of thought
- The interviewer has flexibility to select aspects of the discourse to follow up

A further consideration raised by Coolican (2014) is the demand that semi-structured interviews can place on both interviewer and interviewee. Many researchers have found themselves with many questions remaining following an interview, because the semi-structured interview does not allow for a ‘conversational’ style, but more a ‘prober’ (interviewer) and ‘producer’ (interviewee) of information. One of the ways in which the researcher of the present study managed this was to consider what information was perceived to be ‘missing’ following an interview and reword questions between interviews (Robson & McCarten, 2016).

3.5.5.4 Participants and Sampling

In the online questionnaire, participants were asked if they would be willing to consider being interviewed. If they were, they were asked to share their email address and were sent the Phase 2 information sheets (Appendix 7) and consent form (Appendix 8).

The aim was to interview up to a maximum of 8 parents from those who responded to the option for a follow up interview. This was the maximum number that could be accommodated in the time frames for the doctoral research.

Seven parents responded to the option to be interviewed. Three of those did not continue with correspondence. However, four parents did continue with correspondence and were interviewed using a semi-structured interview schedule (see Appendix 9).

3.5.5.5 Data collection

Interviews were a maximum of an hour in length. All interviews were recorded using audio equipment and then transcribed using the support of Otter AI software.

Interviewees were given the choice of being interviewed in the school their child attends or online via Zoom. The decision was taken to ensure the researcher could recruit participants and that no one was left without an option of participating due to access issues. It was also considered that giving this autonomy to participants may support them to feel most comfortable in their surroundings and then enable the richest data to be gathered. However, if the participant was outside of a suitable geographical area for the researcher to access in-person, the parent would be asked to meet online for the interview. Three interviews were held online and one took place in school. These were all the choice of the interviewees.

Willig (2013) encourages interviewers and researchers to consider the impact of their social identities on the interviewee. This may encourage a participant to more openly provide information and will support the interviewer to maximise their understanding of the information being communicated. Willig encourages researchers to familiarise themselves with the cultural milieu of the interviewee to ensure they are aware of how they may react to what is being asked within the interview. Variability in linguistic understanding may result in the same term holding a different meaning for each participant. During interviews the researcher held this in mind and asked participants what their understanding of key terms were as they were mentioned (e.g., sleep difficulty, sleep hygiene, help-seeking, etc.)

3.5.5.6 Data Analysis

The qualitative data generated from interviews was analysed using reflexive thematic analysis (Braun & Clarke, 2006; 2021). Interview transcripts were searched for themes. Once themes were identified across interviews, they were grouped and evaluated. Patterns and commonalities were then identified and reported to present the findings. Braun and Clarke's six-step model provided a systematic approach to analyse the qualitative data, as shown below:

1. Familiarisation: The researcher becomes familiar with the data by reading and re-reading it.

2. Coding: The researcher identifies meaningful units of data and codes them by assigning labels or tags.

3. Generating themes: The researcher identifies patterns and themes in the coded data.

4. Reviewing themes: The researcher reviews and refines the themes to ensure they accurately reflect the data.

5. Defining and naming themes: The researcher defines and names the themes to create a clear and concise summary of the data.

6. Writing up: The researcher writes up the analysis, including a description of the research question, the data collection process, the analysis process, and the results.

MaxQDA is a computer-assisted qualitative data analysis software that was used in the reflexive thematic analysis of the qualitative data gathered.

3.6 Reliability and Validity

Lincoln and Guba's (1994) reliability framework is a set of evaluative criteria for assessing the trustworthiness of qualitative research studies. As this is a mixed-methods study, the credibility also needs to be examined. The author will now go through each of the four elements that Lincoln and Guba’s framework consists of and how the author considered these.

How I feel my views may have influenced the findings and how did I protect against that? Initially I paid a lot of attention to those views which aligned with my own. This meant that the value I placed on certain comments was skewed. Then through supervision and sharing maxQDA coding with supervisor, I addressed biases.

Criteria	**Explanation**	**Researcher's consideration**
Credibility	This addresses whether the findings and judgments made by the researcher can be trusted and the extent to which they are believable	Supervision and the use of a research diary throughout supported the researcher to meet this criterion
Dependability	This refers to the stability and consistency of the research findings over time and across different researchers	The author is aware that dependability is difficulty to account for with this research due to its small scale. However, triangulation is used with the current literature base and by using a mixed-methods approach to attempt to meet this criterion
Confirmability	This refers to the extent to which the findings are shaped by the researcher's biases and values, rather than the data itself	Researcher reflexivity is commented on within this work to support with this criterion
Transferability	This refers to the extent to which the findings can be applied to other contexts or settings	The researcher sent the questionnaire to primary schools across England to gain a wide participant sample. However, again due to the small scale of this research, the researcher acknowledges that the findings are not able to be widely transferred

Lincoln and Guba (1994) argue that sustaining the trustworthiness of a research report involves examining the validity structure of qualitative research. The framework can complement quantitative research on social protection and facilitate credible and reliable research outcomes in research on improving social protection policy and practice.

Add more about reliability, validity and trustworthiness for the quantitative data. This research design was a big qual and a small quant.

3.7 Ethical Considerations

Ethical approval was received from the Tavistock and Portman NHS foundation Trust (see Appendices 10-14). The British Psychological Society (BPS) Code of Ethics and Conduct (2018) as well as the BPS Code of Human Research Ethics (2021) were abided by throughout this process. Consent was received from participants through consent forms. They were also provided with an information sheet for both parts of the research (questionnaire and interview) to ensure that participants were making an informed decision to take part in the research. Participants were reminded of their right to withdraw throughout and that any information they provided would be kept as confidential as possible unless the researcher was concerned for anyone's safety. It was explained within information sheets that participants' data would be kept for a maximum of 10 years. Efforts were made to keep information anonymous such as ensuring no identifiable information was present. This was also achieved through using pseudonyms and removing information such as school name and location. Participants were verbally debriefed and a debrief sheet (Appendix 16) was provided, containing information on what happens following their involvement and where they can get support.

The following sections consider the areas laid out in the British Psychological Society (BPS) Code of Human Research Ethics that are relevant to this study.

- Consent: Have participants given informed consent? If the participant is under 16 years old, has informed consent been given by their parents or carers?
- Deception: Have the participants been deceived? If so, was the deception necessary and proportionate to the research aims?
- Debriefing: Have participants been fully debriefed after the study?
- Confidentiality: How will participants' data be stored and used?
- Risk: What are the potential risks to participants and how will they be minimized?
- Research with vulnerable populations: What additional safeguards are needed when conducting research with vulnerable populations

Informed consent was ensured by information sheets being provided for all participants of the questionnaire and the interviews.

Following the interviews, the participants received a debrief information sheet. As well as thanking them for their contribution to the study, it signposted possible avenues to take if they felt any emotional distress, including appropriate support services for sleep difficulties in the local area for the participant. This was personalised to the individual if specific difficulties were discussed that the researcher felt they could extract supportive information for.

The questionnaire and interview schedule were designed to be as accessible as possible. They were jargon free and used plain English. There may have been parents accessing the survey who had English as an additional language (EAL) and/or struggle with understanding written or spoken English. For these parents, schools were asked to support them to access the survey using the methods they use to support access to school-based communication.

Interpreting services were offered for any parents who required this, but this was not needed for the four participants who took part in the interviews.

3.6.1 Potential benefits to participants

The researcher's hope was that there may be a positive impact on parents having had an opportunity to share something that had been causing some difficulty or concern with a researcher who intends to influence change in relation to provision of support. Participants may have also benefited from knowing they were contributing to something that could positively impact others. The debriefing sheets also signposted support services that are available.

3.6.2 Potential participant distress

If participants became distressed or concerned during the interviews the researcher was sensitive to the feelings displayed and reminded them of their right to withdraw or take a break if they would like to. The researcher was ready to end the interview in the event of the interviewee showing signs of distress that were not resolved through taking a break, ensuring the participant knew how to access support following the interview. This was not required for the four parents interviewed.

All parents interviewed were given a list of services they could access for support following the interview if needed. The participants also had the researcher's contact details and were reminded that they could contact the researcher if they had any concerns.

3.7 Chapter Summary

This chapter has outlined the method and design used by the researcher for this study. It includes explanations of what, how and why the author carried out the research and awareness of limitations that the design presents. The author has outlined how they attempted to overcome these limitations and also included strengths and rationale throughout. With the following chapter, the author presents the results and findings that were developed from the research.

Chapter 4: Results and Findings

4.1 Chapter Overview

This chapter presents the results and findings obtained from the procedures described in Chapter Three: Methodology.

The quantitative phase answered the research question:

- *What support do parents want and what support have parents sought for their children's sleep difficulties?*

The qualitative phase answered the research question:

- *What do parents consider when deciding whether to seek support for their children's sleep difficulties?*

4.2 Phase One: Quantitative Results

4.2.1 Introduction

Phase one of the study explored what support parents want and what help they have sought for sleep difficulties in children aged 3-11 across the population of England. Results are presented in this chapter with the use of descriptive statistics and content analysis.

4.2.2 Closed Questions: Descriptive Statistics

Information gathered	**Number of Respondents**
Opened the questionnaire	428
Answered yes to all consent questions	416
Child has difficulty with sleep	251
Would like to access support for child's sleep difficulties	207
Have previously sought support for children's sleep difficulties	112

4.2.3 Open Questions: Content Analysis

Content analysis was used to analyse responses to the open question "What type of support would you like to access?" and responses to the request to "Please provide brief details of the support [for your child's sleep difficulty] that you sought." Data from the open questions was read and re-read before codes were extracted, tallied and then categorised into groups.

The first open question '**What type of support would parents like to access?'** was intentionally ambiguous to elicit a richness of data. The responses from the 207 parents who gave information about support they would like were organised into categories based on *how* parents would like support provided or *who* they might like to provide that support; *what* they would like help with and *when* they would really like support for a specific age group or for different stages of their child's life. The *'who'* section was at times somewhat vague such as *'trained sleep professional',* which suggests a level of uncertainty for who it is that would be most supportive of the needs to be met. Tables 8 and 9 show codes comprising each category, the frequency of statements relating to each code and quotes to illustrate the details.

There may be multiple responses from each parent so the numbers will not match up with the number of parents who responded.

Table 8: Content Analysis for the Question 'What type of support would you like to access?'

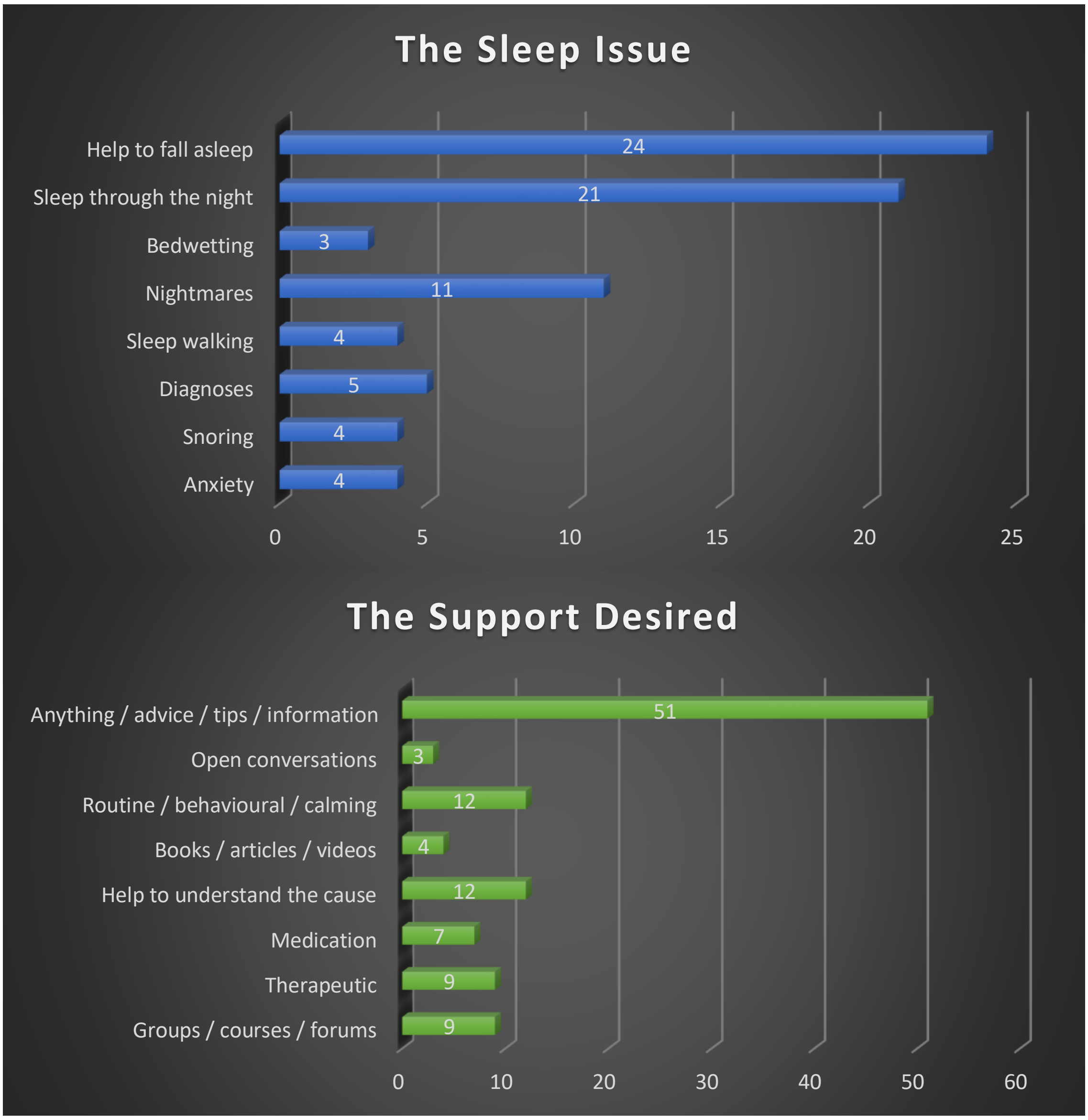
Category	**Sub-category**	**Description**	**Codes**	**Tally**	**Percentage of tally total**	**Quotes**
What	The Sleep Issue	This category covers the codes indicating what specific difficulty with sleep parents stated that they would like support for.	Anxiety	4	1.7%	Behaviour support and advice relating to overthinking at bedtime and anxiety. My Daughter struggles to go to sleep every night for a long time now. Maybe some advice on how to resolve this. Even though it feels as if we have tried everything. Rolling in their sleep. Child will roll their head and bang their head against the side of the bed (high sleeper) and sometimes parent gets woken up by head banging and goes in and child is rolling side to side in deep sleep. Help on why and what I can do, How to help deaf children to settle back to sleep independently also how to support children with ADHD to stay asleep.
			Snoring	4	1.7%	
			Diagnoses	5	2.2%	
			Sleep walking	4	1.7%	
			Nightmares	11	5%	
			Bedwetting	3	1.3%	
			Sleep through the night	21	9.4%	
			Help to fall asleep	24	10.7%	
	The Support	The type of support that participants would like is demonstrated by this category.	Groups / courses / forums	9	4%	Sleep groups with parents in similar situations. I don't feel it needs GP input. Just to be able to have open and honest conversations with others about this Counselling support for my child
			Therapeutic	9	4.1%	

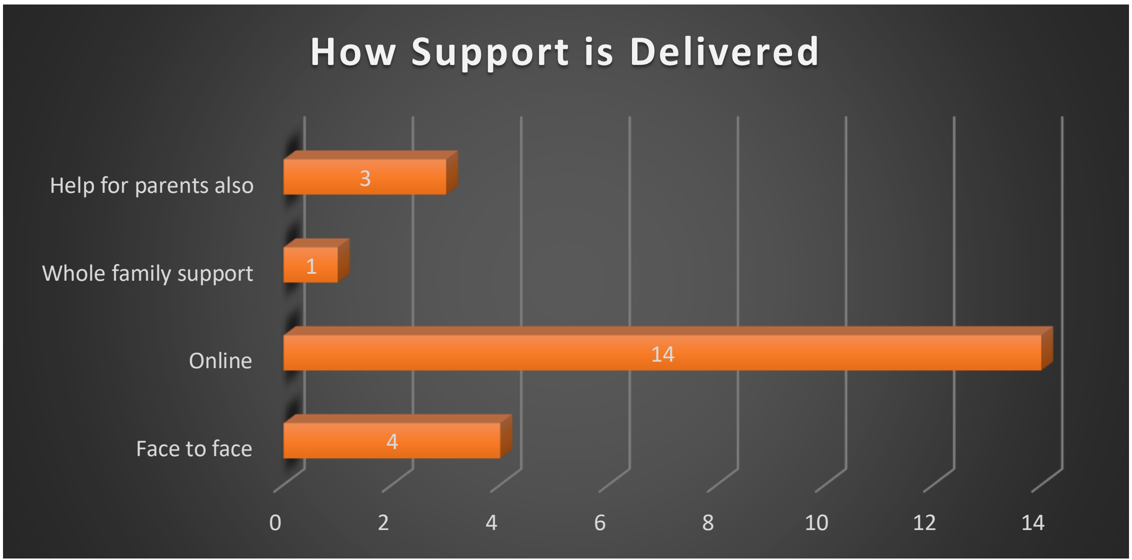
			Medication	7	3.1%	Help in understanding why my child has night terrors and how to prevent them. Help understanding why my child has difficulties sleeping and strategies… Someone to listen instead of saying it’s because of their age and are able to help even if it means that they have medication to help them sleep Articles, videos
			Help to understand the cause	12	5.4%	
			Books / articles / videos	4	1.7%	
			Routine / behavioural support / calming techniques	12	5.4%	
			Open conversations	3	1.3%	
			Advice / tips / information Many said ‘anything’	51	23%	
Who and how	How support is delivered	The method used for supporting was specified by parents within this category.	Face to face	4	1.7%	Face to face with telephone follow up
			Online	14	6.3%	Online information
			Whole family support	1	0.4%	More understanding of the knock on effect to the whole family when a child has sleep difficulties

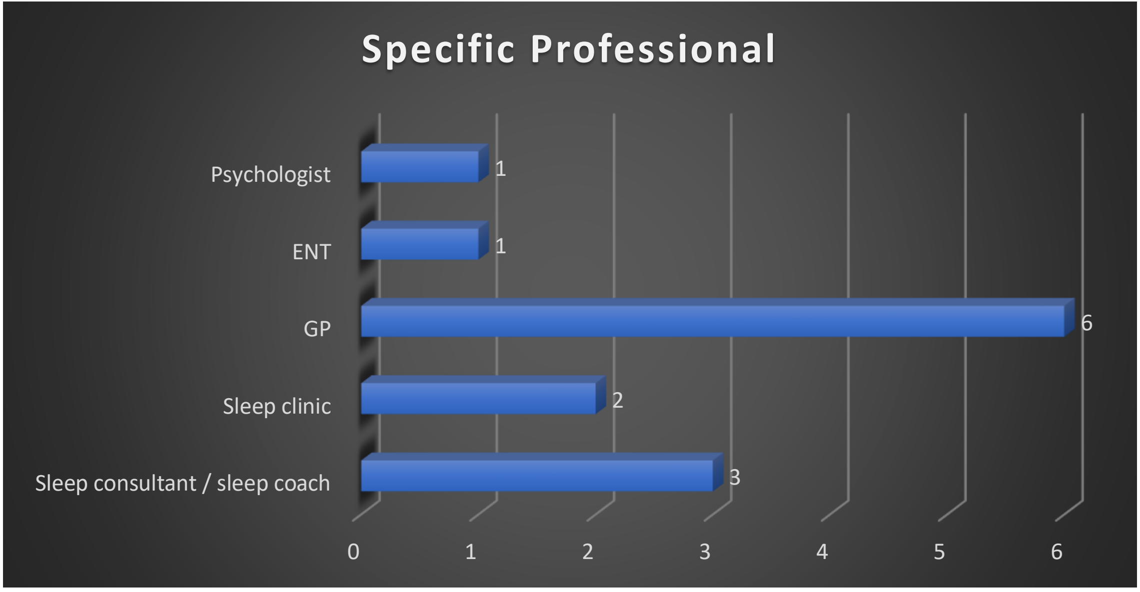
			Help for parents also	3	1.3%	…and support for both my child and me as a parent.
	Specific professional	This category shows where specific people or professions were mentioned.	Sleep consultant Sleep coach	3	1.3%	Doctor or psychologist who specialises in this field Access to specialist people who have knowledge in sleep area Sleep clinics, specialist sleep professionals, one to one support
			Sleep clinic	2	1%	
			GP	6	2.7%	
			ENT	1	0.4%	
			Psychologist	1	0.4%	
When		This category considers when in a child's development their parent would like the support. Also the speed with which support is gained and what happens	Specific age group	3	1.3%	Guidance on how to adapt sleep routines to different stages of a child's life. Support group or more access to health visitor during the early years Sleep course with a follow up and more further help Further help after sleep courses
			Early intervention / Faster referrals / Better aftercare / More follow up support	3	1.3%	

	afterwards is indicated here.				Targeted intervention at an earlier point. Not to be continuously told they will ‘grow out of it’. They have not. I first asked for support when child was 2. Still issues at 10 Faster referrals and better aftercare

Figure 5: Bar Charts Showing Results from Content Analysis of First Open Question: "What Type of Support Would You Like to Access?"




How Support is Delivered
Help for parents also
Whole family support
Online
Face to face
3
1
14
4
0
2
4
6
8
10
12
14


Specific Professional
Psychologist
ENT
GP
Sleep clinic
Sleep consultant / sleep coach
1
1
6
2
3
0
1
2
3
4
5
6

It seemed that the open wording of the question allowed for a varied set of responses in answer to this question. There were many parents who wanted similar things such as online support, support from a GP, support to help the child sleep through the night or to fall asleep. However, it is also clear from the content analysis of responses that there is diversity in the kind of difficulty parents wanted support with, what form they wanted the support to come in and what specific type of support they wanted.

Although not a specific category in the content analysis, there seemed to be suggestions of parents experiencing frustration when accessing support for sleep difficulties. This was indicated in quotes about the sleep difficulty persisting despite parents' best efforts. In Figure 8 below there are statements demonstrating this.

Figure 6: Quotes Suggesting Parental Frustration Around Support for Sleep Difficulties

"My Daughter struggles to go to sleep every night for a long time now. Maybe some advice on how to resolve this. Even though it feels as if we have tried everything"

"Targeted intervention at an earlier point. Not to be continuously told they will 'grow out of it'. They have not. I first asked for support when child was 2. Still issues at 10"

"Anything as I don't think children's sleep problems are taken seriously, it's always put down to parenting"

"Support that will actually help, NOT online course for the parents . In extreme cases making it easier to access suitable sleep medication"

"Someone to listen instead of saying it's because of their age and are able to help even if it means that they have medication to help them sleep"

"I've been to GP, school, community pediatrician, all have said my son needs melatonin but only CAMHS can do this, after over a year on their waiting list were still no closer to getting help for him. As he is growing the issue is getting harder but we still can't access any help without self prescribing and buying on the Internet which I'm not prepared to do as the dosages vary so greatly."

The second open question, worded as a statement, ‘**Please provide brief details of the support that has been sought’** resulted in a range of responses and drew out a broad range of support mechanisms that parents had sought so far. The responses from the 339 parents who gave information about support they had sought were organised into 4 groups listed below:

- Specific individual professional sought
- A group or organisation sought
- Medical or other procedure or intervention sought
- Independent support sought

Tables 8 and 9 show codes comprising each category and include additional quotes to illustrate the details.

There may be multiple responses from each parent so the numbers will not match up with the number of parents who responded.

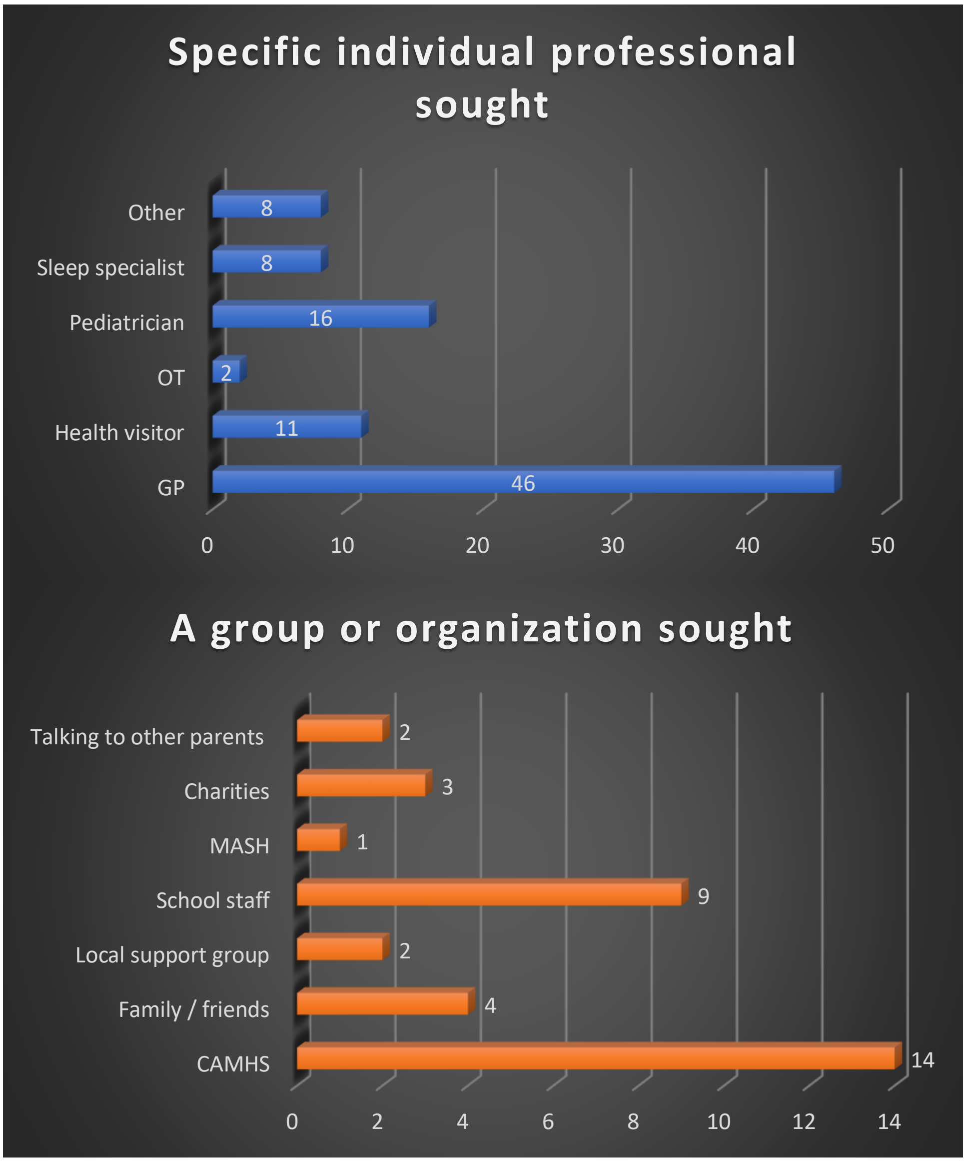
Table 9: Content Analysis for second open question ‘Please provide brief details of the support [for your child’s sleep difficulty] that you sought.’

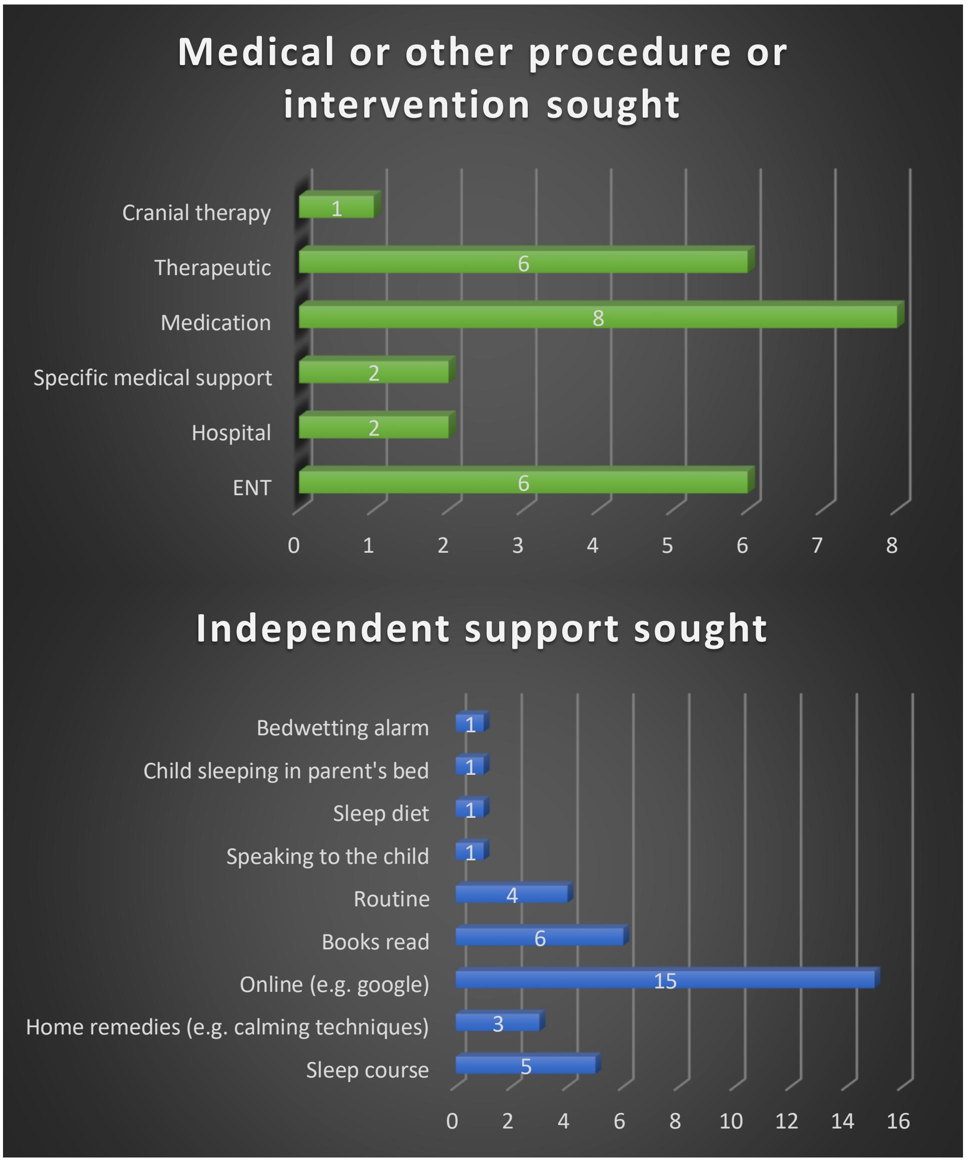
Category	**Code**	**Tally**	**Percentage of tally total**	**Quotes**
Specific individual professional sought	GP / doctor	46	25%	Doctor- regarding bed wetting, ongoing, not resolved Went to gp but they said there is nothing they can do Spoke to the Dr regarding child’s snoring and possible apnoea. Was referred to ENT who stated tonsils were not enlarged enough to remove and dismissed from care. No further support received. Lack of communication between MDT. Spoke to my child’s occupational therapist but her suggestion didn’t work In early years the health visitor We had an NHS sleep nurse for our baby
	OT	2	1%	
	Health visitor / health support worker	11	5.6%	
	Other professionals Children’s support worker School nurse / sch health service Child psychologist (private) Psychologist	8	4.2%	
	Pediatrician	16	8.7%	
	Sleep specialist / consultant / sleep clinic	8	4.1%	
	CAMHS (sometimes for other issues e.g. ADHD /	14	7.7%	

A group or organisation sought	ASD assessment) / on long waiting list			I spoke to CAMHS but they didn't offer any useful help or advice at all. I also spoke to the GP but only pointed me to advice on the internet. Help with our 10 year old being fearful of sleeping alone, waking multiple times in the night and not being able to settle back again. Informally from a friend who used to be a nanny None. Other than talking with friends and other mums with the same problem. Spoken to teachers at school to ensure we are helping to soothe any anxieties there that may be affecting sleep.
	Family and friends	4	2.1%	
	Local support / support group	2	1%	
	School staff	9	4.6%	
	Multi-agency safeguarding hub (MASH)	1	0.5%	
	Charities Peak sleep Sleep right The sleep charity telephone support	3	1.5%	
	Talked to other (older) parents	2	1%	
Medical or other procedure or intervention sought	ENT	6	3.1%	I did cranial therapy with her for about 4 months but it didn't work and I spend about £700 on it Doctor, children's nurse, family health worker, child psychologist, school teacher, school headteacher, school SENCo We had counselling sessions both from the UK and from Turkey (our home country). However, they helped to some extent and I thought it would not be making much difference. So we stopped.
	Hospital	2	1%	
	Cranial therapy	1	0.5%	
	Specific medical support (e.g. operation / abroad)	2	1%	
	Medication	8	4.1%	
	Therapeutic Inc. sch counsellor / sought help for the anxiety	6	3.1%	
Independent support sought	Sleep course	5	2.6%	Sleep study undertaken with regards to sleep apnea I've done some internet searches, but not approached a doctor
	Home remedies / Mindfulness / yoga / calming techniques / relaxing music	3	1.5%	
	Online (podcasts / google)	15	8.7%	

	Research			Internet search but got more info about sleep training baby's/infants not children Seek advice from GP, set up routine before sleep, story time, sharing thoughts, say I love you
	Read books	6	3.1%	
	Routine	4	2.1%	
	Speaking to the child	1	0.5%	
	Sleep diet	1	0.5%	
	Child sleeping in parent's bed	1	0.5%	
	Bedwetting alarm	1	0.5%	

Figure 7: Bar Charts showing results from content analysis of second open question "Please provide brief details of the support [for your child's sleep difficulty] that you sought."




Medical or other procedure or intervention sought
Cranial therapy
1
Therapeutic
6
Medication
8
Specific medical support
2
Hospital
2
ENT
6
0
1
2
3
4
5
6
7
8
Independent support sought
Bedwetting alarm
1
Child sleeping in parent's bed
1
Sleep diet
1
Speaking to the child
1
Routine
4
Books read
6
Online (e.g. google)
15
Home remedies (e.g. calming techniques)
3
Sleep course
5
0
2
4
6
8
10
12
14
16

As can be seen from the frequency table and bar charts above, there is an overwhelming result of parents seeking support from medical professionals, namely the GP in the first instance.

Around 12 respondents were unsure what support was available or how to answer the open questions. Some examples of their responses are shown in Figure 8 below.

Figure 8: Quotes regarding participants not knowing where to go for support

“To know what is available”

“Not sure on available support. So initially would appreciate to know the options regarding support”

“Any that is available as I am not aware of the services that could support”

“I’d just like to know what support is available and how to access it when and if necessary.”

“Wouldn’t know where to be signposted as child is 9.”

“Not sure on available support. So initially would appreciate to know the options regarding support”

“Wasn’t sure where to go.”

“I haven’t sought any support as I don’t know who can help us.”

I have not known where to seek support.”

“I haven’t [sought support, I’m] not sure where to go for support.”

“Unsure how to access reliable and helpful resources.”

“I have mentioned about it but feels like I can’t really go anywhere. It’s something child always has done so feels normal.”

As can be seen from the quotes throughout this section, there are both positive and negative responses to this question which are held in mind throughout this write up. The author feels that it is important to acknowledge that it is not an entirely negative picture that is painted with these results.

Summary of Quantitative Results

This part of the chapter has presented an analysis of quantitative data in response to the question:

- *What support do parents want and what support have parents sought for their children's sleep difficulties?*

Descriptive Statistics

As can be seen from the analysis in this section, around 60% of respondents felt that their child had difficulties with their sleep. Roughly half of the respondents wanted support for their children's sleep difficulties and roughly one quarter have sought support.

Content Analysis

This section discusses parents' responses to questions about their preferences and reservations about resources for their child's sleep. Some participants responded that they did not require support, while others specified the type of difficulty they wanted support with, what form they wanted the support to come in, and what specific type of support they wanted.

A high number of respondents did not know what support was available and this was their reason for not having sought support. This point will be drawn upon in Chapter 5: Discussion.

The following points were drawn out from the analysis as a summary:

- Parents overwhelmingly seek support from medical professionals, particularly General Practitioners (GPs), as their first point of contact for sleep-related issues
- It is noted that there were participants who did not feel it was necessary to provide support for children's sleep
- Children may receive support for sleep when they are on a medical pathway for another specific diagnosis, such as ADHD or an upper airway infection
- There are both positive and negative responses to the question, and it is important to acknowledge that the results do not paint an entirely negative picture
- Some parents found it difficult when they disagreed with advice provided by professionals and chose to continue providing comfort to their child despite recommendations

Phase Two: Qualitative Findings

Introduction

Phase two of the study aimed to explore the following question:

- *What do parents consider when deciding whether to seek support for their children's sleep difficulties?*

Four interviews, each around one hour in length were conducted with parents of children with sleep difficulties.

Table 10: Demographic Information about Participants (pseudonyms are used)

Parent interviewee	Child	Child's age	Family members	The main sleep difficulty	Support seeking
Ellen	Olivia	8	Mother – Ellen Daughter – Olivia Son – Thomas Father – name unknown	Olivia has difficulty getting to sleep. She often goes to bed very late and reads for a long time. Once she is asleep, she sleeps soundly. It can be very difficult to get her out of bed in the morning.	Sleep consultant employed for second younger child (Thomas) with the view that they may also help Olivia. Initially it helped her sleep with her brother in the room.
Tara	Harry	10	Mother – Tara Son – Harry Father – name unknown	Harry has a diagnosis of ADHD. Harry struggles with anxiety and settling at bedtime. Wakes up repeatedly through the night.	Harry takes Melatonin. They have been given some 'sleep hygiene' advice. Tara has reached out to CAMHS for therapeutic support but has been told that Harry is not 'bad enough' to receive support.
Diana	Georgio	7	Mother – Diana Child – Georgio Father – John	He doesn't want to go to sleep at night. It takes a long time to get him up in the morning.	Read a lot of articles. Some therapeutic support through school.

				He looks very tired in the daytime. He is not getting enough sleep.	There are waiting lists for therapeutic support.
Anna	Fred	8	Mother – Anna Father – Andrew Son – Fred Daughter – Isla	Doesn’t want to go to sleep. He is physically restless and distracts self at bedtime and continually leaves bedroom to come back downstairs. Fred is frightened by environmental factors such as scary book read at school causing nightmares. Fred seeks security through the comfort of soft toys. He is complex and sensitive in nature. He struggles and feels bad about self which prevents relaxation at bedtime.	Family members offering suggestions or sharing research. Occupational Therapy (OT) support. CAMHS support from clinical psychologist discussing anxiety. On CAMHS waiting list for ADHD and autism.

Analysis was completed using Braun and Clarke’s (2006) thematic analysis six step model (outlined in the methodology chapter).

Five themes were generated from the data as being relevant to the qualitative research question. Each theme had several subthemes as shown in the thematic map (Figure 9).

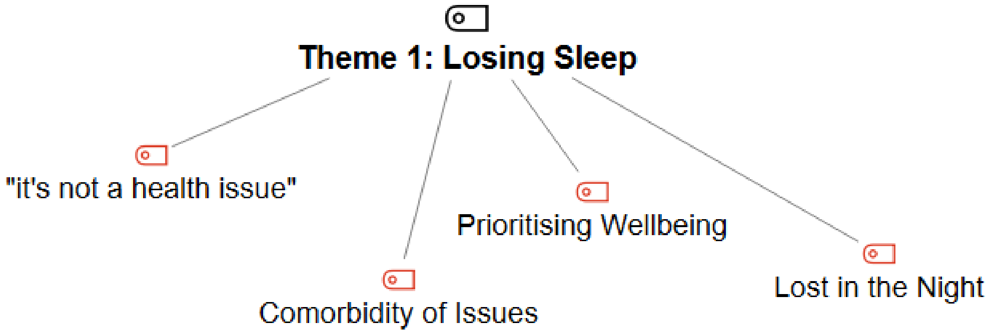
Figure 9: Thematic Map showing themes and subthemes

Table 11: RTA Themes and Subthemes

Number	Theme	Subtheme
1	Losing Sleep	It’s not a health issue
		Comorbidity of issues
		Prioritising wellbeing
		Lost in the night
2	Weighing it up	Building independence in child’s future
		Parental view of importance of sleep
		It’s not easy
		I know what it’s like
3	Experiences of Support	Hope: lost or restored
		Prescriptions
		A sense of trust
		It is complex: one size does not fit all
		Valuing community
4	Family Matters	Money matters
		Other members of the family
		Sleep disturbing relationships
		Practical logistics and family routines
5	What about me?	Is it my fault?
		I am a person too
		I’m only human

Appendix 19 shows which codes and participants are represented by each subtheme. Throughout, *parents* may be referred to as *participants.* Codes and quotes are entered in the text using *italics* to tell the story through the words of the participants as far as possible.

Theme 1: Losing Sleep



The title for this theme has been chosen because as well as physical sleep being lost, the topic of sleep is also lost amidst the number of other considerations discussed. This theme captures how lost sleep can become and how difficult it can therefore be to focus on it for sufficient time to seek out support. Participants also discussed the difficulty of distinguishing between whether sleep issues are a cause for or outcome of other difficulties. Discussions often shifted into diagnoses as perhaps something that is easier to talk about.

“It’s not a health issue”

This subtheme captures how sleep impacts on so many areas that it is hard to see a simple solution. Parents saw sleep difficulties as a set of behaviours, rather than a specific health issue. The following codes provide a non-exhaustive list of sleep behaviours discussed by participants:

- *Waking up through the night*
- *Tiredness in the morning*
- *Night owl – child doesn't want to go to sleep*
- *Gets to sleep very late*
- *Trouble falling asleep*
- *Trying to manage bedwetting issues*

Parents said that it was easier to talk about health issues than sleep, as people assume it is something you should just be able to resolve. The deviation in the interviews away from sleep was occasionally questioned by the researcher. Responses to this question included how much easier it was to talk about something that they felt was more widely understood. The following statements refer to how much simpler it felt for participants to gain support for a health issue for example in a specific part of the body.

"I mean it just sort of seems like you know I find it easier if I've got a problem with my teeth to go to the dentist because I pay for the dentist. So therefore I feel justified in taking this you know it doesn't matter how much time I take up" (E:498-501)

"yeah, I think because it seems, sometimes it seems like with food, I think it's easier because it's in a way more obvious. Problem, and the fact that people don't eat well, it's, you know, it has an immediate effect on your health. I think with sleep is everything gets more subtle. And I a lot of time you feel that is it's not a health issue. It's more like, yeah, it's a behavioural thing." (D:388-392)

When the researcher steered the conversation back towards the sleep difficulty, Tara explored this in detail and, later in the interview reflected on how it had been helpful to isolate the sleep issue as they do not usually get the opportunity to do so.

"it's been really helpful. It has helped me think a little bit more about. I don't know, these kind of conversations. I think it feels like therapy session that, you know, they help you draw your own conclusions because they draw out, you know, information. And it's actually, I think, the first time I verbalise that actually, what I want for Harry is a community. It's, it's actually helped me come to that realisation." (T:700-705)

Comorbidity of Issues

Sleep sometimes got 'lost' when other co-presenting issues were seen as a more of a priority. These included behavioural difficulties, attention deficit hyperactivity disorder (ADHD), anxiety and Developmental Coordination Disorder (DCD). Although participants came to the research explaining that their child had difficulties with sleep, some did not feel that this was the main presenting concern, but in fact a side-effect of other, more pressing concerns. The 'sleep' was not the thing that they would seek the help for or potentially even mention at all.

"I think one of the barriers might be that there are so many other things that we're dealing with with him. I mean, it's just a huge list" (A:495-500)

When they felt that sleep could impact on other things related to the child's health and wellbeing, they were often more likely to seek out support.

"But my worry is that this is not good for her, erm and that there's obviously all sorts of issues that can arise from not getting enough sleep." (E:151-152)

"And as I say once he's asleep, he stays asleep now, where he used to... it was it was very frustrating. You know, the, constantly getting up and then you think he was

going to be tired at school tomorrow. He's not gonna be able to concentrate. So he's not gonna learn anything?" (T:179-182)

Prioritising wellbeing

This subtheme captures the contribution of the anxieties the child had around the difficulties they were experiencing. This was often more prevalent and concerning for parents and so took ahold of the spotlight, leaving the 'sleep' lost, secondary to the wellbeing of the child. Significant wellbeing issues such as suicidal ideation were a trigger to seeking help from mental health professionals.

Tara described how she sought help from CAMHS but was refused support as Harry was not 'bad enough' according to their criteria even though Tara explained that Harry had gone through a stage of some suicidal ideation.

"He went through a phase of saying, 'I wish I was dead', all the time. Usually related to his condition. I don't want to have it I wish I was dead. Yeah. [coughing]. Sorry." (T:414-415)

Anna's son Fred felt bad about himself and things he did. She tried not to make him feel worse when the difficulties arose, but his anxiety was a concern for her, and she did not want to add to this.

"And… oh no, he's wet the bed again. And… we don't make him feel that like like that. I mean we try not to, I hope we don't. But I used to say I just don't want you in the bed all night. Because soon you'll you'll be able to but you know just stay anyway. As well, you know, I know that that's probably a bit of my anxiety about it." (A:260-262)

Discussion around the child's sensitive nature or young age having an impact on the sleep issue was also a key indicator of whether the parent would access support. The child would often seek security from the parent or from other means such as soft toys. Some children were frightened by environmental factors (such as a frightening book), had difficulty with anxiety, were bullied or had reached a point of suicidal ideation. These areas of wellbeing led parents to view the situation in a way which impacted the likelihood of accessing support.

The way in which Tara responded to her son's sensitivity is demonstrated by the following extract:

"he's, he's very aware, you know, we don't we, I mean, maybe it sounds I don't know, we never really babied him in, you know, we would talk about the real world in terms we thought he would understand. And he's very inquisitive about life, the world people. He asked me last night, why abortion is illegal in some places in America." (T:357-366)

Anna takes her son's wellbeing into consideration when managing her decisions around what help to seek for his sleep difficulties:

"And the other thing that happened was that they started reading a book at school, which really frightened him and I looked it up and it was advertised as a children's horror novel. Which I found a bit strange they were reading in year four. It really freaked him out and he just didn't want to go to sleep by himself." (A:48-52)

"I know he wants to be close. He would be he wants lots of, he wants to feel secure. He doesn't like being on his own. But at the same time it means that there's never any time without him. Haha, and we do need a bit!" (A:58-60)

Lost in the night

The difficulty not being apparent during the day made participants less likely to seek support whereas if the child was very tired in the daytime or had trouble waking up, they were more likely to hold the issue in mind and then seek out help.

“I think, I think possibly during the day, I don't really think about it.” (A:511)

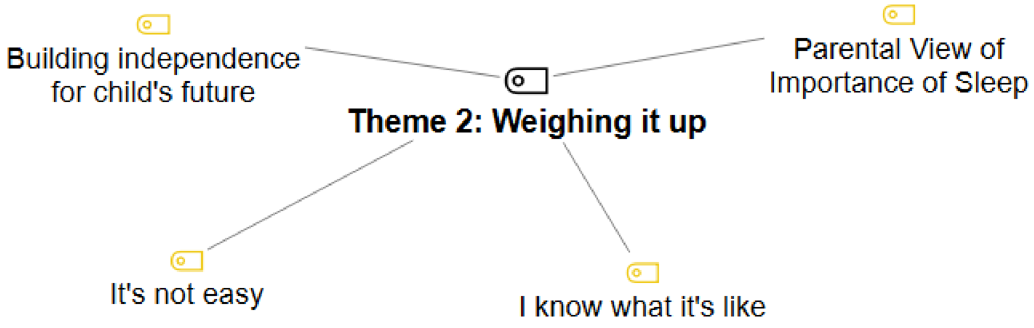
Compared to

“I mean I am literally having to lift her out of bed in the mornings” (E:11-12)

The following extract from Anna suggests that when sleep was not an issue in the day, it seemed forgotten about then emerged as a surprise in the evening. This may have affected steps to seek out support.

“I’m thinking about all this other stuff for you know, I need to answer or reply to or fill in or initial. And I spend, I start thinking about it when it's really not bad at getting in the bath and he enjoys that, it’s relaxing, but it's just after that. When we're at our most tired, we just really need to eat just, to switch off and then it starts and then it's like oh, no, not this again.
[laughing]” (A:515-520)

Theme 2: Weighing it up



This theme captures what participants considered when making decisions regarding help-seeking, weighing up the benefits and challenges of seeking support. These thoughts led to a significant consideration of whether it was worth seeking help. Discussions revolved around these factors and the impact on participants reaching out for support or accepting support offered to them. The balance was being weighed and considered as participants discussed their thoughts with the researcher.

Building independence for child's future

This subtheme captures hopes held by parents of increasing their child's independence for sleep in the future as they grow up. Parents often linked a difficulty with independence for sleep with potential future difficulties with other things. When this was linked to other areas of life, the author has tried here to ensure that the analysis does not deviate away from the original research question.

Participants became surer that they would seek support when concerns were discussed that had been held in mind about how a child's future may be impacted by their difficulties with poor sleep. For example:

"I worry that when he gets older, if it affects his relationships […] If he loses a job because of timekeeping, right. You know, the, if he gets into financial difficulty, because of, you know, financial management, you know…" (T:402-406)

Parent concerns for their child's future, particularly their gaining of independence in managing their own life, were often a facilitating factor to accessing support for the sleep issue.

"it's kind of about getting him to want to be more independent around his sleep and manage his sleep himself. It's like we don't shower him anymore. You know, he does his own showering. You know? I want him to kind of be able to get to that phase." (T:256-259)

The desire to build independence by reducing expectations of parents' presence is reflected here in a quote from Anna:

"And I certainly wasn't the sort of person who would just stay in the bed with them until they fell asleep. I never wanted to do that. I never wanted it to be a habit. So maybe that's still with me is that I just can't lie with him for that long, because that will be what he expects every single night and I can't give it." (A:563-567).

It's not easy

Resistance behaviours from the child to following instructions or bedtime routines was raised by participants as a frustration. This frustration made it somewhat difficult for parents to approach the sleep issues but at the same time motivated them to want to do something about it.

“both children routinely after we’ve put them to bed come out come down the stairs and find excuses as to why they need to get up so you know we can tell them off until the stage when they stay in their bed” (E:22-24)

“but he does, he resists going to bed. And I don't know if normal kids resist going to bed. But I noticed that when he's ... I say normal, but you know what I mean,” (T:212-214).

Tara was concerned that these behaviours may then increase if strategies were tried. This made her question whether it was in fact worthwhile or whether the seeking of support would in fact be fruitless.

“So I kind of think. I feel like we can't make him do anything anymore. He's 10 and a half. And you just I mean you can but he, you know, he'll push back on it, he'll try and negotiate, he won't want to do it or whatever.” (T:240-243).

I know what it’s like

This subtheme reflects how parents’ own experiences and feelings around sleep influenced their approach to support. Their empathy increased their desire to seek help.

Tara and Anna reported having experienced similar difficulties to their children, which influenced how they viewed the sleep issue and the need for support:

"Um...And then I realised, I was like [laughing] I was a terrible fidgeter. I couldn't get to sleep. But I wasn't like him, sort of being a pest. I was just lying in my bed for hours not asleep. But I always ended up with everything on the floor from my wriggling around, and he can be a bit like that.” (A:300-305)

“I have ADHD and I have the same sleep problems. So you know, totally. I've really got no vocabulary today, like I can sympathise with you know how he feels with regards to sleep.” (T:16-18)

Tara had experienced the benefits of medication which may have made her more open to following this approach for her child.

“I've never slept better than since I started taking this melatonin, you know, I feel like I wake up and I feel like a human being.” (T:299)

Parental view of importance of sleep

Participants’ feelings around the importance of sleep varied, which linked to the likelihood that they would seek support for their child’s sleep difficulty. This subtheme captured what participants said about the level of importance they placed on sleep and whether it was a priority. When it was not perceived as something specifically problematic, participants did not see it as something to seek help for.

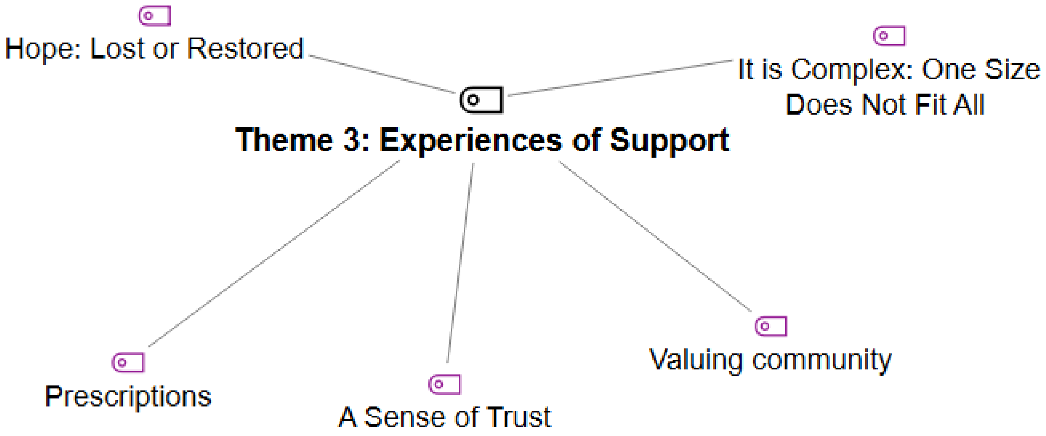
Diana explained how she felt it was possibly not an issue worth doing something about and that others may also view it as an issue not important enough to support.

“I mean, I feel it's, I feel it's a problem, but I don't feel it's so extreme, to bother people that are not, that don't have really the time to do these things. Even if maybe they can help. Maybe not, I don't know.” (D:301-304)

The following quote shows the influence that differing views on importance had on parent choices and actions around help seeking.

“But my worry is that this is not good for her, erm and that there’s obviously all sorts of issues that can arise from not getting enough sleep.” (E:151-152)

Theme 3: Experiences of Support



This theme captures how participants' experiences of support have shaped their approach to help seeking. The experiences of support participants had received from a variety of professionals, friends and family members impacted on the level of support they were likely to seek going forward.

Hope: Lost or Restored

All four participants' sense of hope were impacted by the experiences that they had gone through in terms of attempting to find solutions for their children's sleep difficulties. Those who had positive experiences of support gained hope that changes may continue to be possible. In comparison, negative experiences often led to parents losing hope and not seeking further support. Table 12 shows codes pertaining to hope lost or gained through these experiences.

Ellen thought that the sleep issues were a reflection of how things were and that it was not going to be possible for change to occur:

“I think possibly with Olivia I wasn’t aware that it was something that was even poss… you know that that help might not have even been there. Erm,” (E:263-264)

There was a strong emotional undertone behind the following quote from Tara and it was a salient theme in her story.

“He's constantly asking me for therapy. And I've talked to CAMHS about it, and they basically just said, well, which really pissed me off frankly, I found it a bit frustrating because, you know, someone's asking for help, and literally asking for help,” (T:381-384)

She continued to express her concern for his future and potential difficulties developing. CAMHS were inferring that he did not currently show *enough* signs of these difficulties to warrant support:

“What if he then becomes suicidal? You know, young men, suicide it's a big thing. Yeah. If he doesn't tell people that he's struggling, and I feel like, you know, I'm asking for help early. And I'm just not getting it.” (T:407-410)

On at least three occasions through her interview, Diana explored that the professionals from whom she had received support did not provide her with much confidence that help would lead to change.

“I think we get a referral to have some counselling for this issue, but it seems there is a long waiting list. So we're just waiting. I think it's just time. Yeah, that's the main thing” (D:160-162)

“I feel that it's not going anywhere. We’ll see what the blood tests say. But other than doing that, I think mainly just to check, he gets just, he's healthy. I don't think they have any other solution for him, or there is any?” (D:181-183)

“But from the GP way, there was not much, much. Yeah. much concern or that. Yeah, they didn't have any idea of what they could do.” (D:186-188)

Anna expressed a similar thought:

"So we, then they, they referred us to family therapy, but that was all a lie, absolutely hopeless. We carried on as parents, but it wasn't including the children at all." (A:118-120)

Hope was restored when help was beneficial and worked well. For example:

"I think but it was fairly easy that you know she kind of tweaked the daytime routine gave us instructions as to what to do in terms of what to do in terms of putting him to bed. Within seven days he was sleeping through." (E: 258-261)

Sometimes there were unexpected improvements as Ellen describes here:

"once we got Thomas sleeping through the night we then put Thomas in Olivia's bedroom and that resolved the immediate problems with Olivia's sleep in that she was no longer getting up in the night and wanting to come into bed with us." (E:52-55)

Diana discussed some feelings of hope that there are people who want to help, but that it is still difficult to come to a decision about whether the help-seeking was going to be worthwhile.

"Yeah, we've been talking around with people who are trying to be helpful in a way or another but yeah, you know, it's it's a bit tricky." (D:100-101)

Table 12: Codes Indicating Hope being Lost or Restored

Hope Lost	**Hope Restored**
Feeling despondent about help *Feeling frustrated with mental health services* *Thinking improvement was not possible* *Wondering if it is just how the child is*	*Unexpected improvements* *Professionals involved and level of support* *A positive change occurring from a change in routine* *CAMHS practitioner involvement*

Positive changes don't necessarily last long *Professionals not knowing what else to do* *The system involves re-referrals and persistence* *Mismatch from results from different professional assessments* *Concern that others don't have time to help* *Support received not feeling helpful*	*Consultant tweaking the routine helped quickly*

Medication: A tangible support?

Medication being issued following some diagnoses was discussed by Tara as a concrete source of support for Harry that, although helpful, resulted in some concerns being raised.

"And I mean, I don't think my husband likes that he takes melatonin. I think he feels like oh, you know, he won't be able to sleep without it and he will become addicted to the notion of it. And he's probably right." (T:259-262)

"But yeah, okay, he could become, you know, reliant on this medication, but at the same time, it's allowing him to get good quality sleep, which I notice the benefit of. And who knows what the health impacts of that are? You know?" (T:267-270)

Medication was also thought about by Anna in a more neutral way:

"The only other thing I think that my sister goes on about this a bit. She said, she's always sending me articles on. On lack of... I suppose is it lack of hormones? Melatonin? That, that doctors sometimes prescribe for children who were lacking it and need to, you know, just to get them down." (A:363-367)

A Sense of Trust

Participants found it difficult to know who to trust. They found that there was often no definitive support service or recognised, trusted professional for sleep health. This consideration made by parents around seeking support for their children’s sleep difficulties may increase hesitancy when initially reaching out. The sense of overwhelm is shown in a quote from Ellen:

“I think the difficulty is in some ways there’s… there seems to be so much out there that you don’t, you know if you were to do an internet search it’s very difficult to know what to trust.” (E:303-306)

Ellen had quite a strong sense of trust in her child’s school:

“And then when I showed it to the school, they said, oh okay, and then they referred him to [London Borough’s CAMHS service]. So then he got a bit more OT there.” (A:157-159)

Two other participants did not trust the school were able to support in the best way. Their confidence in the school was knocked by the school’s reluctance to support and they did not feel that the school necessarily had their best interests:

“And plus, I feel okay, teachers might have an understanding of kids, but I don't know how much they're training on that specific level. Yes. So I don't know if they're the best people to help.” (D:304-306)

“Even the educational health care plan, which would allow him to absolutely get his choice of high school. The school discouraged us from getting one, right. Oh, you know, you probably get rejected because he's not bad enough.” (T631-633)

Sometimes trust reduced due to referrals being lost or having to be redone.

“So she said, you know, have you tested him for ADHD? And we were like, no. And she said, You know, I think we should be getting checked out. So she referred him, they lost the referral. We had to take it for like a year and a half. He was

about five. When this whole thing kicked off. I don't think we got the proper diagnosis until he was 8, 7 or 8." (T:486-490)

"She recommended that he be referred in 18 months, to CAMHS, again, for screening for ASC and ADHD, which I completely agreed with. So we we did that application. And that got lost. I found out after that after letting the school follow it up. So this is July 2021. And the school was saying "oh he's still on a waiting list is still on a waiting list." I said I just can't believe this. And I phoned them up and there was no record of the application at all. But it didn't get through something went wrong. So I've just finished another application." (A:121-128)

To develop a sense of trust in support, Diana found that she needed to try things out for a while first.

*"**Interviewer**: That's, that's quite a helpful point to think about trying something. So if you're, for example, given some suggestions and given opportunities to trial them out for a period of time, and then speak to someone again about how it's gone and how to tweak it. Do you think that that would be a helpful way of working?*
***Diana**: Yeah, yeah, absolutely. Yeah. Because sometimes you know, the, you get some suggestions, you know, you should try to do this and that, but there are minor minor things that can get in the way do not realise it that doesn't make that specific thing work for you know, yeah, so yeah." (D:217-225)*

Alternatively, when support came up organically or 'came to them' from a trusted source (e.g. this interview coming from school) they were grateful and would accept the support.

*"**Interviewer**: I'm wondering err what it is that facilitated you to do that? What helped you to do that?*
***Ellen**: Well I think because it's very kind of specific and it's come from the school and it's come from X. You know it's actually that I can kind of s… say that's a trustworthy source." (E:349-353)*

Other examples of this included a family member sending through ideas, tips, advice or articles that may support.

*“**Interviewer**: Who… do you remember who suggested white noise? Was that the OT or the EP?*
***Anna**: My sister again. She's somebody constantly, you know, looking at articles and this that the other. “Oh, that's a good one for you” Ping. I'm much less sort of, into all of that. So I don't know. I rely on her really.” (A:425-429)*

Valuing community

Participants who sought like-minded people with similar issues felt that empathy may support them in a way that no professional truly could.

*“**Interviewer**: And what what kind of things made you feel able to potentially reach out for that help?*
***Diana**: Ah, well, they it's just that they offered to meet with parents one morning, and we've just exchanged some thoughts.” (D:129-132)*

Tara felt that it would help her to seek support if she had a community who could empathise with her and share resources and information.

“So I want to be part of I suppose some kind of community where that through that community, I would get to know more about resources.” (T:600-602)

When talking about the interview process, Tara explained the experience of isolating the sleep issue during discussion:

“And it's actually, I think, the first time I verbalise that actually, what I want for Harry is a community. It's, it's actually helped me come to that realisation.” (T:703-705)

It is Complex: One Size Does Not Fit All

This subtheme captures the complexity of sleep and that every child has nuanced and individual experiences so general advice does not appear to be entirely helpful.

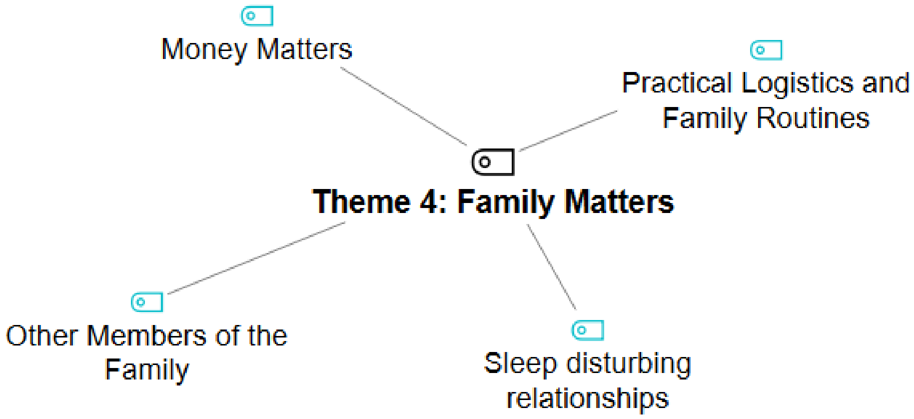
*"**Interviewer**: in terms of help seeking, have you sought help already? Or has any help been offered to you by any services or even friends and family for the difficulty with*
getting Georgio to sleep?
***Diana**: Well, we had a chat, there is a group that comes to school. [...] And yeah, I did mention to that, but they I don't know they just send you links of things and you know, the just send tips of things that that are quite... I mean, they're helpful, but quite generic." (D:90-97)*

Some professionals would provide such generic support, that parents felt the professional did not understand their child and could not help them.

"I think it's really important that, you know, especially for the sleep side of things, you know, kids aren't robots, and I think this kind of research is really important, whether they have ADHD or not, or cry it out and do this and do they're not robots that people with emotions and feelings and stimulus from the world." (T:748-752)

"People always go on about it. And then they… but they just give you the obvious like, Oh, has he got a good diet? Well, yeah, we try. But he won't eat most things. Give him a bath. Yeah, he has a bath every single night. It is, It's it's really difficult." (A:360-363)

Theme 4: Family Matters



This theme captures discussions about elements relating to family routines, impact on siblings, the dynamics of interactions and the physical home environment such as bedroom locations. All of these may have influenced thoughts around how to address sleep difficulties.

Other Members of the Family

The impact on siblings sometimes contributed to changes being made or help being sought. When there were siblings, parents explained the difficulty managing sleep issues in more than one child. With one child, some found they would just ‘give in’ and allow the child to do whatever they needed to for sleep.

“I think it was just it’s kind of like you know I think you know with the first child you’re just kind of feeling your way. And the sort of second time around as I say it was, it was sort of I couldn’t do you know I couldn’t have both of them in my bed erm and it was just and I couldn’t do you know one of them in my bed and then having to get up to another as well.” (E:242-246)

Whereas with the second child it became harder to manage.

"when Thomas you know got to about four months and he started to regress because he started off to be much better in terms of sleeping. Erm and when that… when he wasn't, it was like well I can't do this a second time round." (E:216-219)

This was sometimes due to disagreements:

"So, because we had both children in the same room in a bunk bed, Isla got very annoyed with him and his fidgeting around and lights on and not, you know, and all of this. And she said, 'I can't bear it any longer. He has to go.' So for quite some time, she was in the room, in the bunk bed, and he was on the floor with us. and he liked that," (A:35-39)

Anna found that Fred's sleep difficulties were impacting on all other members of the family. This was a motivating factor to seeking support.

"Well, I've got to get onto it, because erm [pause] it's er… Yeah, it's affecting everybody." (A:644-645)

Sleep disturbing relationships

The impact on family members leads onto the subtheme of considering the impact on relationships between family members.

Sometimes parents disagreed with each other:

"I do try and explain to my husband, 'I could get your position on it. But you don't know what it feels like to be us.' I've never slept better than since I started taking this melatonin, you know, I feel like I wake up and I feel like a human being." (T:298-301)

Other times, parents wanted to spend time together, rather than dealing with the child's sleep difficulty every night. Both situations impacted the relationship and then influenced their decision to seek out support.

“And so Andrew and I have felt like these, when occasionally we try to do nice things together, it’s just been awful. Just so I think we're pretty tired. But this thing about the evenings. I think it bothers us because [PAUSE] we just need a little bit of time together. You know, it we feel sometimes that we can’t communicate because it feels like all we're doing is trying to deal with children's needs and behaviour and it ends up being that… it’s all we do.” (A:220-226)

The disruption to siblings’ relationships with each other was discussed as problematic as one would often be disturbed by the other’s difficulties with sleep.

“And then the relationship between him and his sister has been difficult as well, even though they're very close, they fight, they really fight.” (A:218-220)

Practical Logistics and Family Routines

The physical environment of the home often impacted on how much change was possible in response to advice provided. For example, the locations and number of bedrooms, whether siblings shared a room and children’s access to disruptive influences such as games consoles, tablets and light switches in their room limited what changes could be made.

The use of screens:

“And, you know, he was all you know, no blue screen after seven o'clock at night. It's just unrealistic. You know, Harry's 10. You know, he wanted him to be up in his room, say, up in his room at eight. And that, apparently, because he had ADHD, he needed to sleep for 12 hours. But he's 10.” (T:27-31)

“You know, television, right? So if we wouldn't be able to watch television, because the blue screen would affect him. And the guy said, you know, we shouldn't use our mobile phones. In Harry's presence after seven o'clock because of the blue screen. It was just, no one can live like that. In the modern world. It's just ridiculous.” (T37-41)

Family routines:

“I think it's that sort of hour, hour and a half before bed. But you know, completely turning off every screen in the house at seven or eight o'clock is just not realistic in any way, shape or form. It's not going to happen, right?” (T:237-240)

“When I get home from work until six o'clock, sometimes we don't have dinner until seven sometimes 7.30 Last night, you know what I meant to then get him upstairs in half an hour and right you got to go to... it's just too unrealistic.” (T:34-37)

Changing strategies that worked:

“we've been reading in all the routine things. But first of all I got I don't know, I just didn't like the idea of leaving him doing that. But then as soon as soon as we got rid of the cot bed,
he had his own bed that was not feasible anymore because he could just leave the bed and do his own thing. You know. So there was just a physical barrier that stopped him to do those things done.” (D:285-290)

Habits creeping back in:

“then we had a new floor, put on our house, so that then the idea was, she would go to her new room, he would go back in the other room, and for once, I'd be able to move around our
bedroom. Not creep round with a torch, and you know, the same thing in the morning. And that went... the whole thing went on for about 18 months. We moved him into his room that made it nice for him. And then he sort of okay. And then after a while he was, kept coming back into the room.” (A:39-45)

Money Matters

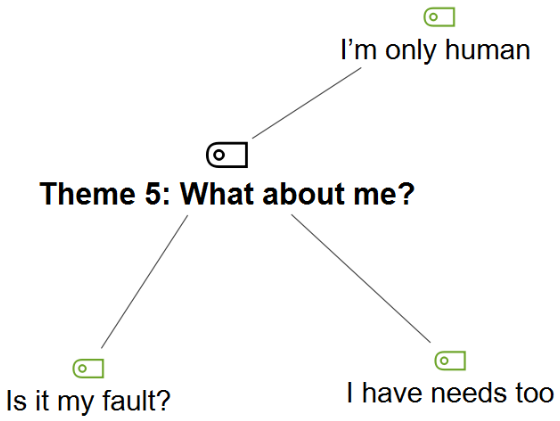
This subtheme captures two parents’ comments about paying for services. Free use of the NHS did not feel acceptable to Ellen if she was capable of paying for services.

“I sort of perhaps sort of have a slight issue with the NHS in that often I don’t like to go to the GP because I don’t like to put pressure on the resources. And I don’t… If it’s not something I feel warrants it then I feel oh you know so I think with the sleep consultant you know I was the fact that it was a paid for service…” (E:464-469)

In comparison, Tara was not able to or felt it was not right that she should have to pay for private health care.

“I think what's stopping me is, yeah, there's nowhere else to go. Except for private, which is obviously, you know, very expensive.” (T:538-539)

Theme 5: What about me?



This theme captures what the parents were expressing about themselves as individuals in relation to their child’s sleep difficulties. Some would lay blame on themselves whilst others considered their own wellbeing as equally important. Whatever the considerations were, these were brought without prompting and explored alongside the issues their children were experiencing with sleep.

Is it my fault?

This subtheme captures how parents would often lay blame on themselves about why their children were experiencing sleep difficulties.

There were comments across participants of the pressure they felt to be a certain way. This pressure was often built around a concern for what other people were thinking about them ‘as parents’ and perceived critiques on their parenting style. Two particularly apt comments are shown from Diana below:

“We're happy if he's fast asleep before 10. But it doesn't always happen. And I know that a lot of people that looks at still a bit late” (D:42-44)

“I think sometimes people can't. Yeah, they are often a bit shocked when I say what time Georgio falls asleep, because it is late for his age, and he doesn't get enough sleep.” (D:417-419)

This extended to participants feeling as though the sleep issues experienced by their child may be their fault as they had done something wrong or should have known what to do to create the best situation for their child.

“Interviewer: No, yeah, that's it. So maybe it's other people's opinions that can impact you
as well.
Diana: But I mean, I'm not saying that this is preventing me to ask help. I know this, you know, if I'm doing something all wrong. I want to know what it is.” (D:422-425)

Anna also laid some blame on herself:

“But I think what I feel is that we're not giving enough time, even though we're doing the routine, and we're trying to do everything, we're not putting enough time into maybe the massage and the touch and the properly... This getting
him down.” (A:305-308)

Ellen felt that she ought to simply know what to do in this area of health, without guidance:

“I guess it’s like anything with parenting you just feel that you ought to know what you’re doing and unless there’s a real sort of medical condition or something I think it’s… yeah I don’t think the natural tendency was certainly you know that’s just the way I was brought up that there’s sought of you know natural tendency not to make a fuss and not to kind of you know in some ways you kind of think oh well actually I could do with sort of lessons in being a parent full stop but actually that’s not something that is necessarily kind of offered and it’s just yeah you feel that actually seeking help is (sigh) it’s… it just doesn’t come naturally I think to kind of… you just think I ought to be able to solve this or… or actually it’s not something I should be making a fuss about… you know.” (E:172-182)

Ellen’s feelings around what she thought she ought to be able to do may have impacted what she felt she was entitled to in terms of support. She had placed expectations on herself which she also explained were in line with the way she was raised by her own parents. Ellen’s views about what she thought she ought to do may have been a barrier to her seeking support because she felt like she should be able to deal with it.

I have needs too

This subtheme captures the impact of participants’ views of themselves and their value of their own sleep health on the likelihood of support seeking for sleep difficulties.

The sleeping patterns that participants followed for themselves was often discussed within the interviews:

"I start to lose my temper. You know, I'm trying to go bed, I've got to get up early, I need sleep as well. And you know, by the time it's 1030, then it's 1040, then it's 1042. And you're looking at the clock thinking it's basically 11 o'clock. And I'm still awake. And I don't want to be like awake at 11 o'clock." (T:233-236)

Diana discussed the impact of Georgio's sleep issues on her own life as well as her son's:

"It's just, you know, it's the timing that is really bad and he's affecting this is his life and our life." (D:47-48)

Participants talked about their child's sleep difficulty at times feeling all-consuming. Anna described how she and her husband were unable to have time alone because they would be working with the issue in the evening, which would be their typical opportunity to spend time together. When this was discussed as something that was valued by the participant, they would be motivated to seek out support for their child.

"So I try and spend you know 5 minutes with Andrew, my husband. But no, that gets interrupted can't watch any television because that he'll want to be down knowing what we're doing." (A:22-24)

I'm only human

This subtheme opens up the acknowledgement and statement from parents that they have limitations and discusses issues such as the difficulty of trying to attend to these issues at night when everyone is tired.

"Yeah, it's just you know, sometimes you're tired, right? And you just want to veg out in front of the telly, you come home from work like adults are human beings as well. And we can't always be perfect parents, you know, like phones off at seven. It's just unrealistic." (T:48-51)

Diana explained how the sleep issues had been prevalent since her child was a baby. She explored the exhaustion from the consistency of the difficulties:

"the routine is helping but even when he used to go to nursery was like, we were always late always super tired. You know? Just yeah, yeah. And since he was a baby, I think he kind of when he was born, I think he happens to a few babies. They this. They switch the day with the daytime with a nighttime, so he used to sleep more during the day than during the night. And I think maybe that's one of the reasons why. Yeah, but yeah, is there's always been like that." (D:263-268)

Anna describes her exhaustion:

"But these things that I need to do more of, but by the time we're getting to this point is just everyone's pretty much exhausted. It's not that late. And then there he is all settled. And give him countdown warnings of you know, right 10 more minutes, and then the 10 minutes is up an "no no no I want more I want more!" goes on, finally might be able to get him to sleep. And then he's up again." (A:16-22)

"in the last few months, he's been really demanding of me massively demanding and screaming down the stairs "When are you coming, when are you coming?!" And so it's only now that I'm starting to think 'hang on a minute. This is worse than it was before.' And I don't really know how to get out of it." (A:476-480)

Summary of Qualitative Results

This part of the chapter has presented an analysis of qualitative data in response to the question:

- *What do parents consider when deciding whether to seek support for their children's sleep difficulties?*

Through analysis of the interview data, five themes each with a number of subthemes were generated in response to the question above. These themes are summarised below:

- *Losing Sleep* covers how difficult it can be for parents to seek out support for something that happens at night, when physical tiredness possibly leaves parents less able to hold strategies in mind to manage their children's health and wellbeing.
- *Weighing it Up* covers how there are many different elements that must be taken into consideration when deciding whether and how to seek out any support.
- *Experiences of Support* sees parents considering what has happened so far for them in response to their support-seeking for their children's sleep difficulties.
- *Family Matters* explains the pressures that are often felt on other members of the family with regards to the sleep difficulties of a child.
- *What about me?* takes into account what parents were considering in relation to themselves as an individual with needs, feelings and also a requirement to sleep well.

Chapter Summary

Using descriptive statistics, content analysis and reflexive thematic analysis, the author has, with this chapter provided an analytical outline and summary of the results and findings from both phases of the research. In the next section, Chapter 5: Discussion the author aims to draw together results and findings from this chapter, psychological theory considered or developed during analysis and literature drawn upon in Chapter 2: Literature Review. In doing so, the author aims to address the two research questions:

- *What support do parents want and what support have parents sought for their children’s sleep difficulties?*
- *What do parents consider when deciding whether to seek support for their children’s sleep difficulties?*

Chapter 5: Discussion

5.1 Chapter Overview

This chapter provides a review of the researcher's results and findings, alongside a review of the current literature. Psychological theory is also considered and developed to provide interpretation in response to the RQs. The process undertaken by the researcher is reflected upon and discussion of the implications for EPs and others is provided. Strengths and limitations are considered, and finally the ethical considerations for the participants who graciously gave their time and thoughts are presented.

5.2 Summary of Findings

Findings are presented in depth in Chapter 4: Results and Findings. Here, the author provides a summary of what was found in response to the RQs:

RQ 1: What support do parents want and what support have parents sought for their children's sleep difficulties?

RQ 2: What do parents consider when deciding whether to seek support for their children's sleep difficulties?

5.2.1 Quantitative

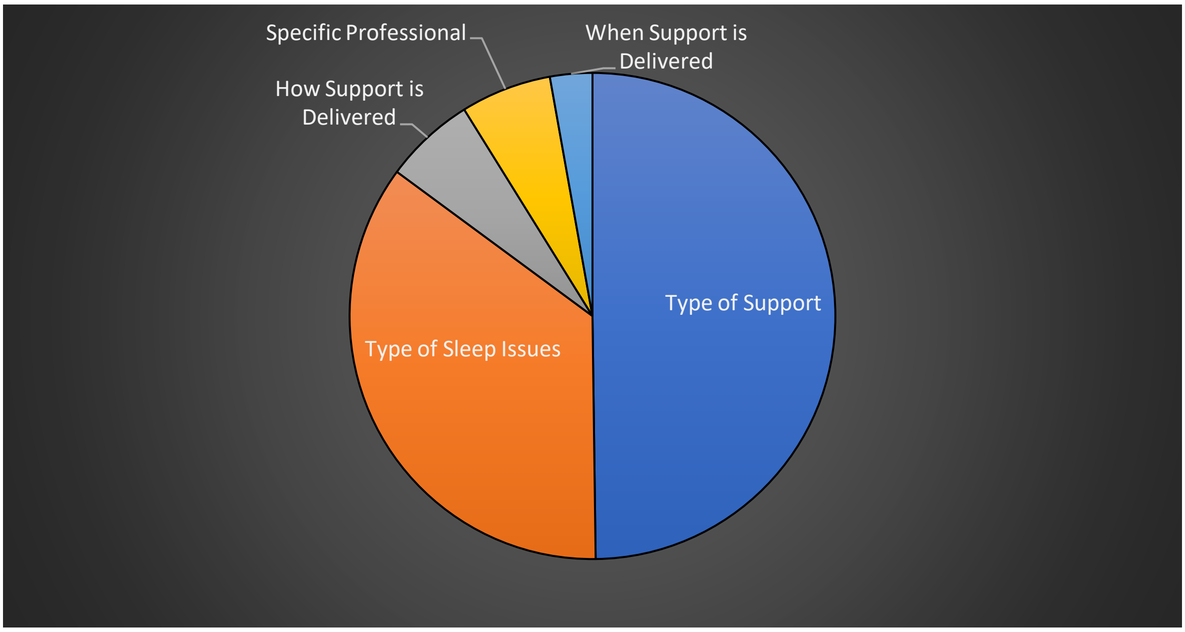
Of the 251 parents whose questionnaire responses were included in the analysis, 82% said they would like help with their child's sleep difficulties and 45% said that they had already sought some form of support. The researcher was intrigued by the finding that55% of respondents had not sought support. Cook et al., (2022) demonstrated with their recent qualitative study around parental help-seeking for child sleep that reservations around seeking help include concerns about reliability, being judged and challenges of filtering vast amounts of information. They found that reservations were also held by parents who had previous negative experiences of support. These findings align with and support the current study.

The two open questions from the survey were analysed using content analysis, and led to more specific and detailed analysis of responses as to the support desired and sought. There was a range of support that parents wanted. The most common were *information, advice or tips* and specifically something that helped them to understand the cause of the difficulty. Support with routines, behaviour and calming techniques were amongst the highest types of support mentioned. For some parents the timing of support was also important.

Figure 10 below shows the categories within which parents were choosing to specify the support they wanted. The type of support (e.g., information, routine, therapeutic, medication) and the type of sleep issue (e.g., help to fall asleep, nightmares, snoring) were the two most highly occurring categories.

This provides information in response to RQ 1 in that it can guide professionals towards what parents are likely to have in mind when considering what support to seek. This is an important element of consideration as Pyper et al. (2017) showed with their research. They found that parental behaviours in relation to support-seeking for children’s sleep can be a determining factor for child sleep health.

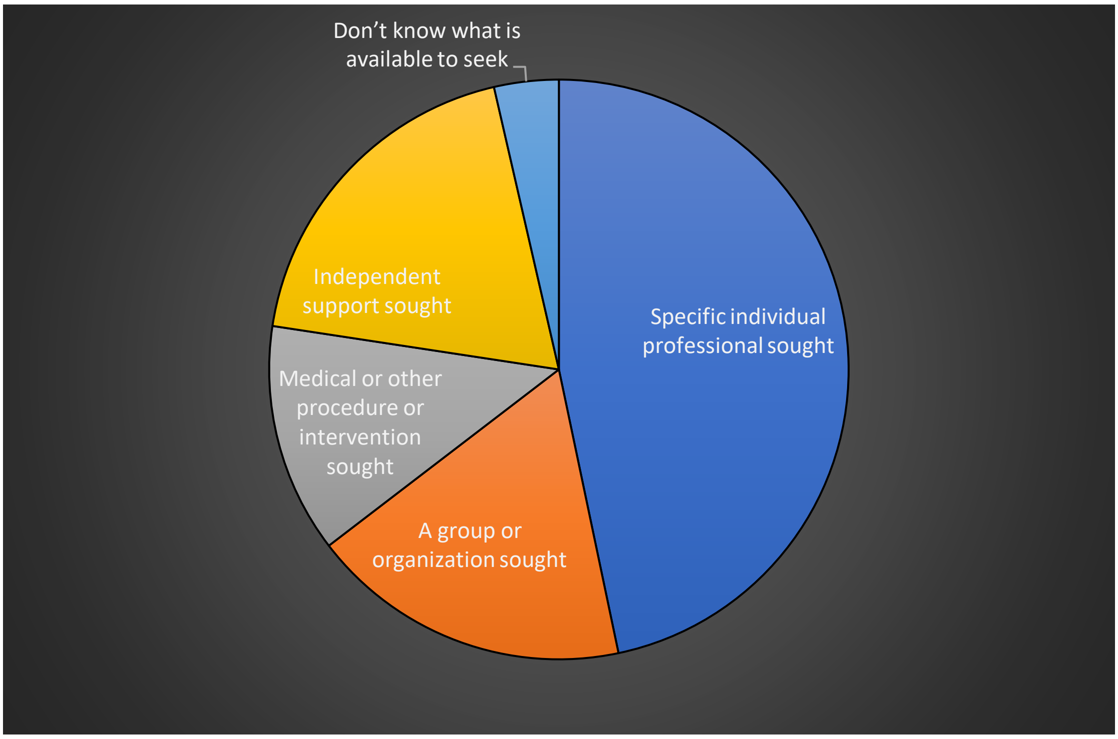
Figure 10: Percentage (%) of Parents Who Desired Help Within Each Category



The actual support sought saw most parents seeking a *specific individual professional*, the majority opting to go to a *GP* or *doctor*. This may provide evidence that visiting a GP is one of the most commonly recommended strategies for any health concern when HCPs feel their expertise is limited in the area of concern (Edwards, 2019; McDowal et al., 2016). *'Independent support'* such as reading books or searching online for information and *'a group or organisation'* such as CAMHS or a charity were also amongst the highest categories mentioned. Some parents had also sought medical procedures or interventions such as medication, cranial massage or ENT investigations.

Figure 11 shows the percentage of parents who have sought support in each category. Specific individual professional (e.g., GP, pediatrician, psychologist, OT) and independent support sought (e.g., online searching, reading books, speaking to the child) were the two most highly occurring categories. Cook et al. (2022) also found that the most commonly used sources of support by parents for children’s sleep issues were internet searching and contacting professionals such as health visitors. Cook et al.’s (2022) findings support the results of this research, adding to the reliability of the data set.

Figure 11: Percentage of parents who sought help within each category



5.2.2 Strengths and Limitations of Quantitative Phase

It is important to consider possible response biases including non-response bias and acquiescence bias. For the former, although the survey was sent to around 25,000 primary schools on the database retrieved, around 400 responses were received. It is not possible to know how many parents did not respond to the survey who may also have concerns about their children’s sleep and the reasons for non-response can only be hypothesised. For the latter, in attempt to alleviate acquiescence bias, by which participants tend to agree with statements regardless of their experiences, the author made questions intentionally ambiguous and open rather than leading or influential in any way.

A strength is that the author reached out to primary schools across England to gain views of parents for the quantitative element to attempt to provide families in a large geographical area with an invitation to respond to the survey. A limitation is that the people involved in the study were already more likely to engage in help-seeking by virtue of responding to the survey or volunteering to be interviewed by a researcher about a concern they have, in this case regarding their children's sleep.

The quantitative phase gathered the views of a large number of parents, setting the context for the qualitative element of the study which viewed decision making around sleep difficulties. Decision making was able to be more thoroughly explored in the interviews.

5.2.3 Qualitative

Figure 12 below shows the main themes (without subthemes) that were developed from the reflexive thematic analysis of the interview data in answer to the second RQ:

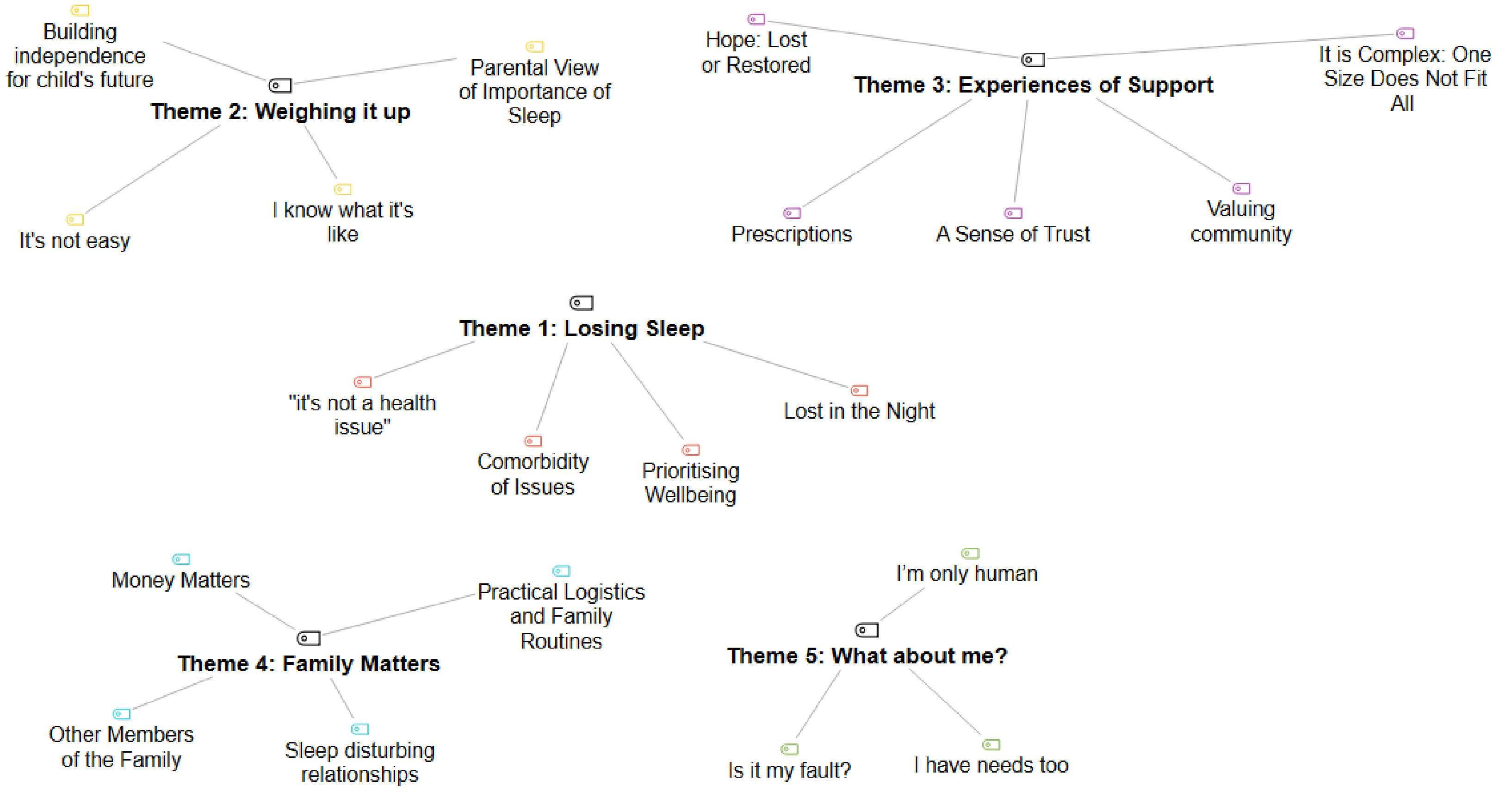
- *What do parents consider when deciding whether to seek support for their children's sleep difficulties?*

Figure 15 then shows the full thematic map including subthemes.

With this section the author will discuss these themes to utilise the gathered data to respond to the second RQ.

Figure 12: Qualitative Themes (without subthemes)

Figure 13: Thematic map from qualitative findings



5.2.3.1 Losing Sleep

‘Losing sleep’ encompasses how difficult it can be to talk about sleep in isolation. Other health diagnoses can take precedence and during the interviews it was often hard for parents to specify what the sleep difficulty actually was. This theme also encompasses the idea that sleep itself is lost by not being able to healthily succeed at gaining enough of it at night. It is also interesting that parents often commented on experiencing the same difficulties with sleep as their children experienced. The empathy parents felt often came from experiencing similar difficulties in their own childhood which have sometimes continued into their adulthood. A psychodynamic theory to help explain this is called ‘parallel process’ which is when two people in a relationship mirror dynamics, emotions and behaviours. For example, parents project experiences they had in childhood onto their own children (Watkins, 1990). Other literature has also found that parents can find it difficult to isolate sleep as a topic to talk about (Nilsen et al., 2022; Kitsaras et al., 2021).

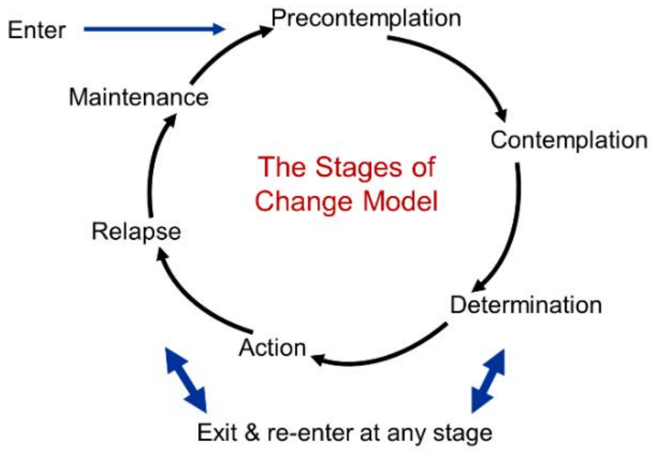
5.2.3.2 Weighing it up

This theme shows the vast array of different considerations parents needed to make when deciding whether to seek support or not. They would think about the positive outcomes from seeking help, such as building independence in their children by helping them to sleep independently; but also the negative, such as how difficult it can be to approach and how exhausting it was to work on. Parents making a choice to seek out help could be seen as an indication of how importantly they viewed sleep. Sometimes, weight was added by the fact that the parent shared an experience either retrospectively as a child, or currently as an adult; for example, if they were having issues with their own sleep because of their child’s sleep issues.

This often made a parent more likely to seek support but conversely could reduce their likelihood of seeking help whilst the parents were in the dilemma of considering whether it was the sleep being affected by other issues or indeed if the sleep was itself impacting on other issues. The resultant confusion could lead to ambivalence and inaction. A psychological theory to support understanding of the way parents think about seeking support for sleep difficulties is explained here.

Readiness for change requires a number of stages to take place. A theory developed from behavioural psychology can support understanding of this. The model depicted in Figure 14, developed in the 1970s by Prochaska and DiClemente shows a thread pulled from the researcher’s findings. The stages of change that parents went through, to feel able to source help, took the length of the interviews to explore, unpick and dissect.

Figure 14: The Transtheoretical Model (Stages of Change) by Prochaska and DiClemente adapted and accessed from https://sphweb.bumc.bu.edu/otlt/mph-modules/sb/behavioralchangetheories/behavioralchangetheories6.html



There is a state of ambivalence parents were having around decision making which could be viewed within the context of the change cycle. It could be argued that all parents involved in the study were at the contemplation stage by virtue of the fact that they completed the questionnaire. Some might be at more of an ‘action’ or ‘determination’ stage, but many of the decisions that would lead to change start with the weighing up process. Taking the subtheme ‘it’s not easy’ into consideration, it is important for professionals to think about how complicated this process can be; it is not simple and there is a lot to consider.

5.2.3.3 Experiences of support

This theme encompasses what parents had been through so far in terms of support seeking for their child(ren)’s sleep concerns. Their experiences influenced their choices going forwards. Parents found that often, professionals did not value the CYP as an individual, but instead tried to take a ‘one size fits all’ approach by offering generic advice. Parents felt that there was a lack of focus on the individual child, or that professionals simply did not have access to the tools or expertise to support in the tailored way that would be appropriate. This is demonstrated from the analysis in the subtheme ‘It is complex: One size does not fit all’.

Discussion of some psychological theory is used in this section to support explanation of development of some themes. The need for community and hope can be explained by Maslow’s hierarchy (1943). According to Maslow, once basic physiological and safety needs are met, individuals seek to fulfil social needs, such as the need for belongingness and love. This includes the need for a sense of community and interconnectedness, which is something that people had been missing during the COVID-19 pandemic. By interviewing parents in an open-ended, semi-structured interview style, the researcher of the current study unveiled knowledge previously unknown to themselves.

“I've realised that not getting it helped me realise as well, I'm not getting anywhere with the you know, the system. But there must be other people like me, who aren't getting anywhere with this system and have another way to come together.” (T-2; pos 700-706)

5.2.3.4 Family matters

Practicalities and relational matters of family life are covered by this theme. Decisions around help-seeking for a parent are often significantly impacted by how they perceive the changes required will impact on the other members of their family, and how the sleep difficulty is already impacting. The previous theme of ‘Experiences of Support’ links in to this theme by how the experiences have impacted on the family so far. Family Systems Theory (Haefner, 2014) supports this study by showing that with some support and encouragement to fit their thinking around the individual child, the parent took the opportunity to consider more than just the child themselves. They were able to step back, pause and reflect on what they felt about the impact of the situation not only on the directly affected child, but the rest of the family members also. Within the literature review, the author did not come across literature that specifically focused on the impact of the sleep difficulty on the family. As mentioned already, it may be the nature of openness in the interview that allowed parents the freedom to think around more than just the child themselves. This leads onto the final theme below of ‘What About Me?’.

5.2.3.5 What about me?

This theme covers the emotional and physical burden of supporting a child with sleep issues. This sense of being burdened could also be a factor affecting decision making. Parents talked about their own levels of fatigue, not being able to have time with their partner due to the incessant demands at night time and worrying that it may be their fault that the issues arose in the first instance. This could be seen as two parts that may be conflicting within the parent. Parents either felt that they may be to blame so were negative towards themselves, or they felt that their wellbeing was equally as important as their child's, so held a more of a positive view towards themselves. This resonated quite strongly with the author when writing the research journal. The researcher felt personally impacted by the emotion poured out by the participants in relation to this theme. Their research journal reflected the following in relation to the emotion that the author felt:

I have just come away from the first in-person interview and I'm wondering why I feel so defeated in my work. Although I am completing an exploratory study, I want to make an impact on the community struggling with these issues and the hopelessness projected during this interview felt strong.

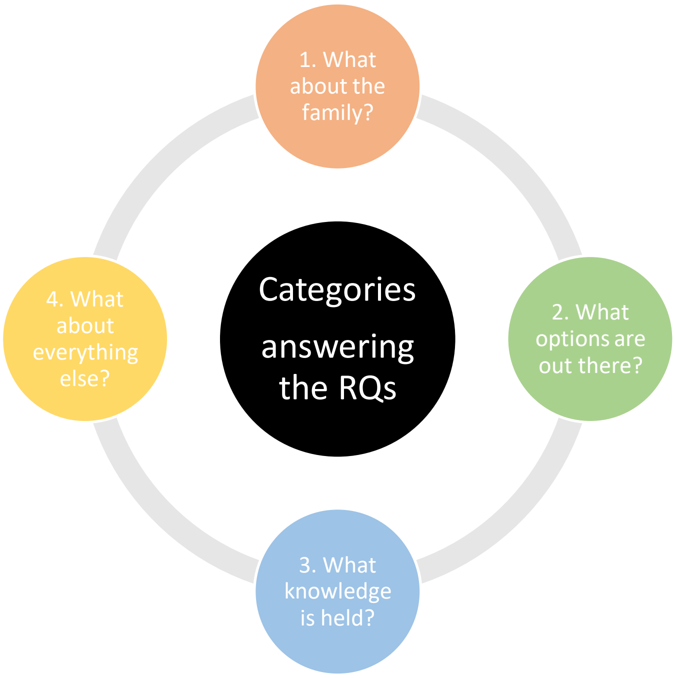
It is of note that the theme 'Weighing It Up' could be seen to be involved in every other theme. Everything discussed needs to be *weighed up* by parents when they think about whether to seek out help. Each theme is something that they are *weighing* against everything else, so this theme provides a thread that is consistent through the answer to the second RQ in this study.

5.3 How the Findings Fit within Current Research

Themes from the data analysis were considered alongside themes from the literature review. The researcher's goal was to present an encompassed view of the findings, amalgamating them to create a clear and succinct presentation. The amalgamation resulted in four core categories being generated which are shown in figure 15.

The results of both the qualitative and quantitative data will be discussed here under these four category headings. Psychological theory has been further explored to support explanation of the significance of the findings, and what this study adds to the current research base.

Figure 15: Four Core Categories to Answer the RQs.



The core categories are presented as questions that the author found that parents appeared to hold in mind when making decisions about help-seeking. A key finding was that there is so much for parents to consider when deciding whether to seek support for their children’s sleep difficulties; and it was not always easy to segregate these considerations from one another within this summary.

5.3.1 What about the family?

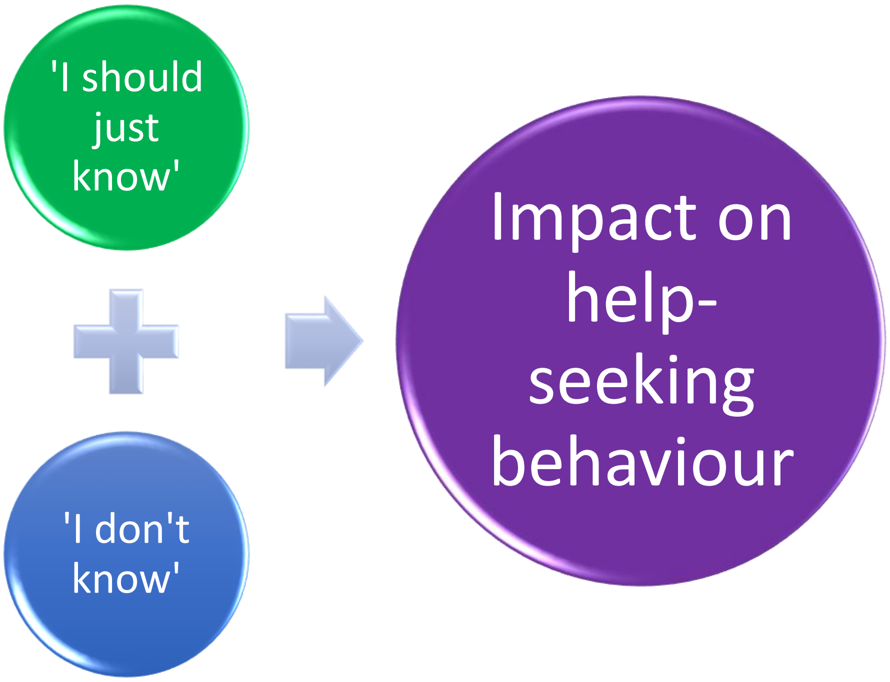
From analysis of the data and the literature, the researcher extracted this category around parental consideration of themselves and other family members in the decisions about help-seeking. The category encompasses the literature review theme ‘What will they think of me?’ and the qualitative themes ‘Family Matters’ and ‘What About Me?’. Quantitative themes were also included in the development of this category. Responses to the open questions in the survey included a number of points about what would work best for the parent in accessing support. Parents considered that support for themselves or the whole family would be preferable. ‘Open, honest conversations’ and ‘Speaking to someone’ were amongst responses to the survey that fell in this category. It appeared that parents were considering here what might be the best method by which they might receive support. There were parents who were clear on what they wanted and specified the way in which they felt they would most like support delivered. This could be seen as a way in which parents were thinking about a more holistic view of support around the child. The child for whom sleep is an issue, can only be helped by their family if the way in which support is provided is suitable for all family members.

Furthermore, parents explained that they wanted help to understand the cause, which may link to the qualitative subtheme ‘Is it my fault?’. Parents’ concern that they may be to blame for the sleep difficulties could reflect their attempt and desire to ‘dig deeper’ into what the causes may be.

5.3.2 What options are out there?

The 'Experiences of Support' qualitative theme encompassed discussions about what parents had encountered so far in their support-seeking journeys. This can be compared to the 'A range of options' theme from the literature review which was about the variety of responses that other researchers found from parents who commented on what it was like for them to be presented with an assortment of options of support. Sometimes it was overwhelming and at other times they felt there were not enough presented to them. This category was drawn from a number of articles including Hatton and Gardani’s (2018) ‘Maternal perceptions of advice on sleep in young children: How, what, and when?’ Parents interviewed in Hatton and Gardani’s study had specific comments on the way in which they felt that sleep hygiene advice should be delivered, and by whom. The apparent overlap with the current research themes is portrayed with this category, by the range of quantitative codes from the content analysis depicting what parents felt would be their preferred form in which to receive advice, support or guidance. The researcher developed the broad categories within the content analysis of the open questions within the survey of ‘what’, ‘who and how’ and ‘when’. Many parents *‘did not know’* what support was available. Tying in with the thought that they *‘should just know’* what to do, the author has developed the image in Figure 16 below to show the relationship of these thoughts impacting on help-seeking behaviours.

Figure 16: Relationship of Factors Impacting on Help-Seeking Behaviour.



Choice overload or ‘overchoice’ can contribute to explanation of the impact on the number of different options that some parents felt negatively impacted their help-seeking behaviours. This term was introduced in the 1970s by Alvin Toffler and explains how decision fatigue can be caused by too many options being available. It may be difficult for someone to seek help if they don’t know what is available; particularly if they perceive there to be a vast array of unknown options for the particular difficulty they are experiencing. The options found from the responses of support that participants have sought so far was vast. There were over twenty different options including ear, nose and throat (ENT) hospital department, home remedies such as meditation and music, alarms for bedwetting, medication and alternative therapies such as cranial massage.

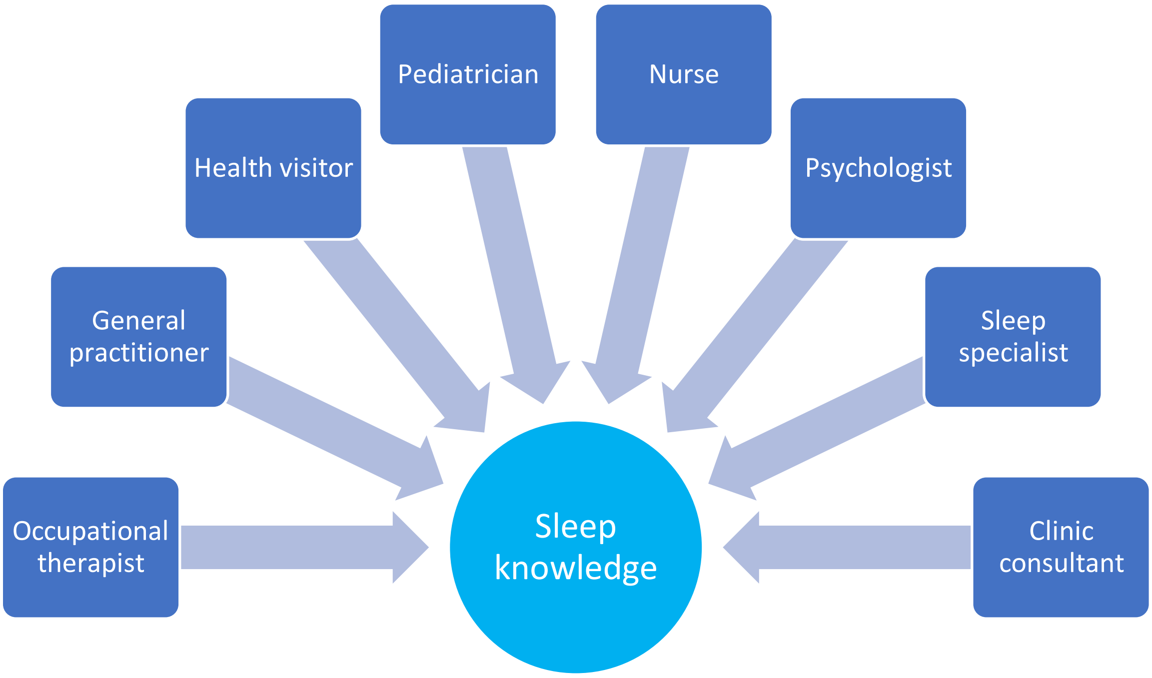
Particularly with knowing what support is available, the author found that help-seeking behaviour could be impacted by previous experiences that the parents have had with health professionals. Experiences can lead to assumptions being made about potential future experiences.

5.3.3. What knowledge is held (about sleep)?

In the ‘Weighing It Up’ theme from qualitative analysis, the knowledge that parents had would be weighed against other factors such as personal experience and what they wanted for their child’s future, to determine the importance they felt sleep had and whether it was important enough to warrant specifically seeking support.

The professionals considered by parents who may be able to support varied between responses to the survey. Participants had reached out to a range of professionals including those in Figure 17 below.

Figure 17: Professionals Contacted by Participants Feeding into Their Knowledge Base



This category considers the knowledge held by parent and professional about sleep and sleep difficulties, and how that may impact the support the parent seeks. This is arguably one of the most prevalent areas arising in sleep research in general. The author found in the review of current literature, that parents would like ‘Assessment of sleep difficulties’ and ‘Knowledge about sleep and sleep difficulties’ when considering any support that they may seek. ‘Assessment of sleep difficulties’ was important to six out of nine parents interviewed in Sutton et al.’s (2019) study. In a number of reviewed studies, authors covered parents’ consideration of the knowledge they or the professionals they contacted had about sleep. Parents involved in Cook et al.’s (2020) study were concerned that professionals lack training in this area leading to a lower knowledge base from which to begin to support their child.

5.3.4 What about everything else (apart from sleep)?

During the interviews, when the researcher queried detail of the child’s specific difficulties with sleep it was often complicated. There were a multitude of areas in which the child struggled with sleep, and the parent found it difficult to know where to begin with discussing the issue or with seeking the help. Figure 18 shows some difficulties discussed.

Figure 18: Variety of Sleep Difficulties Discussed in Interviews.

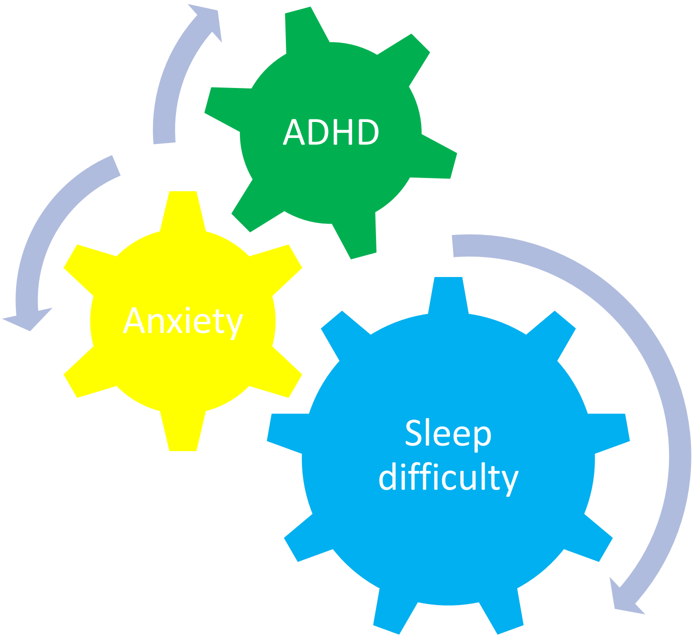
Understandably, when parents considered whether to seek support for their child, many other factors had to be held in mind. This category covers the author's findings in relation to this, and the impact on support-seeking for sleep.

This category was developed from the combination of the qualitative theme 'Losing Sleep' and the literature review theme 'Specific needs or diagnoses'. Subthemes developed from the former included 'Comorbidity of Issues' and 'It's not a Health Issue'. These contribute specifically towards the RQ regarding what parents consider when deciding whether to seek support. Namely, parents consider whether the other difficulties that the child is experiencing should be prioritised over sleep, and whether sleep is in fact a health issue or not.

General health comorbidity in children, increases the likelihood that there will be other factors to consider, for any child experiencing sleep issues (Konen et al., 2015; Luo et al., 2019; Pike, 2019).

From interview data, the author found that parents were more likely to seek support when their child had another specific health issue which led to support for sleep. It was found that it can be difficult to work out what is cause and what is effect with the array of issues discussed by research and within the current study's findings. Figure 19 below shows the complications that can arise from the relationship between issues a child may have.

Figure 19: An Example of How Health Issues Can Impact One Another



Rather than a simple cause and effect relationship, there is a cyclical, cog-style impact of elements on each other. This can be highly complicated for parents when it comes to decisions around seeking support for their children. It can be very difficult to determine what is the cause and what is the effect. Sometimes sleep issues will cause something else or make existing issues worse. At other times, other things will make the sleep issue worse.

Within the literature review theme of ‘Specific needs or diagnoses’, the articles explored depicted three specific diagnoses (epilepsy, autism and cerebral palsy) that impacted on sleep (Cook et al., 2021; McLay et al., 2020; Petersen et al., 2021)). For these parents, the medical need was such that medical support was a non-negotiable, they had to seek it. This led to them indirectly seeking help for the sleep issue or being offered support for the sleep issue even if they had not directly sought it. Please see appendix 21.

5.3.5 Summary of findings

This research has attempted to support understanding of how parents engage in help-seeking for their children’s sleep difficulties. It did so by focusing on what parents want, what they have sought and what they consider in the process. Findings show that sleep is a complex issue and there are many different avenues of support parents take and would like to take. However, there is often a mismatch between what they want and what is available. In addition, they may feel uncertain of what is available or what they want.

In the following section, the author will review this research with regards to ethical practice, reliability of results, implications and suggestions for future research.

5.4 Impact on participants

The author followed plans laid out in the methodology to ensure ethical practice when interviewing participants. This was based on the Tavistock and Portman's Research Ethics Committee (TREC) and British Psychological Society's (BPS) Code of Human Research Ethics, (2021).

At the end of the interviews, the interviewer asked participants how they found the experience and how it felt to reflect on their experiences. All provided rich responses, not all of which were positive, but none appeared to have been significantly negatively impacted on by the interviews and the discussion. They felt safe to be open about their experiences which was a positive outcome from the interviews. Below the author has outlined responses from participants.

Figure 20: Quotes from Participants Regarding how they Felt about the Process

Hmm. Err, probably helpful I think you tend to sort of not think about… aren't you programmed not to remem… to forget the baby years …
it is helpful to kind of think oh well what happened and what might be happening and impacting now. (E - 1, Pos. 527-531)

Yeah, I think it's always beneficial to isolate the thing you want to talk about and talk about it because sometimes you can talk about it alongside a whole load of other things and and there's the sleep and [miming lots of other things to discuss] there's you could go on and on.. (A - 4, Pos. 595-601)

No, it's been really helpful. It has helped me think a little bit more about. I don't know, these kind of conversations.

So I think that's probably the biggest takeaway for me is that I've realised that not getting it helped me realise as well, I'm not getting anywhere with the you know, the system. But there must be other people like me, who aren't getting anywhere with this system and have another way to come together. (T - 2, Pos. 700-719)

yeah, I think because it seems, sometimes it seems like with food, I think it's easier because it's in a way more obvious. Problem [to talk about], and the fact that people don't eat well, it's, you know, it has an immediate effect on your health. I think with sleep is Everything gets more subtle…

So, I think that there is the aspect as well, that it's not such, you know, a major obvious issue. You know, (D - 3, Pos. 388-398)

So it is helpful to think about it and also to remember the things that I've thought of before and then they've just gone in the, in the mists. (A - 4, Pos. 606-607)

Although there was a small sample size, findings from the interviews carried out in this study are poignant in content. The author found that families often feel there is much out there that can support them, but they are overwhelmed and unsure where to turn.

5.5 Implications and Dissemination of Findings

5.5.1 Implications for Families

From the findings derived from the current research, the author has uncovered a number of implications for families when there is a child with sleep difficulties. These are explored more fully above within this discussion chapter. This section will explore the implications for professionals working in the field of supporting children with cognition, learning, social, emotional, mental health needs, communication, interaction and sensory differences.

5.5.2 Implications for EPs:

5.5.2.1 Consultation and assessment

The research carried out with this study can contribute to the current research data base in the following ways. For EPs, consultation regularly involves discussion of parents' concerns of their children's sleep issues. The themes from this research could be used as prompts by EPs in their meetings to try and gain an idea of what support the parent has gained so far and what led to this. The findings can also be used as information for EPs to hold in mind as to what barriers may have been in place making it difficult for parents to seek help so far and/or what may be facilitators to support parents to seek out support. For example: trusting professionals, having the knowledge to support help-finding and having awareness of the importance of managing the issue. If awareness can continue to be raised with families and professionals regarding the issue of sleep, it may alleviate the issues presented within the subtheme ‘lost in the night’. EPs are also well placed in consultation to support parents though the decision-making process. Solution focused approaches or motivational interviewing (MI) techniques could be utilised to help reduce any ambivalence. EPs could also support with assessment since some parents said they wanted more information. The research findings also highlighted the individual nature of each child’s needs and how hard it can be to tease sleep apart from other issues. EPs are well placed to support with this if they are provided with more training around sleep.

5.5.2.2 Intervention and training

EPs could consider the training opportunities that may be created for their work in schools with staff and families. Signposting and supporting families or schools to link up with services that may aid them to support their children with sleep difficulties. The findings from this study showed that parents often felt a sense of not knowing enough and feeling that they ‘ought’ to know what to do. Alleviation of the impact that this has on help-seeking behaviours could be supported by provision of training and knowledge giving as then parents would see sleep as something requiring support and so hopefully feel a greater sense of permission to seek out support.

5.5.2.3 Research

There are further research opportunities that can be considered by a range of health professionals around the area of parental help-seeking for children’s sleep difficulties. It is clear from this research that families feel that more knowledge is needed amongst professionals about sleep science and specifically the difficulties children experience and what can be done to support them. There is unfortunately not scope within this study to explain the further research opportunities in detail, but suggestions for further research are discussed later in this chapter in section 5.9.

5.5.3 Implications for Schools and other Professionals working with CYP:

Implications for work include what has been written above, but also a consideration of what must be held in mind for parents not only with the issue of sleep but potentially so many other hidden areas. Sleep is very much a ‘hidden’ area possibly shown by the lack of research. It is known that sleep is important but it often appears to remain hidden and is rarely discussed. Schools need to keep bringing this to mind when thinking about the education of their pupils and planning of interventions, teaching plans or communication with families.

It is important to hold in mind some predictors for parental help-seeking for their children’s sleep difficulties as brought to light by this research. They include but are not limited to:

- Attitude towards the importance of sleep
- The child having other diagnoses
- Impact on other members of the family
- Impact on other areas of the child’s life
- Experience of help-seeking generally

5.6 Dissemination strategy

It will be important for the researcher to feedback to the participants as to what the overarching findings were. This is in line with ethical research procedures laid out in the BPS Code of Human Research Ethics (2021), but also feels to the researcher the most gracious way to thank the interviewee participants and acknowledge the positive and important impact that they have made to the research base. The researcher will produce a document to send that clearly shows the results, findings and interpretation based on the evidence from literature review. The researcher also plans to produce a peer-reviewed paper or blog to share their research more widely.

Steps have already been taken in the researcher's own practice to start to respond to parent views about the support they would like for their children's sleep. For example, the researcher produced a sleep support document that will be sent to the service in which the researcher had their placement. This will be available for EPs to use or send out to families experiencing relevant difficulties. A sleep workshop was held by the researcher in one school in their placement borough to support parents of children with sleep difficulties. From this, they gained some insight by asking school staff and families who attended what it was that they felt would be most beneficial in terms of a document to be produced following this research.

The simplified findings document that is produced to be sent to participants will also be used for sending out to stakeholders in the researcher's current EPS. It will be supportive to have ready to send out to anyone whenever it comes up as relevant or necessary within work. It will also be important to update this regularly and align it with the local area that the researcher is working within at any time.

Finally, the researcher plans to develop training for families, schools and other professionals working with children, regarding the findings from this research and how they can be utilised in practice. This will include a discussion with the researcher's current EPS team to gain an idea of whether they feel it is an area worth pursuing in terms of training for qualified EPs.

5.7 Researcher Reflexivity

With this section, the author will demonstrate and explain their learning and positioning in relation to the study. Researcher reflexivity is commented on in Chapter 1: Introduction, but it is relevant to add here that a limitation could be seen as the researcher having certain biases. They were approaching the research with the preconceived thought that families are not supported well with regards to children's sleep difficulties. There is a possibility that this belief may have clouded the author's interpretation of the data. Braun and Clarke (2006) view the practice of thematic analysis as inherently subjective, emphasizing researcher reflexivity, and rejecting the notion that coding can ever be fully accurate. They encourage researchers to link their personal positioning to their analytic process and engage in reflexivity.

Ethical considerations were made throughout the research process in line with content presented within the methodology. A research diary was kept by the author throughout the process, with which they collated their reflections on the experience. By reflecting on the process throughout, the author was able to interpret their findings more fully based on any preconceptions and the shift in thinking that occurred. Some learning points from these reflections are presented below in italics and first person. They are derived from the researcher's diary and show how their thinking changed through and following the research.

I came into this project with some preconceived thoughts around the poor quality of support for children's sleep problems. This preconception has developed through my work with families so far. As I worked on the research and carried out interviews, I noticed feelings of hopelessness in the system and it felt like too big a problem to try and explore or make any impact towards solving. This fed into my feelings about the writing up of my work. I noticed feelings of hopelessness in the project which were likely projections of my connection with the participants.

I came into the work thinking about sleep difficulties, but have now realised that even the defining of the sleep problems is far more complicated than that, and that the explanation of what the issue with the sleep was became complex and time consuming for the parent.

When I was coding the qualitative data, I noticed that I was losing certain themes amongst others, including the 'Losing Sleep' theme as I found the focus often shifted away from the sleep itself. During the interviews themselves this was the case as well which is why I chose the aptly named theme of 'Losing Sleep'. For this reason, I was sure to read and re-read the data several times so I did not miss anything. Finally, I used supervision to draw out any themes that I may have missed. I felt that it was important to maintain awareness that I am just one person looking at all of this.

Sleep issues, appeared to often become 'invisible problems', as they so often seem to disappear in the light of day.

5.8 Strengths and Limitations of this Research

The following section will cover strengths and limitations of both the quantitative and the qualitative elements of the research that the author felt most important to bring to the reader's attention.

5.8.1 Strengths

Parental help-seeking for children's sleep difficulties is an under-researched area and it is raised a lot during EP work. The author was sure to reach out with a questionnaire to the whole country so as not to focus on just one geographical region. The goal here was to provide all primary schools in England with an invitation to be involved. The quantitative phase obtained a reasonable sample from across the country which supported and added to findings from the qualitative phase and the findings obtained from a review of the literature. A mixed methods approach supported the gathering of rich data as the study benefited from the strengths of both quantitative and qualitative research methods (Johnson & Onwuegbuzie, 2004). Distinctiveness is demonstrated by presenting the two sets of findings and then forming them into one coherent narrative, which provides a more credible account than either set of findings in isolation. The researcher found that the interviews provide a chance for much more in-depth discussions than the answers to the questionnaire alone. Finally, the author has uncovered new information that is not in currently existing research. These new findings have been triangulated with existing research to add to the validity.

5.8.2 Limitations

The author can see that by creating new themes in the literature review, at every point they are assuming and imposing on the data. In fact, a richer way to review the data would have been to impose simply the literature review question (LRQ) on the literature. The author is aware that ideally the story they tell would make those distinctions. The author is aware that this is a very unusual way of synthesizing the literature. It is not really a thematic synthesis as such, it is more of a theme-wise organization of the data.

The qualitative element of the study uses a very small data set as it was much harder to gather participants than the researcher anticipated. (The researcher hypothesised that this may have been because sleep is an area lacking a ‘health’ focus. There may have been more take up for example for a study around something that has a specific diagnosis.)

There is a lack of generalisability partially due to the sample size of the quantitative part of the study. The author also acknowledges that the views of the parents represented in the questionnaire and the interviews are those who are already actively engaged in a help seeking process which may have caused some bias in participants. The author is also aware that they did not use a range of sampling methods which may have supported a more ethically sourced approach.

Participants, particularly for the questionnaire are a group who have access to a device that connects to the internet and who look at school communications. The author is aware that this will not therefore represent the views of everyone, particularly those who are already disengaged with help-seeking.

It is important to acknowledge that the questionnaire did not ask for demographic information such as geographical location, sex, age, race, ethnicity, education or employment. The questionnaire also did not ask about family structure, e.g., single-parent, other family members, siblings, etc. It may have been beneficial to gather some demographic information with the questionnaire to gain more insight into predictors of parental help-seeking behaviours. The researcher felt that it was not directly answering the research question, but it may still have supported information gathering. Finally, the questionnaire had a design flaw in that it did not filter for only those parents who perceived their child(ren) to have sleep difficulties.

5.8.3 Reliability, validity and trustworthiness

In the methodology, the author set out the plans to ensure reliable, valid and trustworthy research would be carried out. Here, the author discusses how reliable, valid and trustworthy the findings are now that the research is complete.

As this study utilised a mixed-methods approach, during both quantitative and qualitative elements of the study steps have been taken to address the reliability and validity of the research. Triangulation with other research from the literature review also supports validity of the findings; and the in-depth nature of the interviews support reliability. Interviews provide a richness of data that a questionnaire cannot.

5.8.4 Generalisability

It was never the researcher’s intention to generalise information as this was an exploratory study. Although the responses of 251 parents can't be used to make estimates of the prevalence of sleep difficulties across the country, the content analysis of what they were concerned about and wanted support for is still useful in thinking about trends.

5.9 Suggestions for Future Research

Following on from the limitations mentioned above, the following gaps still exist and the author would like to see research continue in these areas:

- What do parents feel is going well to support their children’s sleep issues and how can we expand on this?
- What the main presenting needs are nationwide in relation to children’s sleep difficulties?
- Who are the most supportive professionals when it comes to children’s sleep and how can access to them be made easier for families?
- Future research would also benefit by focusing on how to engage parents and families who are less likely to seek help.

6.0 Conclusions

This chapter covered the depth of findings extracted from this research and interpreted them in a way that adds to the development of what can happen next to support this area. The ‘so what?’ question is vital to supporting the development of practice in all professions that support families and young people. A summary of findings is provided with the first half of the chapter, bringing together quantitative results and qualitative findings alongside the themes developed following the review of the literature. The second half took the reader through some researcher reflections on strengths, limitations, implications for practice and recommendations for future research.

The researcher has also reflected on their own thoughts and feelings about carrying out the research, and would like to end by commenting on the thoroughly fascinating journey they have taken. Discoveries have been made throughout in relation to not only the topic of help-seeking for sleep difficulties, but for EP practice in general and the engagement of families in services offered by education, health and other children's services. It is the sincere hope of the researcher, that this study contributes to a continued, positive change in the way families can access the support they most need for the areas they need it, whatever they may be.

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Appendices

Appendix 1: Critical Appraisal Skills Programmes (CASP) Checklists

Critical Appraisal Skills Programmes (CASP) question	Author(s) of study Colour key: Green = yes Red = no Yellow = can’t tell				
	Cook et al., 2020	Cook et al., 2021	Hatton & Gardani, 2018	Petersen et al., 2021	Sutton et al.,
Was there a clear statement of the aims of the research?	🟩	🟩	🟩	🟩	🟩
Is a qualitative method appropriate?	🟩	🟩	🟩	🟩	🟩
Was the research design appropriate to address the aims of the research?	🟩	🟨	🟩	🟩	🟩
Was the recruitment strategy appropriate to the aims of the research?	🟩	🟨	🟩	🟩	🟩
Was the data collected in a way that addressed the research issues?	🟩	🟩	🟩	🟩	🟩
Has the relationship between researcher and participants been	🟨	🟨	🟩	🟨	🟨

adequately considered?	🟨	🟨	🟩	🟨	🟨
Have ethical issues been taken into consideration?	🟩	🟩	🟩	🟨	🟩
Was the data analysis sufficiently rigorous?	🟩	🟩	🟩	🟩	🟩
Is there clear statements of findings?	🟩	🟩	🟩	🟩	🟩
How valuable is the research?	Very. Throughout the report the author explains what appear to be important next steps bae on the results found. Triangulation and supportive evidence backs up points made. Findings grouped and pulled together well in ‘Discussion’. Practical approaches to addressing barriers are suggested. Outcomes are suggested based on results.	Moderately in response to my LRQ. Focused on specific additional need (epilepsy).	A statement of contribution is made on page 476 of this research. There is detail provided around three aspects of parental views on seeking advice for sleep difficulties (how, what and when).	Valuable locally to the study with some contribution also to existing research. Presents previously unknown findings about parents help seeking.	Very valuable. Helping understanding of reasons behind help seeking for sleep difficulties.

Appendix 2: Critical Appraisal of a Survey, Center for Evidence-Based Management (CEBMa) Checklists

Question	Author(s) of study Colour key: Green = yes Red = no Yellow = can’t tell	
	McLay et al., 2020	Newton et al., 2021
Did the study address a clearly focused question / issue?	🟩	🟩
Is the research method (study design) appropriate for answering the research question?	🟩	🟩
Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described?	🟩	🟩
Could the way the sample was obtained introduce (selection) bias?	🟩	🟨
Was the sample of subjects representative with regard to the population to which the findings will be referred?	🟥	🟩
Was the sample size based on pre-study considerations of statistical power?	🟨	🟨
Was a satisfactory response rate achieved?	🟩	🟩
Are the measurements (questionnaires) likely to be valid and reliable?	🟨	🟩
Was the statistical significance assessed?	🟩	🟩
Are confidence intervals given for the main results?	🟨	🟩
Could there be confounding factors that haven’t been accounted for?	🟨	🟨
Can the results be applied to your organisation?	🟨	🟨

Appendix 3: Full List of Excluded Studies and Rationale for Exclusion

Reference	Reason for Exclusion
Ben-Zion, H., Volkovich, E., Meiri, G. & Tikotzky, L. (2020). Mother-Infant Sleep and Maternal Emotional Distress in Solo-Mother and Two-Parent Families. *Journal of Pediatric Psychology, 45*(2), 181-193.	Focus on emotional distress around sleep difficulties rather than help-seeking.
Cavalieri, A. (2016). Sleep Issues in Children with Autism Spectrum Disorder. *Paediatric Nursing, 42*(4), 169-188.	Discussion around why it is hard to find treatment for sleep issues in ASD population of children
Corkum, P., Lingley-Pottie, P., Davidson, F., McGrath, P., Chambers, C. T., Mullane, J., Laredo, S., Woodford, K. & Weiss, S. K. (2016). Better Nights/Better Days—Distance Intervention for Insomnia in School-Aged Children With/Without ADHD: A Randomized Controlled Trial. *Journal of Pediatric Psychology, 41*(6), 701-713.	Measuring effectiveness of intervention to support sleep difficulties.
Galland, B. C., Sayers, R. M., Cameron, S. L., Gray, A. R., Heath, A. M., Newlands, A., Taylor, B. J. & Taylor, R. W. (2017). Anticipatory guidance to prevent infant sleep problems within a randomised controlled trial: infant, maternal and partner outcomes at 6 months of age. *BMJ Open.*	Measuring the effectiveness of a sleep intervention.
Hall, W. A., Hutton, E., Brant, R. F., Collet, J. P., Gregg, K., Saunders, R., Ipsiroglu, O., Gafni, A.,	Measuring the effects of a sleep intervention.

Triolet, K., Tse, L., Bhagat, R. & Wooldridge, J. (2015). A randomized controlled trial of an intervention for infants' behavioural sleep problems.	
Hulst, R. Y., Pillen, S., Voorman, J. M., Rave, N., Visser-Meily, J. M. A. & Verschuren, O. (2020). Sleep health practices and sleep knowledge among healthcare professionals in Dutch paediatric rehabilitation. *Child: Care, Health and Development, 46,* 703-710.	Descriptive about assessment of Health Care Professional (HCP) knowledge and practices.
Lai, J., Blackwell, C. K., Tucker, C. A., Jensen, S. E. & Cella, D. (2022). Measuring PROMIS Physical Activity and Sleep Problems in Early Childhood. *Journal of Pediatric Psychology, 47*(5), 534-546.	Descriptive of a measure for sleep difficulties.
Lang, C. P., Boucaut, A., Guppy, M. & Johnston, L. M. (2021). Children with cerebral palsy: A cross-sectional study of their sleep and their caregiver's sleep quality, psychological health and well-being. *Child: Care, Health and Development, 47,* 859-868.	Focus is on caregiver's sleep quality alongside child's sleep.
Mclay, L. K., Hansen, S. G., Blampied, N. M., France, K. G. & Rispoli, M. (2023). The Type, Severity, and Impact of Sleep Problems in Children With Angelman Syndrome and Parental Help-seeking Patterns. *Behavioural Sleep Medicine,* DOI: 10.1080/15402002.2023.2241943	Focus is on parental help-seeking *patterns* rather than parental *views* about the help available.

MacKenzie, N. E., Keys, E., Hall., W. A., Gruber, R., Smith, I. M., Constantin, E. Godbout, R., Stremler, R., Reid, G. J., Hanlon-Dearman, A., Brown, C. A., Shea, S., Weiss, S. K., Ipsiroglu, O., Witmans, M., Chambers, C. T., Andreou, Pantelis, Begum, E. & Corkum, P. (2021). Children's Sleep During COVID-19: How Sleep Influences Surviving and Thriving in Families. *Journal of Pediatric Psychology, 46*(9) 1051-1062.	Focus on changes in sleep difficulties during COVID-19.
Mansolf, M. & Blackwell, C. K. (2023). Sleep-Related Items on the School-Age CBCL and the PROMIS Sleep Disturbance 4-Item Short-Form: A Psychometric Comparison From the Environmental Influences on Child Health Outcomes (ECHO) Program. *Psychological Assessment, 35*(5), 443-452.	Using a tool to measure child sleep disturbance.
McQuillan, M. E., Bates, J. E., Staples, A. D. & Deater-Deckard, K. (2019). Maternal Stress, Sleep, and Parenting. *Journal of Family Psychology, 33*(3), 349-359.	Focused on parent sleep and associated stress and parenting style.
Nieto, M., Motos, B., Navarro, B., Jimeno, M. V., Fernandez-Aguilar, L., Ros, L., Ricarte, J. J. & Latorre, J. M. (2022). Relation between nighttime sleep duration and executive functioning in a nonclinical sample of preschool children. *Scandinavian Journal of Psychology, 63,* 191-198.	Focus was on analysing the association between night time sleep duration and executive functioning.

Quach, J., Gold, L., Hiscock, H., Mensah, F. K., Lucas, N., Nicholson, J. M. & Wake, M. (2013). Primary healthcare costs associated with sleep problems up to age 7 years: Australian population-based study. *BMJ Open, 3,* 1-8.	Comparison of government health-care services for children with sleep problems.
Rudd, B. N., Reilly, M. E., Holtzworth-Munroe, A., D'Onofrio, B. M. & Waldron, M. (2021). Interactive Effects of Parental Separation and Socioeconomic Status on Child Sleep Quality and Child Development. *Journal of Child and Family Studies, 30,* 2180-2190.	Focus was on the effect of parental separation and socioeconomic status on child sleep quality.
Santos, I. S., Bassani, D. G., Maatijasevich, A., Hala, C. S., Del-Ponte, B., Henreques da Cruz, S., Anselmi, L., Albernaz, E., Fernandes, M., Tovo-Rodrigues, L., Silveira, M. F. & Hallal, P. C. (2016). Infant sleep hygiene counselling (sleep trial): protocol of a randomized controlled trial. *BMC Psychiatry, 16*(307), 1-9.	Measuring effectiveness of intervention on self-regulated sleep duration for babies and very young children.
Schwichtenberg, A. J., Hensle, T., Honaker, S., Miller, M., Ozonoff, S., Anders, T. (2016). Sibling Sleep – What Can It Tell Us About Parental Sleep Reports in the Context of Autism? *Clinical Practice in Paediatric Psychology, 4*(2), 137-152.	Assessing parental report accuracy of children with ASD's sleep difficulties.
Sciberras, E., Hiscock, H., Cortese, S., Becker, S. P., Fernando, J. W. & Mulraney, M. (2023). Variation in sleep profiles in children with ADHD and associated	The focus was on correlation of sleep profiles in children with ADHD and clinical factors.

clinical characteristics. *The Journal of Child Psychology and Psychiatry, 64*(10), 1462-1469.	
Singh, B. S. K., Danckaerts, M. & Van den Bergh, B. R. H. (2021). Helping Families of Infants With Persistent Crying and Sleep Problems in a Day-Clinic. *Frontiers in Psychiatry 12,* 591389.	Assessing impact of parental self-regulation on children's sleep difficulties.
Stuttard, L., Clarke, S., Thomas, M. & Beresford, B. (2015). Replacing home visits with telephone calls to support parents implementing a sleep management intervention: findings from a pilot study and implication for future research. *Child: care, health and development, 41*(6), 1074-1081.	Exploring feasibility and acceptability of 'home visit' vs 'telephone call' as intervention to support parents of children with sleep-difficulty.

Appendix 4: Online Questionnaire Questions

1) Do you feel that your child has difficulties with their sleep?

Yes / No

(If No is answered, this will end the questionnaire and the participant will be thanked for their participation)

(If Yes is answered, the participant will be moved to question 2)

2) Would you like to be able to access support in relation to the concerns you have about your child's sleep?

Yes/No

(If No is answered, this will end the questionnaire and the participant will be thanked for their participation)

(If Yes is answered, the participant will be moved to question 3)

3) What type of support would you like to access?

4) Have you sought support for your concerns about your child's sleep?

Yes/No

(If No is answered, the final question will be presented)

(If Yes is answered, the participant will be moved to question 5)

5) Please provide brief details of the support that you sought.

If you are willing to consider participating in an interview to provide more detailed information about your concerns about your child's sleep and the sort of support you would like to be able to access, please provide an email address that you can be contacted on. Further information about the interviews will be supplied to enable you to make an informed decision about whether to participate.

Thank you for your participation

Appendix 5: Information Sheet for Phase 1 (Quantitative Phase)

The Tavistock and Portman
NHS Foundation Trust

Thank you for taking the time to read this information sheet regarding my research project about your child's sleep.

A research project will be running in your child's school soon, and this information sheet has been written to provide you with information to help you decide if you would like to participate. If, having read this information, you would like to take part, please click on the link to the questionnaire below.

Who am I?
My name is Amy Tyler. I am a Year 3 trainee Educational Psychologist at the Tavistock and Portman NHS Trust. I am studying for the professional Doctorate in Educational and Child Psychology. I am on placement in ________ Local Authority and am carrying out this research as part of my training.

What is the research about?
I am interested in hearing about parents'/carers'/guardians' views of their child/children's sleep difficulties. The study aims to identify what support local parents want and what might help or get in the way of accessing wanted support.

What am I hoping to achieve?
It is my hope that this information will help people working in the Local Authority to better understand:

- The demand/need for sleep related support for parents of children aged 3-11
- What sleep related support parents would like
- What would help or get in the way of parents accessing support that could be made available

Why are you being invited to participate?
Your child's school has agreed to send this information sheet to all parents/carers. I am hoping to include as many parents as possible.

What will taking part involve?
The study has two parts. The first involves completing a simple online questionnaire that should take no more than 10 minutes to complete. The second part involves an interview that will last a maximum of one hour.

It is possible to take part in just the questionnaire. Once the questionnaire is completed, there is an option for participants to express an interest in taking part in an interview. Should they choose to, there will be space to add their contact details to allow me to contact them about this.

If you agree to take part in the questionnaire, what happens next?
If you would like to take part, please click on the link to the questionnaire below. This will take you to a short consent form which needs to be completed. You will then automatically be connected to the questionnaire.

Do you have to take part?
Taking part is entirely voluntary and is not connected to any support your child has or will receive from the Local Authority.

Your personal information
Your participation and data in this part of the study will be anonymous. I will not receive any personally identifiable details that will enable your data to be linked to you.

Can you change your mind?
Participation in this research is voluntary and you are free to withdraw from the research at any time without giving a reason. Because your participation in this part of the research is anonymous, once you have submitted the questionnaire, I will not be able to remove the data as I will not know who the responses belong to.

What happens to the information I gather?
Information collected from the questionnaire will be analysed and written up in a document that will be held at the Tavistock and Portman library. I also hope to publish the general themes from the study in the future.

Ethical Approval
If you have any queries about the ethical approval of this research, or other aspects of this project, please contact, the Tavistock and Portman NHS Trust Quality Assurance Officer, using this email address:

If you would like to find out more about this study, you can contact me using the following email address:

Thank you for reading this information sheet.

If you would like to take part in the questionnaire, please click on the link below:
[link will appear here]

Appendix 6: Consent Form for Phase 1 (Quantitative Phase)

Title: Parental concerns about children’s sleep; the support parents would like to access; and how they would like to access support

Thank you for clicking on the link to the questionnaire about Children’s sleep and the support parents might like in relation to this.

Before completing the questionnaire, I need to make sure that you understand what the research involves and that you consent to participating. To do this, please complete the following:

	Yes	No
I have read and understood the information sheet about this questionnaire and have had a chance to have any questions I have about it answered		
I understand that this research is being conducted as part of a university degree that the researcher is studying for		
I understand that my participation in this research is entirely voluntary, and I am free to withdraw from it before completing the questionnaire		
I understand that my data in this questionnaire is anonymised and once I have submitted it, I will not be able to withdraw it as the researcher will not be able to identify it as belonging to me		
I understand that the findings from this research will be published in a research report and they may also be shared in other presentations or publications		
I am happy to participate in the questionnaire		

If the answers to all of the above are ‘Yes’, the respondent will automatically be linked to the questionnaire.

If the answer to any of the above is ‘No’, the respondent will not be able to access the questionnaire. Instead, they will be invited to contact the researcher to discuss their participation.

Appendix 7: Information Sheet for Phase 2 (Qualitative Phase)

NHS
The Tavistock and Portman
NHS Foundation Trust

Thank you for your interest in my research project about your child's sleep.

I am grateful to you for volunteering to participate in this interview. Please read the information sheet below and then please complete the attached consent form. Feel free to contact me with any questions on the email address below:

Who am I?

My name is Amy Tyler. I am a Year 3 trainee Educational Psychologist at the Tavistock and Portman NHS Trust. I am studying for the professional Doctorate in Educational and Child Psychology. I am on placement in ________ Local Authority and am carrying out this research as part of my training.

What is the research about?

I am interested in hearing about parents'/carers'/guardians' views of their child/children's sleep difficulties. The study aims to identify what support local parents want and what might help or get in the way of accessing wanted support.

What am I hoping to achieve?

It is my hope that this information will help people working in the Local Authority to better understand:

- The demand/need for sleep related support for parents of children aged 3-11
- What sleep related support parents would like
- What would help or get in the way of parents accessing support that could be made available

Why are you being invited to participate?

When you completed my online questionnaire about your child's sleep, you stated that you would be willing to consider participating in an interview and provided your email address. This information sheet is being sent to you in response to that expression of interest.

What will taking part involve?

This information sheet is about participating in an interview.

The interview will last for no more than one hour. It will explore your concerns about your child's sleep, what help you feel you would like and how you would like to access this help. I will make an audio recording of the interview which I will delete once I have typed up what was said. When I do this, I will change any details that could identify you, to ensure your responses are anonymised.

The interview will be arranged at a time that is convenient to you at your child's school. Alternatively, it can take place online, via Zoom, if you prefer.

Your personal information

I will be the only person who has access to your identifiable information in this study. Any information collected will be kept following the Data Protection Act (2018) and GDPR guidance.

All records related to your participation will be handled and stored securely on an encrypted drive using password protection. Any identifying information on these records will be changed, to avoid your identification. However, due to the small sample size, there is a potential for identification. The data will be kept for a maximum of 10 years.

However, if you share any information linked to your safety or the safety of others, I have a duty of care to share this information under safeguarding procedures. I will tell you if there is information which I need to share.

Can you change your mind?
Participation in this research is voluntary and you are free to withdraw from the research at any time without giving a reason. Any information you provide (including what you say in the interviews) can be deleted and removed from the study, at your request, up until the point that the analysis has been completed and submitted for review by my supervisor.

What happens to the information I gather?
Information collected from the interview will be analysed and written up in a document that will be held at the Tavistock and Portman library. I also hope to publish the general themes from the study in the future.

Ethical Approval
If you have any queries about the ethical approval of this research, or other aspects of this project, please contact, the Tavistock and Portman NHS Trust Quality Assurance Officer, using this email address:

If you would like to find out more about this study, you can also contact me using the following email address:

Thank you for reading this information sheet.

Appendix 8: Consent Form for Phase 2 (Qualitative Phase)

Title: Parental concerns about children’s sleep; the support parents would like to access; and how they would like to access support

Thank you for your interest in taking part in an interview about Children’s sleep and the support parents might like in relation to this.

Before taking part in the interview, I need to make sure that you fully understand what the research involves and that you fully consent to participating. To do this, please complete the following:

	Yes	No
I have read and understood the information sheet about this interview and have had a chance to have any questions I have about it answered		
I understand that this research is being conducted as part of a university degree that the researcher is studying for		
I understand that my participation in this research is entirely voluntary and I am able to withdraw consent, and my data, up until the data analysis has been conducted		
I agree for my interview to be recorded		
I understand that my data will be anonymised so that people reading the research will not link my data to me but that due to the small sample size, there is a potential for identification.		
I understand that there are limits to confidentiality and if I share information about potential harm to myself or others, the researcher is legally required to share this information		
I understand that the findings from this research will be published in a research report and they may also be shared in other presentations or publications		
I am happy to participate in the interview		

Parent/carer/guardian’s signature:
…………………………………………………………………………………….
Parent/carer/guardian’s name (BLOCK CAPITALS):
…………………………………………………………………………………….
Relationship to the child:
……………………………………………………………………………………..
Contact Email:
……………………………………………………………………………………..

Date: ……………………..………………
Please return to:
Amy Tyler

Appendix 9: Semi-structured Interview Schedule

The interview schedule has yet to be developed. The aspects of parental experiences that will be explored will be limited to the following:

- The concerns parents have about their child’s sleep
- Whether they have accessed support
- Where support has been accessed, their experiences/views about what was received
- What did or would encourage/discourage them to seek help
- Whether they have been offered and decline support

Appendix 10: Tavistock and Portman Trust Research Ethics Committee (TREC) form (original)

The Tavistock and Portman NHS
NHS Foundation Trust

Tavistock and Portman Trust Research Ethics Committee (TREC)
APPLICATION FOR ETHICAL REVIEW OF STUDENT RESEARCH PROJECTS

This application should be submitted alongside copies of any supporting documentation which will be handed to participants, including a participant information sheet, consent form, self-completion survey or questionnaire.

Where a form is submitted and sections are incomplete, the form will not be considered by TREC and will be returned to the applicant for completion.

For further guidance please contact

FOR ALL APPLICANTS

If you already have ethical approval from another body (including HRA/IRAS) please submit the application form and outcome letters. You need only complete sections of the TREC form which are NOT covered in your existing approval

Is your project considered as 'research' according to the HRA tool? (http://www.hra-decisiontools.org.uk/research/index.html)	Yes
Will your project involve participants who are under 18 or who are classed as vulnerable? (see section 7)	No
Will your project include data collection outside of the UK?	No

SECTION A: PROJECT DETAILS

Project title	Parents' views on their Key Stage 2 children's sleep difficulties and their approach to help seeking: An exploratory study.		
Proposed project start date	June 2022	**Anticipated project end date**	August 2023
Principle Investigator (normally your Research Supervisor): Jude Mortell			
Please note: TREC approval will only be given for the length of the project as stated above up to a maximum of 6 years. Projects exceeding these timeframes will need additional ethical approval			
Has NHS or other approval been sought for this research including through submission via	**YES (NRES approval)** ☐ ☐ **YES (HRA approval)** ☐		

Research Application System (IRAS) or to the Health Research Authority (HRA)?	**Other** ☒ **NO**
If you already have ethical approval from another body (including HRA/IRAS) please submit the application form and outcome letters.	

SECTION B: APPLICANT DETAILS

Name of Researcher	Amy Tyler
Programme of Study and Target Award	Professional Doctorate for Child, Community and Educational Psychology
Email address	
Contact telephone number	

SECTION C: CONFLICTS OF INTEREST

Will any of the researchers or their institutions receive any other benefits or incentives for taking part in this research over and above their normal salary package or the costs of undertaking the research? **YES** ☐ **NO** ☒ If **YES**, please detail below:
N/A
Is there any further possibility for conflict of interest? YES ☐ **NO** ☒
Are you proposing to conduct this work in a location where you work or have a placement? **YES** ☒ **NO** ☐ If **YES**, please detail below outline how you will avoid issues arising around colleagues being involved in this project:
The design of the study excludes involvement of colleagues from the Educational Psychology Service. The design involves participating/consenting school staff playing a supporting role in disseminating information to potential participants (parents from their school communities). Their involvement will be limited to disseminating information

Is your project being commissioned by and/or carried out on behalf of a body external to the Trust? (for example;	**YES** ☐ **NO** ☒

commissioned by a local authority, school, care home, other NHS Trust or other organisation). *Please note that 'external' is defined as an organisation which is external to the Tavistock and Portman NHS Foundation Trust (Trust)	
If **YES**, please add details here: N/A	
Will you be required to get further ethical approval after receiving TREC approval? If **YES**, please supply details of the ethical approval bodies below AND include any letters of approval from the ethical approval bodies (letters received after receiving TREC approval should be submitted to complete your record):	**YES** ☐ **NO** ☒
N/A	
If your project is being undertaken with one or more clinical services or organisations external to the Trust, please provide details of these:	
N/A	
If you still need to agree these arrangements or if you can only approach organisations after you have ethical approval, please identify the types of organisations (eg. schools or clinical services) you wish to approach:	
N/A	
Do you have approval from the organisations detailed above? (this includes R&D approval where relevant) Please attach approval letters to this application. Any approval letters received after TREC approval has been granted MUST be submitted to be appended to your record	**YES** ☐ **NO** ☐ **NA** ☒

SECTION D: SIGNATURES AND DECLARATIONS

APPLICANT DECLARATION

I confirm that:

- The information contained in this application is, to the best of my knowledge, correct and up to date.
- I have attempted to identify all risks related to the research.
- I acknowledge my obligations and commitment to upholding ethical principles and to keep my supervisor updated with the progress of my research

- I am aware that for cases of proven misconduct, it may result in formal disciplinary proceedings and/or the cancellation of the proposed research.
- I understand that if my project design, methodology or method of data collection changes I must seek an amendment to my ethical approvals as failure to do so, may result in a report of academic and/or research misconduct.

Applicant (print name)	AMY TYLER
Signed	ATyler
Date	30.05.22

FOR RESEARCH DEGREE STUDENT APPLICANTS ONLY

Name of Supervisor/Principal Investigator	Jude Mortell

Supervisor –

- Does the student have the necessary skills to carry out the research?
  YES ☒ **NO** ☐
- Is the participant information sheet, consent form and any other documentation appropriate?
  YES ☒ **NO** ☐
- Are the procedures for recruitment of participants and obtaining informed consent suitable and sufficient?
  YES ☒ **NO** ☐
- Where required, does the researcher have current Disclosure and Barring Service (DBS) clearance?
  YES ☒ **NO** ☐

Signed	
Date	30.05.22

COURSE LEAD/RESEARCH LEAD

Does the proposed research as detailed herein have your support to proceed? YES ☐ NO ☐

Signed	
Date	

SECTION E: DETAILS OF THE PROPOSED RESEARCH

1.	**Provide a brief description of the proposed research, including the requirements of participants. This must be in lay terms and free from technical or discipline specific terminology or jargon. If such terms are required, please ensure they are adequately explained (Do not exceed 500 words)**

The proposed research will explore the views and experiences of parents/carers/guardians of Key Stage 2 (KS2, aged 7-11) children, who have concerns around their child(ren)'s sleep. It will explore their desire for help and experiences of seeking help in relation to their concerns about their child(ren)'s sleep. (NB. The term 'parents' will be used throughout this form to refer to parents/carers/guardians).

Parents of KS2 children in the local authority (LA) where the researcher is undertaking a training placement will be sent a link to an online survey via their child's school. This will seek to find out whether they have concerns around their child's sleep; the nature of these concerns; whether they have sought support or not; and potential reasons behind this. This should take no longer than 10 minutes to complete.

Between six and eight of the participants who respond to the survey will be invited to attend an interview for a more in-depth exploration of their experiences. These will be parents who have sleep related concerns and would like to access support. Interviews will be conducted at the child's school, at the parental home, or online – whichever the participant prefers. They will last for a maximum of one hour.

2.	**Provide a statement on the aims and significance of the proposed research, including potential impact to knowledge and understanding in the field (where appropriate, indicate the associated hypothesis which will be tested). This should be a clear justification of the proposed research, why it should proceed and a statement on any anticipated benefits to the community. (Do not exceed 700 words)**

The research aims to find out what form of support parents of KS2 children would like to access to help with their child's sleep and what are the facilitators and barriers to seeking help. The intention behind the research is to inform the researcher's LA of the prevalence of sleep difficulties within the KS2 population and how best to provide support when it is needed.

The significant impact of sleep on both physical and mental health is evidenced in a wide range of literature (Williamson et al., 2020) including on educational and personal outcomes for young people (Konen et al, 2015). The patterns and habits that children form in early life can support them to develop positive sleep habits and routines into adulthood (Sutton et al., 2019). Between the ages of 7 and 11, parents still largely manage or heavily support their children's bedtime and sleep routine/hygiene. However, the Early Years support from health professionals, such as health visitors, has usually ended by this age. This research aims to explore what support parents of children in this age range would like with their child's sleep, how likely they are to access this if it were available and what may help them to access it. Research has shown that parents can be reluctant to seek support for their children's sleep difficulties (Cook et al., 2020). In a longitudinal study by Williamson et al. (2020), 5107 children were recruited at birth and monitored for sleep difficulties up to the ages of 11; almost half of the children in this study had some form of reported sleep difficulty. This high prevalence provides further rationale for the current exploratory study. Despite how well-established the importance of sleep is, there is little research into what specifically parents would seek or use in terms of support, especially in the age range being researched with this study. The barriers Cook et al. (2020) put forward included perceptions of service quality and parental expectations of what they would be offered.

Educational psychologists (EPs) in the researcher's LA have raised concerns about sleep difficulties in primary school children. It is an issue that arises in their case work on a regular basis. This supports thinking that it warrants further exploration. Answering the research questions proposed in this study could help inform decision making for the Local Offer.

The research questions that this study will aim to answer are:

What is the prevalence of parental concern about the sleep patterns of Key Stage 2 children in X LA?
What support would parents like in helping their children's sleep?
What support have parents accessed in relation to helping their children sleep?
Of those parents who want help but haven't accessed it, what are the barriers and facilitators to accessing support?

References

Cook, G., Appleton, J. V. & Wiggs, L. (2020). Parentally reported barriers to seeking help and advice for child sleep from healthcare professionals. *Child: Care, Health and Development, 46*(4), 513-521.

Konen, T., Dirk, J. & Schmiedek, F. (2015). Cognitive benefits of last night's sleep: daily variations in children's sleep behavior are related to working memory fluctuations. *Journal of Child Psychology and Psychiatry, 56*(2), 171–182.

Sutton, J. E., Huws, J. C. & Burton, C. R. (2019). *Experiences of sleep hygiene education as an intervention for sleep problems in children with developmental disabilities: Findings from an exploratory study*. Wiley.

Williamson, A. A., Mindell, J. A., Hiscock, H. & Quach, J. (2020). Longitudinal sleep problem trajectories are associated with multiple impairments in child well-being. *Journal of Child Psychology and Psychiatry, 61*(10), 1092-1103.

3. Provide an outline of the methodology for the proposed research, including proposed method of data collection, *tasks* assigned to participants of the research and the proposed method and duration of data analysis. If the proposed research makes use of pre-established and generally accepted techniques, please make this clear. (Do not exceed 500 words)

The study will be a mixed-methods, sequential exploratory design and will be conducted in two phases.

Quantitative Phase:
Data for the quantitative element of the study will be collected via an online survey sent to all parents of KS2 pupils attending publicly funded mainstream schools (who have agreed to participate) in the researcher's placement LA (see Appendix A). Data from the survey will be analysed using descriptive statistics (Byrne, 2007). The survey will be developed using guidance around clearly defined questions (Robson and McCarten, 2016). It will be developed according to the BRUSO model (Peterson, 2000), which stands for 'brief', 'relevant', 'unambiguous', 'specific' and 'objective'.

Qualitative
Between six and eight parents will be interviewed using a semi-structured interview schedule (see Appendix B). Interviews will be roughly an hour in length. Semi-structured interviews are a style of interviewing where the interviewer has only a brief number of topics or questions for each interview initially, but has freedom between interviews to adapt the pace, order and wording of each question according to the interview content as it emerges (Robson and McCarten, 2016). All interviews will be recorded using audio equipment and will be transcribed. Interviews will be held either in the school which the parent's child attends, the parent's home or online via Zoom; they will be given the choice.

The qualitative data generated from interviews will be analysed using reflexive thematic analysis (Braun & Clarke, 2021). Interview transcripts will be searched for themes emerging. Once themes are identified across interviews, they will grouped and evaluated. Patterns and commonalities will then be identified and reported to present the findings.

References

Braun, V., & Clarke, V. (2021). Thematic Analysis: A practical guide.

Byrne, G. (2007). A Statistical Primer: Understanding Descriptive and Inferential Statistics

Peterson, R.A. (2000) Constructing Effective Questionnaires. Sage

Robson, C. & McCartan, K. (2016). *Real world research. A resource for users of social research methods in applied settings.* Wiley.

SECTION F: PARTICIPANT DETAILS

4. Provide an explanation detailing how you will identify, approach and recruit the participants for the proposed research, including clarification on sample size and location. Please provide justification for the exclusion/inclusion criteria for this study (i.e. who will be allowed to / not allowed to participate) and explain briefly, in lay terms, why these criteria are in place. (Do not exceed 500 words)

Headteachers and SENCos of all state funded primary schools in the LA will be contacted (Appendix C) to ask if they are willing to advertise the research to their KS2 parents by emailing the Phase 1 information sheets (Appendix D) and the link to the online questionnaire. The participating schools will also send a ‘reminder’/ follow up email 3 weeks after the initial one is sent. The Phase 1 consent form (Appendix F) will be incorporated into the online survey and participation in the survey will be restricted to only those who consent.

In the online questionnaire, where parents indicate that they have concerns about their child’s sleep and would like to access help but have not accessed help, they will be asked if they would be willing to consider being interviewed. Where they are, they will be asked to share their email address. These parents will then be sent the Phase 2 information sheets (Appendix E) and consent form (Appendix G) and, where consent is obtained, they will be interviewed in the order in which the returned forms are received, up to a maximum of 8. This is the maximum number that can be accommodated in the time frames laid out by M4. Interviews will take place either at the parent’s home (the home visiting policy is provided in Appendix H), at their child’s school, or online using Zoom.

5. Please state the location(s) of the proposed research including the location of any interviews. Please provide a Risk Assessment if required. Consideration should be given to lone working, visiting private residences, conducting research outside working hours or any other non-standard arrangements.

If any data collection is to be done online, please identify the platforms to be used.

Interviewees will be given the choice of being interviewed in the school their child attends, their own home or online via Zoom. See appendix H for LA home visiting policy for managing risks associated with home visiting.

6. Will the participants be from any of the following groups?*(Tick as appropriate)*

☐ Students or Staff of the Trust or Partner delivering your programme.
☒ Adults (over the age of 18 years with mental capacity to give consent to participate in the research).
☐ Children or legal minors (anyone under the age of 16 years)[1]
☐ Adults who are unconscious, severely ill or have a terminal illness.
☐ Adults who may lose mental capacity to consent during the course of the research.
☐ Adults in emergency situations.
☐ Adults[2] with mental illness - particularly those detained under the Mental Health Act (1983 & 2007).

☐ Participants who may lack capacity to consent to participate in the research under the research requirements of the Mental Capacity Act (2005).
☐ Prisoners, where ethical approval may be required from the National Offender Management Service (NOMS).
☐ Young Offenders, where ethical approval may be required from the National Offender Management Service (NOMS).
☐ Healthy volunteers (in high risk intervention studies).
☐ Participants who may be considered to have a pre-existing and potentially dependent[3] relationship with the investigator (e.g. those in care homes, students, colleagues, service-users, patients).
☐ Other vulnerable groups (see Question 6).
☐ Adults who are in custody, custodial care, or for whom a court has assumed responsibility.
☐ Participants who are members of the Armed Forces.

[1]If the proposed research involves children or adults who meet the Police Act (1997) definition of vulnerability[3], any researchers who will have contact with participants must have current Disclosure and Barring Service (DBS) clearance.
[2] 'Adults with a learning or physical disability, a physical or mental illness, or a reduction in physical or mental capacity, and living in a care home or home for people with learning difficulties or receiving care in their own home, or receiving hospital or social care services.' (Police Act, 1997)
[3] Proposed research involving participants with whom the investigator or researcher(s) shares a dependent or unequal relationships (e.g. teacher/student, clinical therapist/service-user) may compromise the ability to give informed consent which is free from any form of pressure (real or implied) arising from this relationship. TREC recommends that, wherever practicable, investigators choose participants with whom they have no dependent relationship. Following due scrutiny, if the investigator is confident that the research involving participants in dependent relationships is vital and defensible, TREC will require additional information setting out the case and detailing how risks inherent in the dependent relationship will be managed. TREC will also need to be reassured that refusal to participate will not result in any discrimination or penalty.

7. Will the study involve participants who are vulnerable? YES ☐ NO ☒

For the purposes of research, 'vulnerable' participants may be adults whose ability to protect their own interests are impaired or reduced in comparison to that of the broader population. Vulnerability may arise from:

- the participant's personal characteristics (e.g. mental or physical impairment)
- their social environment, context and/or disadvantage (e.g. socio-economic mobility, educational attainment, resources, substance dependence, displacement or homelessness).
- where prospective participants are at high risk of consenting under duress, or as a result of manipulation or coercion, they must also be considered as vulnerable
- children are automatically presumed to be vulnerable.

7.1. If YES, what special arrangements are in place to protect vulnerable participants' interests?

N/A

If YES, a Disclosure and Barring Service (DBS) check **within the last three years** is required.

Please provide details of the "clear disclosure":

Date of disclosure:
Type of disclosure:
Organisation that requested disclosure:
DBS certificate number:

*(NOTE: information concerning activities which require DBS checks can be found via https://www.gov.uk/government/publications/dbs-check-eligible-positions-guidance). Please **do not** include a copy of your DBS certificate with your application*

8. Do you propose to make any form of payment or incentive available to participants of the research? YES ☐ NO ☒

If **YES**, please provide details taking into account that any payment or incentive should be representative of reasonable remuneration for participation and may not be of a value that could be coercive or exerting undue influence on potential participants' decision to take part in the research. Wherever possible, remuneration in a monetary form should be avoided and substituted with vouchers, coupons or equivalent. Any payment made to research participants may have benefit or HMRC implications and participants should be alerted to this in the participant information sheet as they may wish to choose to decline payment.

N/A

9. What special arrangements are in place for eliciting informed consent from participants who may not adequately understand verbal explanations or written information provided in English; where participants have special communication needs; where participants have limited literacy; or where children are involved in the research? (Do not exceed 200 words)

The questionnaire and interview schedule will be designed to be as accessible as possible. They will be jargon free and use plain English. There may be parents accessing the survey who have English as an additional language (EAL) and/or struggle with understanding written or spoken English. For these parents, schools will be asked to support them to access the survey using the methods they use to support access to school-based communication.

If parents requiring an interpreter come forward to be interviewed, interpretation will be provided using the service associated with the researcher's LA.

<u>SECTION F: RISK ASSESSMENT AND RISK MANAGEMENT</u>

10. Does the proposed research involve any of the following? *(Tick as appropriate)*

☒ use of a questionnaire, self-completion survey or data-collection instrument (attach copy)
☒ use of emails or the internet as a means of data collection
☐ use of written or computerised tests
☒ interviews (attach interview questions)
☐ diaries (attach diary record form)
☐ participant observation
☐ participant observation (in a non-public place) without their knowledge / covert research
☒ audio-recording interviewees or events
☐ video-recording interviewees or events
☐ access to personal and/or sensitive data (i.e. student, patient, client or service-user data) without the participant's informed consent for use of these data for research purposes
☐ administration of any questions, tasks, investigations, procedures or stimuli which may be experienced by participants as physically or mentally painful, stressful or unpleasant during or after the research process
☐ performance of any acts which might diminish the self-esteem of participants or cause them to experience discomfiture, regret or any other adverse emotional or psychological reaction
☐ Themes around extremism or radicalisation
☐ investigation of participants involved in illegal or illicit activities (e.g. use of illegal drugs)
☐ procedures that involve the deception of participants
☐ administration of any substance or agent
☐ use of non-treatment of placebo control conditions
☐ participation in a clinical trial
☐ research undertaken at an off-campus location (risk assessment attached)
☐ research overseas (please ensure Section G is complete)

11. Does the proposed research involve any specific or anticipated risks (e.g. physical, psychological, social, legal or economic) to participants that are greater than those encountered in everyday life?

YES ☐ **NO** ☒

If **YES**, please describe below including details of precautionary measures.

N/A

12. Where the procedures involve potential hazards and/or discomfort or distress for participants, please state what previous experience the investigator or researcher(s) have had in conducting this type of research.

N/A

13. **Provide an explanation of any potential benefits to participants. Please ensure this is framed within the overall contribution of the proposed research to knowledge or practice. (Do not exceed 400 words)**
NOTE: Where the proposed research involves students , they should be assured that accepting the offer to participate or choosing to decline will have no impact on their assessments or learning experience. Similarly, it should be made clear to participants who are patients, service-users and/or receiving any form of treatment or medication that they are not invited to participate in the belief that participation in the research will result in some relief or improvement in their condition.

The researcher's hope is that there could be a positive impact on parents having had an opportunity to share something that has been causing some difficulty or concern with a researcher who intends to influence change in relation to provision of support. Participants may also benefit from knowing they are contributing to something that could positively impact others. The debriefing sheets will also signpost support services that are available.

14. **Provide an outline of any measures you have in place in the event of adverse or unexpected outcomes and the potential impact this may have on participants involved in the proposed research. (Do not exceed 300 words)**

If participants become distressed or concerned during the interviews

- The researcher will be sensitive to the feelings displayed by the participants throughout the interview and remind them of their right to withdraw/take a break if they would like to.
- The researcher will end the interview if they deem the interviewee to be showing signs of distress that are not resolved through taking a break, ensuring that they know how to access support following the interview
- The parents involved in this study may be sleep deprived so may be more prone to upset or distress. They will have the chance to withdraw from the study which will be made clear through the information sheet (appendix D) and consent form (appendix F).

If participants become distressed or concerned following participation in the research

- All the people interviewed will be given a list of services they can access for support following the interview if needed.
- The participants will have the researcher's contact details and will be told to contact the researcher if they have any concerns

15. **Provide an outline of your debriefing, support and feedback protocol for participants involved in the proposed research. This should include, for example, where participants may feel the need to discuss thoughts or feelings brought about following their participation in the research. This may involve referral to an external support or counseling service, where participation in the research has caused specific issues for participants.**

Following the interviews, the participants will receive a follow up sheet signposting possible avenues to take if they feel any emotional distress, including appropriate support services for sleep difficulties in the researcher's LA.

Once data analysis has been undertaken, participants will receive a summary of the findings.

16. **Please provide the names and nature of any external support or counselling organisations that will be suggested to participants if participation in the research has potential to raise specific issues for participants.**

- Sleep Right (SCOPE)

https://www. localoffer.co.uk/kb5/ /localoffer/service.page?id=5XzBDpSrOo8&localofferchannel=0

- Tired Out

https://www. localoffer.co.uk/kb5/ /localoffer/service.page?id=0NL2HPMg60Q

17. **Where medical aftercare may be necessary, this should include details of the treatment available to participants. Debriefing may involve the disclosure of further information on the aims of the research, the participant's performance and/or the results of the research. (Do not exceed 500 words)**

N/A

FOR RESEARCH UNDERTAKEN OUTSIDE THE UK

18. **Does the proposed research involve travel outside of the UK?**
☐ **YES** ☒ **NO**

If YES, please confirm:

☐ I have consulted the Foreign and Commonwealth Office website for guidance/travel advice? http://www.fco.gov.uk/en/travel-and-living-abroad/

☐ I have completed ta RISK Assessment covering all aspects of the project including consideration of the location of the data collection and risks to participants.

All overseas project data collection will need approval from the Deputy Director of Education and Training or their nominee. Normally this will be done based on the information provided in this form. All projects approved through the TREC process will be indemnified by the Trust against claims made by third parties.

If you have any queries regarding research outside the UK, please contact academicquality@tavi-port.nhs.uk:

Students are required to arrange their own travel and medical insurance to cover project work outside of the UK. Please indicate what insurance cover you have or will have in place.

19. Please evidence how compliance with all local research ethics and research governance requirements have been assessed for the country(ies) in which the research is taking place. Please also clarify how the requirements will be met:

N/A

SECTION G: PARTICIPANT CONSENT AND WITHDRAWAL

20. **Have you attached a copy of your participant information sheet (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials.**

YES ☒ **NO** ☐

If **NO**, please indicate what alternative arrangements are in place below:

21. Have you attached a copy of your participant consent form (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials.

YES ☒ **NO** ☐

If **NO**, please indicate what alternative arrangements are in place below:

N/A

22. The following is a <u>participant information sheet</u> checklist covering the various points that should be included in this document.

☒ Clear identification of the Trust as the sponsor for the research, the project title, the Researcher and Principal Investigator (your Research Supervisor) and other researchers along with relevant contact details.
☒ Details of what involvement in the proposed research will require (e.g., participation in interviews, completion of questionnaire, audio/video-recording of events), estimated time commitment and any risks involved.
☒ A statement confirming that the research has received formal approval from TREC or other ethics body.
☐ If the sample size is small, advice to participants that this may have implications for confidentiality / anonymity.
☒ A clear statement that where participants are in a dependent relationship with any of the researchers that participation in the research will have no impact on assessment / treatment / service-use or support.
☒ Assurance that involvement in the project is voluntary and that participants are free to withdraw consent at any time, and to withdraw any unprocessed data previously supplied.
☒ Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations.
☒ A statement that the data generated in the course of the research will be retained in accordance with the Trusts 's Data Protection and handling Policies.: https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/
☒ Advice that if participants have any concerns about the conduct of the investigator, researcher(s) or any other aspect of this research project, they should contact Simon Carrington, Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk)
☒ Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

23. The following is a consent form checklist covering the various points that should be included in this document.

☒ Trust letterhead or logo.
☒ Title of the project (with research degree projects this need not necessarily be the title of the thesis) and names of investigators.
☒ Confirmation that the research project is part of a degree
☒ Confirmation that involvement in the project is voluntary and that participants are free to withdraw at any time, or to withdraw any unprocessed data previously supplied.
☒ Confirmation of particular requirements of participants, including for example whether interviews are to be audio-/video-recorded, whether anonymised quotes will be used in publications advice of legal limitations to data confidentiality.
☐ If the sample size is small, confirmation that this may have implications for anonymity any other relevant information.
☒ The proposed method of publication or dissemination of the research findings.
☐ Details of any external contractors or partner institutions involved in the research.
☐ Details of any funding bodies or research councils supporting the research.
☒ Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

SECTION H: CONFIDENTIALITY AND ANONYMITY

24. Below is a checklist covering key points relating to the confidentiality and anonymity of participants. Please indicate where relevant to the proposed research.

☒ Participants will be completely anonymised and their identity will not be known by the investigator or researcher(s) (i.e. the participants are part of an anonymous randomised sample and return responses with no form of personal identification)? **PHASE 1**
☐ The responses are anonymised or are an anonymised sample (i.e. a permanent process of coding has been carried out whereby direct and indirect identifiers have been removed from data and replaced by a code, with no record retained of how the code relates to the identifiers).
☒ The samples and data are de-identified (i.e. direct and indirect identifiers have been removed and replaced by a code. The investigator or researchers are able to link the code to the original identifiers and isolate the participant to whom the sample or data relates).
☐ Participants have the option of being identified in a publication that will arise from the research.
☒ Participants will be pseudo-anonymised in a publication that will arise from the research. (I.e. the researcher will endeavour to remove or alter details that would identify the participant.)
☐ The proposed research will make use of personal sensitive data.
☐ Participants consent to be identified in the study and subsequent dissemination of research findings and/or publication.

25. Participants must be made aware that the confidentiality of the information they provide is subject to legal limitations in data confidentiality (i.e. the data may be subject to a subpoena, a freedom of information request or mandated reporting by some professions). This only applies to named or de-identified data. If your participants are named or de-identified, please confirm that you will specifically state these limitations.

YES ☒ **NO** ☐

If **NO**, please indicate why this is the case below:

NOTE: WHERE THE PROPOSED RESEARCH INVOLVES A SMALL SAMPLE OR FOCUS GROUP, PARTICIPANTS SHOULD BE ADVISED THAT THERE WILL BE DISTINCT LIMITATIONS IN THE LEVEL OF ANONYMITY THEY CAN BE AFFORDED.

SECTION I: DATA ACCESS, SECURITY AND MANAGEMENT

26. Will the Researcher/Principal Investigator be responsible for the security of all data collected in connection with the proposed research? YES ☒ **NO** ☐

If **NO**, please indicate what alternative arrangements are in place below:

N/A

27. In line with the 5th principle of the Data Protection Act (1998), which states that personal data shall not be kept for longer than is necessary for that purpose or those purposes for which it was collected; please state how long data will be retained for.

☐ 1-2 years ☐ 3-5 years ☒ 6-10 years ☐ 10> years

NOTE: In line with Research Councils UK (RCUK) guidance, doctoral project data should normally be stored for 10 years and Masters level data for up to 2 years

28. Below is a checklist which relates to the management, storage and secure destruction of data for the purposes of the proposed research. Please indicate where relevant to your proposed arrangements.

☐ Research data, codes and all identifying information to be kept in separate locked filing cabinets.
☐ Research data will only be stored in the University of Essex OneDrive system and no other cloud storage location.
☒ Access to computer files to be available to research team by password only.
☐ Access to computer files to be available to individuals outside the research team by password only (See **23.1**).
☒ Research data will be encrypted and transferred electronically within the UK.
☐ Research data will be encrypted and transferred electronically outside of the UK.

NOTE: Transfer of research data via third party commercial file sharing services, such as Google Docs and YouSendIt are not necessarily secure or permanent. These systems may also be located overseas and not covered by UK law. If the system is located outside the European Economic Area (EEA) or territories deemed to have sufficient standards of data protection, transfer may also breach the Data Protection Act (1998).

Essex students also have access the 'Box' service for file transfer:
https://www.essex.ac.uk/student/it-services/box

☒ Use of personal addresses, postcodes, faxes, e-mails or telephone numbers.
☐ Collection and storage of personal sensitive data (e.g. racial or ethnic origin, political or religious beliefs or physical or mental health or condition).
☒ Use of personal data in the form of audio or video recordings.
☐ Primary data gathered on encrypted mobile devices (i.e. laptops).

NOTE: This should be transferred to secure University of Essex OneDrive at the first opportunity.

☒ All electronic data will undergo secure disposal.

NOTE: For hard drives and magnetic storage devices (HDD or SSD), deleting files does not permanently erase the data on most systems, but only deletes the reference to the file. Files can be restored when deleted in this way. Research files must be overwritten to ensure they are completely irretrievable. Software is available for the secure erasing of files from hard drives which meet recognised standards to securely scramble sensitive data. Examples of this software are BC Wipe, Wipe File, DeleteOnClick and Eraser for Windows platforms. Mac users can use the standard 'secure empty trash' option; an alternative is Permanent eraser software.

☒ All hardcopy data will undergo secure disposal.

NOTE: For shredding research data stored in hardcopy (i.e. paper), adopting DIN 3 ensures files are cut into 2mm strips or confetti like cross-cut particles of 4x40mm. The UK government requires a minimum standard of DIN 4 for its material, which ensures cross cut particles of at least 2x15mm.

29. Please provide details of individuals outside the research team who will be given password protected access to encrypted data for the proposed research.

N/A

30. Please provide details on the regions and territories where research data will be electronically transferred that are external to the UK:

N/A

SECTION J: PUBLICATION AND DISSEMINATION OF RESEARCH FINDINGS

30. How will the results of the research be reported and disseminated? *(Select all that apply)*

☒ Peer reviewed journal
☐ Non-peer reviewed journal
☐ Peer reviewed books
☐ Publication in media, social media or website (including Podcasts and online videos)
☒ Conference presentation
☒ Internal report
☐ Promotional report and materials
☐ Reports compiled for or on behalf of external organisations
☐ Dissertation/Thesis
☐ Other publication
☒ Written feedback to research participants
☒ Presentation to participants or relevant community groups
☐ Other (Please specify below)

SECTION K: OTHER ETHICAL ISSUES

31. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of Tavistock Research Ethics Committee (TREC)?

None

SECTION L: CHECKLIST FOR ATTACHED DOCUMENTS

32. Please check that the following documents are attached to your application.

☐ Letters of approval from any external ethical approval bodies (where relevant)
☒ Recruitment advertisement
☒ Participant information sheets (including easy-read where relevant)
☒ Consent forms (including easy-read where relevant)
☐ Assent form for children (where relevant)
☐ Letters of approval from locations for data collection
☒ Questionnaire
☒ Interview Schedule or topic guide
☐ Risk Assessment (where applicable)
☐ Overseas travel approval (where applicable)

34. Where it is not possible to attach the above materials, please provide an explanation below.

N/A

A: Online Questionnaire Questions

6) Do you feel that your child in Key Stage 2 has difficulties with their sleep?

Yes / No
(If No is answered, this will end the questionnaire and the participant will be thanked for their participation)
(If Yes is answered, the participant will be moved to question 2)

7) Would you like to be able to access support in relation to the concerns you have about your child’s sleep?

Yes/No
(If No is answered, this will end the questionnaire and the participant will be thanked for their participation)
(If Yes is answered, the participant will be moved to question 3)

8) What type of support would you like to access?

9) Have you sought support for your concerns about your child’s sleep?

Yes/No

(If No is answered, the final question will be presented)
(If Yes is answered, the participant will be moved to question 5)

10) Please provide brief details of the support that you sought.

If you are willing to consider participating in an interview to provide more detailed information about your concerns about your child’s sleep and the sort of support you would like to be able to access, please provide an email address that you can be contacted on. Further information about the interviews will be supplied to enable you to make an informed decision about whether to participate.

Thank you for your participation

B: Interview schedule

The interview schedule has yet to be developed. The aspects of parental experiences that will be explored will be limited to the following:

- The concerns parents have about their child’s sleep
- Whether they have accessed support
- Where support has been accessed, their experiences/views about what was received
- What did or would encourage/discourage them to seek help
- Whether they have been offered and decline support

C: Email to schools

Dear **[insert Headteacher and SENCo's names here]**,

I am a trainee Educational Psychologist working in _______ and part of Tavistock and Portman NHS Trust Doctorate course. I am hoping to recruit parents/carers of children in Key Stage 2 to take part in a study about the views of parents/carers experiencing difficulties with their children's sleep. I am emailing as I would like to invite parents/carers from your school to participate.

It is my hope that this study will help those of us working in the Local Authority to better understand:

- The demand/need for sleep related support for parents/carers of Key Stage 2 children
- What sleep related support parents/carers would like
- What would help or get in the way of parents accessing support that could be made available

The aim is to try and effectively plug any gaps in provision.

In order to include parents/carers from your school, I would need the school to advertise the project. This would involve sending them an email with an Information Sheet about the project. I have attached the Information Sheet to this email for you to review. To ensure equality of opportunity, I would also ask you to follow the protocols you use in the school to support access for those parents/carers who have difficulty understanding written English.

Please let me know if you are happy for your team to support me in advertising this research.

Many thanks and kind regards,

Amy Tyler
Trainee Educational Psychologist
atyler@tavi-port.nhs.uk

D: Phase 1 Information sheet

The Tavistock and Portman
NHS Foundation Trust

Thank you for your interest in my research project about your child's sleep.

This information sheet has been written to provide you with information to help you decide if you would like to participate. If, having read this information, you would like to take part, please click on the link to the questionnaire below.

Who am I?

My name is Amy Tyler. I am a Year 2 trainee Educational Psychologist at the Tavistock and Portman NHS Trust. I am studying for the professional Doctorate in Educational and Child Psychology. I am on placement in _______ Local Authority and am carrying out this research as part of my training.

What is the research about?

I am interested in hearing about parents'/carers'/guardians' views of their Key Stage 2 child/children's sleep difficulties. The study aims to identify what support local parents want and what might help or get in the way of accessing wanted support.

What am I hoping to achieve?

It is my hope that this information will help people working in the Local Authority to better understand:

- The demand/need for sleep related support for parents of Key Stage 2 children
- What sleep related support parents would like
- What would help or get in the way of parents accessing support that could be made available

Why am I being invited to participate?

Your child's school has agreed to send this information sheet to all parents/carers of children in Key Stage 2. I am hoping to include as many parents of Key Stage 2 children as possible.

What will taking part involve?

The study has two parts. The first involves completing a simple online questionnaire that should take no more than 10 minutes to complete. The second part involves an interview that will last a maximum of one hour.

It is possible to take part in just the questionnaire. Once the questionnaire is completed, there is an option for participants to express an interest in taking part in an interview. Should they choose to, there will be space to add their contact details to allow me to contact them about this.

If I agree to take part in the questionnaire, what happens next?

If you would like to take part, please click on the link to the questionnaire below. This will take you to a short consent form which needs to be completed. You will then automatically be connected to the questionnaire.

Do I have to take part?

Taking part is entirely voluntary and is not connected to any support your child has or will receive from the Local Authority.

Your personal information

Your participation and data in this part of the study will be anonymous. I will not ask for any identifiable details in relation to participating in the questionnaire.

Can I change my mind?

Participation in this research is voluntary and you are free to withdraw from the research at any time without giving a reason. Because your participation in this part of the research is anonymous, once you have submitted the questionnaire, I will not be able to remove the data as I will not know who the responses belong to.

What happens to the information I gather?

Information collected from the questionnaire will be analysed and written up in a document that will be held at the Tavistock and Portman library. I also hope to publish the general themes from the study in the future.

Ethical Approval

If you have any queries about the ethical approval of this research, or other aspects of this project, please contact Paru Jeram, the Tavistock and Portman NHS Trust Quality Assurance Officer, using this email address: pjeram@tavi-port.nhs.uk.

If you would like to find out more about this study, you can contact me using the following email address: atyler@tavi-port.nhs.uk.

Thank you for reading this information sheet.

If you would like to take part in the questionnaire, please click on the link below:
[link will appear here]

E: Phase 2 Information sheet

NHS
The Tavistock and Portman
NHS Foundation Trust

Thank you for your interest in my research project about your child's sleep.

I am grateful to you for volunteering to participate in this interview. Please read the information sheet below and then please complete the attached consent form. Feel free to contact me with any questions on the email address below: atyler@tavi-port.nhs.uk

Who am I?

My name is Amy Tyler. I am a Year 2 trainee Educational Psychologist at the Tavistock and Portman NHS Trust. I am studying for the professional Doctorate in Educational and Child Psychology. I am on placement in _______ Local Authority and am carrying out this research as part of my training.

What is the research about?

I am interested in hearing about parents'/carers'/guardians' views of their Key Stage 2 child/children's sleep difficulties. The study aims to identify what support local parents want and what might help or get in the way of accessing wanted support.

What am I hoping to achieve?

It is my hope that this information will help people working in the Local Authority to better understand:

- The demand/need for sleep related support for parents of Key Stage 2 children
- What sleep related support parents would like
- What would help or get in the way of parents accessing support that could be made available

Why am I being invited to participate?

When you completed my online questionnaire about your child's sleep, you stated that you would be willing to consider participating in an interview and provided your email address. This information sheet is being sent to you in response to that expression of interest.

What will taking part involve?

This information sheet is about participating in an interview.

The interview will last for no more than one hour. It will explore your concerns about your child's sleep, what help you feel you would like and how you would like to access this help. I will make an audio recording of the interview which I will delete once I have typed up what was said. When I do this, I will change any details that could identify you, to ensure your responses are anonymised.

The interview will be arranged at a time that is convenient to you, either at your home or at your child's school. Alternatively, it can take place online, via Zoom, if you prefer.

Your personal information

I will be the only person who has access to your identifiable information in this study. Any information collected will be kept following the Data Protection Act (2018) and GDPR guidance.

All records related to your participation will be handled and stored securely on an encrypted drive using password protection. Any identifying information on these records will be changed, to avoid your identification. The data will be kept for a maximum of 10 years.

However, if you share any information linked to your safety or the safety of others, I have a duty of care to share this information under safeguarding procedures. I will tell you if there is information which I need to share.

Can I change my mind?

Participation in this research is voluntary and you are free to withdraw from the research at any time without giving a reason. Any information you provide (including what you say in the interviews) can be deleted and removed from the study, at your request, up until the point that the analysis has been completed and submitted for review by my supervisor.

What happens to the information I gather?

Information collected from the interview will be analysed and written up in a document that will be held at the Tavistock and Portman library. I also hope to publish the general themes from the study in the future.

Ethical Approval

If you have any queries about the ethical approval of this research, or other aspects of this project, please contact Paru Jeram, the Tavistock and Portman NHS Trust Quality Assurance Officer, using this email address: pjeram@tavi-port.nhs.uk.

If you would like to find out more about this study, you can also contact me using the following email address: atyler@tavi-port.nhs.uk.

Thank you for reading this information sheet.

F: Phase 1 Consent form

Title: Parental concerns about Key Stage 2 children's sleep; the support parents would like to access; and how they would like to access support

Thank you for clicking on the link to the questionnaire about Key Stage 2 Children's sleep and the support parents might like in relation to this.

Before completing the questionnaire, I need to make sure that you understand what the research involves and that you consent to participating. To do this, please complete the following:

	Yes	No
I have read and understood the information sheet about this questionnaire and have had a chance to have any questions I have about it answered		
I understand that this research is being conducted as part of a university degree that the researcher is studying for		
I understand that my participation in this research is entirely voluntary, and I am free to withdraw from it before completing the questionnaire		
I understand that my data in this questionnaire is anonymised and once I have submitted it, I will not be able to withdraw it as the researcher will not be able to identify it as belonging to me		
I understand that the findings from this research will be published in a research report and they may also be shared in other presentations or publications		
I am happy to participate in the questionnaire		

If the answers to all of the above are 'Yes', the respondent will automatically be linked to the questionnaire.

If the answer to any of the above is 'No', the respondent will not be able to access the questionnaire. Instead, they will be invited to contact the researcher to discuss their participation.

G: Phase 2 Consent form

Title: Parental concerns about Key Stage 2 children's sleep; the support parents would like to access; and how they would like to access support

Thank you for your interest in taking part in an interview about Key Stage 2 Children's sleep and the support parents might like in relation to this.

Before taking part in the interview, I need to make sure that you fully understand what the research involves and that you fully consent to participating. To do this, please complete the following:

	Yes	No
I have read and understood the information sheet about this interview and have had a chance to have any questions I have about it answered		
I understand that this research is being conducted as part of a university degree that the researcher is studying for		
I understand that my participation in this research is entirely voluntary and I am able to withdraw consent, and my data, up until the data analysis has been conducted		
I agree for my interview to be recorded		
I understand that my data will be anonymised so that people reading the research will not link my data to me		
I understand that there are limits to confidentiality and if I share information about potential harm to myself or others, the researcher is legally required to share this information		
I understand that the findings from this research will be published in a research report and they may also be shared in other presentations or publications		
I am happy to participate in the interview		

Parent/carer/guardian's signature:
…………………………………………………………………………………….
Parent/carer/guardian's name (BLOCK CAPITALS):
…………………………………………………………………………………….
Relationship to the child:
……………………………………………………………………………………..
Contact Email:
……………………………………………………………………………………..

Date: ……………………..……………….
Please return to:
Amy Tyler
atyler@tavi-port.nhs.uk

H: Lone Working Health and Safety Guidance for Employees (page3)

5. Visiting clients within their home

- Ensure your manager and/or team know where you are going and how long you will be
- Carry your mobile phone with you at all times, ensure it is turned on and charged
- Make contact with your manager and/or team as required by the system of work implemented
- Review the client file prior to visiting the property and raise any concerns with your manager (e.g. a history of violence, location of the visit etc)
- If you are provided with a personal alarm carry it with you at all times
- Ensure you are aware of techniques for conflict resolution and diffusing potentially violent situations. Speak to your manager if you have not received training
- Know your exit route from the property and make sure you are always able to leave quickly
- If you feel at risk, make an excuse and withdraw from the property and then notify your manager
- If possible, avoid appointments late at night
- Ask for any animals in the property to be secured before you go in

Appendix 11: Confirmation of Initial Ethical Approval

The Tavistock and Portman NHS
NHS Foundation Trust

Quality Assurance & Enhancement
Directorate of Education & Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: 020 8938 2699
Fax: 020 7447 3837

Amy Tyler

By Email

4 July 2022

Dear Amy,

Re: Trust Research Ethics Application

Title: Parents' views on their Key Stage 2 children's sleep difficulties and their approach to help seeking: An exploratory study.

Thank you for sending your response to the conditions set by the Assessor with regards to your TREC application. I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

Please note that any changes to the project design including changes to methodology/data collection etc, must be referred to TREC as failure to do so, may result in a report of academic and/or research misconduct.

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely,

Paru Jeram
Secretary to the Trust Research Degrees Subcommittee
T: 020 938 2699
E: academicquality@tavi-port.nhs.uk

cc. Course Lead, Supervisor, Course Administrator

Appendix 12: Change to Doctoral Research Request Form

Change to Doctoral Research Protocol

Student name	Amy Tyler
Date	13.11.22
Doctoral programme	Chid, education and community psychology doctorate
Supervisor(s)	Judith Mortell
Has ethical approval been granted? Please include process (TREC/UREC/IRAS) and date	TREC June 2022

Please state clearly and simply the proposed changes to your project (methods of data gathering, changes to design etc)

I plan to contact all mainstream publicly funded mainstream primary schools in England to gain participants for my research. I will contact them by sending the information sheet and consent form regarding the questionnaire to the main school email address. I will ensure the information sheet and consent form are relevant to them as opposed to only relevant for my placement borough. The researcher will also release the information sheet and link to questionnaire (containing consent form) to parent support websites such as ‘Mum’s net’.

My rationale is to widen my search for participants, to ensure I am gaining a full sample of the population and to ensure I gain enough participants to make my findings reliable and more generalisable.

Please also see highlighted text on TREC form for altered or added information.

For information governance purposes and in line with the Trust policies, please be advised that you must use the on-line video conferencing platform Zoom to conduct research/interviews. Please contact the Technology Enhanced Learning - TEL (TELSupport@Tavi-Port.nhs.uk) to set up a zoom account.

If you are requesting a change to data collection (remote interviews for example) please consider the following guides/considerations regarding privacy:

1. Please ensure you have participant’s consent before interviews are convened. All ethical approval documentation including consent forms/information sheets must be updated accordingly
2. Please ensure that meetings with yourself and your participants are conducting in a safe environment and that confidentiality is maintained.
3. Ask participants if they are happy with their environment; if they are alone and if they are assured that they are in a location where they will not be disturbed during the session
4. Please ask participants if they have any concerns about WIFI or the technology which may cause disruption during the meeting.

Please return this form as directed by your supervisor or course lead
You **must** ensure any changes are also approved by your ethical approval body before you start work

Appendix 13: Tavistock and Portman Trust Research Ethics Committee (TREC) form (with amendments for contacting wider research base)

The Tavistock and Portman NHS
NHS Foundation Trust

Tavistock and Portman Trust Research Ethics Committee (TREC)

APPLICATION FOR ETHICAL REVIEW OF STUDENT RESEARCH PROJECTS

This application should be submitted alongside copies of any supporting documentation which will be handed to participants, including a participant information sheet, consent form, self-completion survey or questionnaire.

Where a form is submitted and sections are incomplete, the form will not be considered by TREC and will be returned to the applicant for completion.

For further guidance please contact Paru Jeram (academicquality@tavi-port.nhs.uk)

FOR ALL APPLICANTS

If you already have ethical approval from another body (including HRA/IRAS) please submit the application form and outcome letters. You need only complete sections of the TREC form which are NOT covered in your existing approval

Is your project considered as 'research' according to the HRA tool? (http://www.hra-decisiontools.org.uk/research/index.html)	N/A
Will your project involve participants who are under 18 or who are classed as vulnerable? (see section 7)	No
Will your project include data collection outside of the UK?	No

SECTION A: PROJECT DETAILS

Project title	Parents' views on their children's sleep difficulties and their approach to help seeking: An exploratory study.		
Proposed project start date	June 2022	**Anticipated project end date**	August 2023
Principle Investigator (normally your Research Supervisor): Jude Mortell			
Please note: TREC approval will only be given for the length of the project as stated above up to a maximum of 6 years. Projects exceeding these timeframes will need additional ethical approval			
Has NHS or other approval been sought for this research including through submission via	**YES (NRES approval)** **YES (HRA approval)**	☐ ☐ ☐	

Research Application System (IRAS) or to the Health Research Authority (HRA)?	**Other** ☒ **NO**
If you already have ethical approval from another body (including HRA/IRAS) please submit the application form and outcome letters.	

SECTION B: APPLICANT DETAILS

Name of Researcher	Amy Tyler
Programme of Study and Target Award	Professional Doctorate for Child, Community and Educational Psychology
Email address	atyler@tavi-port.nhs.uk
Contact telephone number	07768024267

SECTION C: CONFLICTS OF INTEREST

Will any of the researchers or their institutions receive any other benefits or incentives for taking part in this research over and above their normal salary package or the costs of undertaking the research? **YES** ☐ **NO** ☒ If **YES**, please detail below:
N/A
Is there any further possibility for conflict of interest? YES ☐ **NO** ☒
Are you proposing to conduct this work in a location where you work or have a placement? **YES** ☒ **NO** ☐ If **YES**, please detail below outline how you will avoid issues arising around colleagues being involved in this project:
The design of the study excludes involvement of colleagues from the Educational Psychology Service. The design involves participating/consenting school staff playing a supporting role in disseminating information to potential participants (parents from their school communities). Their involvement will be limited to disseminating information

Is your project being commissioned by and/or carried out on behalf of a body external to the Trust? (for example; commissioned by a local authority, school, care home, other NHS Trust or other organisation). *Please note that 'external' is defined as an organisation which is external to the Tavistock and Portman NHS Foundation Trust (Trust)	**YES** ☐ **NO** ☒
If **YES**, please add details here: N/A	
Will you be required to get further ethical approval after receiving TREC approval? If **YES**, please supply details of the ethical approval bodies below AND include any letters of approval from the ethical approval bodies (letters received after receiving TREC approval should be submitted to complete your record):	**YES** ☐ **NO** ☒
N/A	
If your project is being undertaken with one or more clinical services or organisations external to the Trust, please provide details of these:	
N/A	
If you still need to agree these arrangements or if you can only approach organisations after you have ethical approval, please identify the types of organisations (eg. schools or clinical services) you wish to approach:	
N/A	
Do you have approval from the organisations detailed above? (this includes R&D approval where relevant) Please attach approval letters to this application. Any approval letters received after TREC approval has been granted MUST be submitted to be appended to your record	**YES** ☐ **NO** ☐ **NA** ☒

SECTION D: SIGNATURES AND DECLARATIONS

APPLICANT DECLARATION

I confirm that:

- The information contained in this application is, to the best of my knowledge, correct and up to date.
- I have attempted to identify all risks related to the research.
- I acknowledge my obligations and commitment to upholding ethical principles and to keep my supervisor updated with the progress of my research
- I am aware that for cases of proven misconduct, it may result in formal disciplinary proceedings and/or the cancellation of the proposed research.
- I understand that if my project design, methodology or method of data collection changes I must seek an amendment to my ethical approvals as failure to do so, may result in a report of academic and/or research misconduct.

Applicant (print name)	AMY TYLER
Signed	ATyler
Date	13.11.22

FOR RESEARCH DEGREE STUDENT APPLICANTS ONLY

Name of Supervisor/Principal Investigator	Jude Mortell

Supervisor –

- Does the student have the necessary skills to carry out the research?
  YES ☒ **NO** ☐
- Is the participant information sheet, consent form and any other documentation appropriate?
  YES ☒ **NO** ☐
- Are the procedures for recruitment of participants and obtaining informed consent suitable and sufficient?
  YES ☒ **NO** ☐
- Where required, does the researcher have current Disclosure and Barring Service (DBS) clearance?
  YES ☒ **NO** ☐

Signed	
Date	13.11.22

COURSE LEAD/RESEARCH LEAD

Does the proposed research as detailed herein have your support to proceed? YES ☐ NO ☐

Signed	
Date	

SECTION E: DETAILS OF THE PROPOSED RESEARCH

31. Provide a brief description of the proposed research, including the requirements of participants. This must be in lay terms and free from technical or discipline specific terminology or jargon. If such terms are required, please ensure they are adequately explained (Do not exceed 500 words)
The proposed research will explore the views and experiences of parents/carers/guardians of children aged 3-11, who have concerns around their child(ren)'s sleep. It will explore their desire for help and experiences of seeking help in relation to their concerns about their child(ren)'s sleep. (NB. The term 'parents' will be used throughout this form to refer to parents/carers/guardians). Parents of children in mainstream schools in the local authority (LA) where the researcher is undertaking a training placement will be sent a link to an online survey via their child's school. All other mainstream primary schools in England will also be contacted with the information sheet and consent form for the questionnaire with the accompanying questionnaire link. The researcher will posts adverts for the research and links to the information sheet and questionnaire (containing consent form) to parent support websites such as 'Mumsnet'. This will seek to find out whether they have concerns around their child's sleep; the nature of these concerns; whether they have sought support or not; and potential reasons behind this. This should take no longer than 5 minutes to complete. Between six and eight of the participants who respond to the survey will be invited to attend an interview for a more in-depth exploration of their experiences. These will be parents who have sleep related concerns and would like to access support. Interviews will be conducted at the child's school or online – whichever the participant prefers. They will last for a maximum of one hour.
32. Provide a statement on the aims and significance of the proposed research, including potential impact to knowledge and understanding in the field (where appropriate, indicate the associated hypothesis which will be tested). This should be a clear justification of the proposed research, why it should proceed and a statement on any anticipated benefits to the community. (Do not exceed 700 words)

The research aims to find out what form of support parents of children would like to access to help with their child's sleep and what are the facilitators and barriers to seeking help. The intention behind the research is to gather information about the prevalence of sleep difficulties within the population and how best to provide support when it is needed.

The significant impact of sleep on both physical and mental health is evidenced in a wide range of literature (Williamson et al., 2020) including on educational and personal outcomes for young people (Konen et al, 2015). The patterns and habits that children form in early life can support them to develop positive sleep habits and routines into adulthood (Sutton et al., 2019). Between the ages of 7 and 11, parents still largely manage or heavily support their children's bedtime and sleep routine/hygiene. However, the Early Years support from health professionals, such as health visitors, has usually ended by this age. This research aims to explore what support parents of children in this age range would like with their child's sleep, how likely they are to access this if it were available and what may help them to access it. Research has shown that parents can be reluctant to seek support for their children's sleep difficulties (Cook et al., 2020). In a longitudinal study by Williamson et al. (2020), 5107 children were recruited at birth and monitored for sleep difficulties up to the ages of 11; almost half of the children in this study had some form of reported sleep difficulty. This high prevalence provides further rationale for the current exploratory study. Despite how well-established the importance of sleep is, there is little research into what specifically parents would seek or use in terms of support, especially in the age range being researched with this study. The barriers Cook et al. (2020) put forward included perceptions of service quality and parental expectations of what they would be offered.

Educational psychologists (EPs) in the researcher's LA have raised concerns about sleep difficulties in primary school children. It is an issue that arises in their case work on a regular basis. This supports thinking that it warrants further exploration. Answering the research questions proposed in this study could help inform decision making for EPs and other professionals supporting parents of children aged 3-11.

The research questions that this study will aim to answer are:

What is the prevalence of parental concern about the sleep patterns of children aged 3-11? ***(removed specific LA)***
What support would parents like in helping their children's sleep?
What support have parents accessed in relation to helping their children sleep?
Of those parents who want help but haven't accessed it, what are the barriers and facilitators to accessing support?

References

Cook, G., Appleton, J. V. & Wiggs, L. (2020). Parentally reported barriers to seeking help and advice for child sleep from healthcare professionals. *Child: Care, Health and Development, 46*(4), 513-521.

Konen, T., Dirk, J. & Schmiedek, F. (2015). Cognitive benefits of last night's sleep: daily variations in children's sleep behavior are related to working memory fluctuations. *Journal of Child Psychology and Psychiatry, 56*(2), 171–182.

Sutton, J. E., Huws, J. C. & Burton, C. R. (2019). *Experiences of sleep hygiene education as an intervention for sleep problems in children with developmental disabilities: Findings from an exploratory study*. Wiley.

Williamson, A. A., Mindell, J. A., Hiscock, H. & Quach, J. (2020). Longitudinal sleep problem trajectories are associated with multiple impairments in child well-being. *Journal of Child Psychology and Psychiatry, 61*(10), 1092-1103.

33. Provide an outline of the methodology for the proposed research, including proposed method of data collection, *tasks* assigned to participants of the research and the proposed method and duration of data analysis. If the proposed research makes use of pre-established and generally accepted techniques, please make this clear. (Do not exceed 500 words)

The study will be a mixed-methods, sequential exploratory design and will be conducted in two phases.

Quantitative Phase:

Data for the quantitative element of the study will be collected via an online survey for parents. It will be sent to all publicly funded mainstream primary schools in England (see Appendix A). Data from the survey will be analysed using descriptive statistics (Byrne, 2007). The survey will be developed using guidance around clearly defined questions (Robson and McCarten, 2016). It will be developed according to the BRUSO model (Peterson, 2000), which stands for 'brief', 'relevant', 'unambiguous', 'specific' and 'objective'.

Qualitative

Between six and eight parents will be interviewed using a semi-structured interview schedule (see Appendix B). Interviews will be roughly an hour in length. Semi-structured interviews are a style of interviewing where the interviewer has only a brief number of topics or questions for each interview initially, but has freedom between interviews to adapt the pace, order and wording of each question according to the interview content as it emerges (Robson and McCarten, 2016). All interviews will be recorded using audio equipment and will be transcribed. Interviews will be held either in the school which the parent's child attends or online via Zoom; they will be given the choice.

The qualitative data generated from interviews will be analysed using reflexive thematic analysis (Braun & Clarke, 2021). Interview transcripts will be searched for themes emerging. Once themes are identified across interviews, they will grouped and evaluated. Patterns and commonalities will then be identified and reported to present the findings.

References

Braun, V., & Clarke, V. (2021). Thematic Analysis: A practical guide.

Byrne, G. (2007). A Statistical Primer: Understanding Descriptive and Inferential Statistics

Peterson, R.A. (2000) Constructing Effective Questionnaires. Sage

Robson, C. & McCartan, K. (2016). *Real world research. A resource for users of social research methods in applied settings.* Wiley.

SECTION F: PARTICIPANT DETAILS

34. Provide an explanation detailing how you will identify, approach and recruit the participants for the proposed research, including clarification on sample size and location. Please provide justification for the exclusion/inclusion criteria for this study (i.e. who will be allowed to / not allowed to participate) and explain briefly, in lay terms, why these criteria are in place. (Do not exceed 500 words)

All state funded mainstream primary schools in England will be contacted (Appendix A) to ask if they are willing to advertise the research to their parents by emailing the Phase 1 information sheets (Appendix D for schools within the researcher's placement LA and Appendix I for all other schools in England) and the link to the online questionnaire. The participating schools will also send a 'reminder'/ follow up email 3 weeks after the initial one is sent. The Phase 1 consent form (Appendix F) will be incorporated into the online survey and participation in the survey will be restricted to only those who consent.

In the online questionnaire, where parents indicate that they have concerns about their child's sleep and would like to access help, they will be asked if they would be willing to consider being interviewed. Where they are, they will be asked to share their email address. These parents will then be sent the Phase 2 information sheets (Appendix E) and consent form (Appendix G) and, where consent is obtained, they will be interviewed in the order in which the returned forms are received, up to a maximum of 8. This is the maximum number that can be accommodated in the time frames laid out by M4. Interviews will take place either at their child's school or online using Zoom.

35. Please state the location(s) of the proposed research including the location of any interviews. Please provide a Risk Assessment if required. Consideration should be given to lone working, visiting private residences, conducting research outside working hours or any other non-standard arrangements.

If any data collection is to be done online, please identify the platforms to be used.

Interviewees will be given the choice of being interviewed in the school their child attends or online via Zoom.

36. Will the participants be from any of the following groups?*(Tick as appropriate)*

☐ Students or Staff of the Trust or Partner delivering your programme.
☒ Adults (over the age of 18 years with mental capacity to give consent to participate in the research).
☐ Children or legal minors (anyone under the age of 16 years)[1]
☐ Adults who are unconscious, severely ill or have a terminal illness.
☐ Adults who may lose mental capacity to consent during the course of the research.
☐ Adults in emergency situations.
☐ Adults[2] with mental illness - particularly those detained under the Mental Health Act (1983 & 2007).
☐ Participants who may lack capacity to consent to participate in the research under the research requirements of the Mental Capacity Act (2005).
☐ Prisoners, where ethical approval may be required from the National Offender Management Service (NOMS).
☐ Young Offenders, where ethical approval may be required from the National Offender Management Service (NOMS).
☐ Healthy volunteers (in high risk intervention studies).
☐ Participants who may be considered to have a pre-existing and potentially dependent[3] relationship with the investigator (e.g. those in care homes, students, colleagues, service-users, patients).
☐ Other vulnerable groups (see Question 6).
☐ Adults who are in custody, custodial care, or for whom a court has assumed responsibility.
☐ Participants who are members of the Armed Forces.

[1] *If the proposed research involves children or adults who meet the Police Act (1997) definition of vulnerability[3], any researchers who will have contact with participants must have current Disclosure and Barring Service (DBS) clearance.*
[2] *'Adults with a learning or physical disability, a physical or mental illness, or a reduction in physical or mental capacity, and living in a care home or home for people with learning difficulties or receiving care in their own home, or receiving hospital or social care services.' (Police Act, 1997)*
[3] *Proposed research involving participants with whom the investigator or researcher(s) shares a dependent or unequal relationships (e.g. teacher/student, clinical therapist/service-user) may compromise the ability to give informed consent which is free from any form of pressure (real or implied) arising from this relationship. TREC recommends that, wherever practicable, investigators choose participants with whom they have no dependent relationship. Following due scrutiny, if the investigator is confident that the research involving participants in dependent relationships is vital and defensible, TREC will require additional information setting out the case and detailing how risks inherent in the dependent relationship will be managed. TREC will also need to be reassured that refusal to participate will not result in any discrimination or penalty.*

37. Will the study involve participants who are vulnerable? YES ☐ NO ☒

For the purposes of research, ‘vulnerable’ participants may be adults whose ability to protect their own interests are impaired or reduced in comparison to that of the broader population. Vulnerability may arise from:

- the participant’s personal characteristics (e.g. mental or physical impairment)
- their social environment, context and/or disadvantage (e.g. socio-economic mobility, educational attainment, resources, substance dependence, displacement or homelessness).
- where prospective participants are at high risk of consenting under duress, or as a result of manipulation or coercion, they must also be considered as vulnerable
- children are automatically presumed to be vulnerable

7.1. If YES, what special arrangements are in place to protect vulnerable participants’ interests?

N/A

If YES, a Disclosure and Barring Service (DBS) check **within the last three years** is required.

Please provide details of the “clear disclosure”:

Date of disclosure:
Type of disclosure:
Organisation that requested disclosure:
DBS certificate number:

*(NOTE: information concerning activities which require DBS checks can be found via https://www.gov.uk/government/publications/dbs-check-eligible-positions-guidance). Please **do not** include a copy of your DBS certificate with your application*

38. Do you propose to make any form of payment or incentive available to participants of the research? YES ☐ NO ☒

If **YES**, please provide details taking into account that any payment or incentive should be representative of reasonable remuneration for participation and may not be of a value that could be coercive or exerting undue influence on potential participants’ decision to take part in the research. Wherever possible, remuneration in a monetary form should be avoided and substituted with vouchers, coupons or equivalent. Any payment made to research participants may have benefit or HMRC implications and participants should be alerted to this in the participant information sheet as they may wish to choose to decline payment.

N/A

39. What special arrangements are in place for eliciting informed consent from participants who may not adequately understand verbal explanations or written

information provided in English; where participants have special communication needs; where participants have limited literacy; or where children are involved in the research? (Do not exceed 200 words)

The questionnaire and interview schedule will be designed to be as accessible as possible. They will be jargon free and use plain English. There may be parents accessing the survey who have English as an additional language (EAL) and/or struggle with understanding written or spoken English. For these parents, schools will be asked to support them to access the survey using the methods they use to support access to school-based communication.

If parents requiring an interpreter come forward to be interviewed, interpretation will be provided using the service associated with the researcher's LA.

SECTION F: RISK ASSESSMENT AND RISK MANAGEMENT

40. Does the proposed research involve any of the following? *(Tick as appropriate)*

☒ use of a questionnaire, self-completion survey or data-collection instrument (attach copy)
☒ use of emails or the internet as a means of data collection
☐ use of written or computerised tests
☒ interviews (attach interview questions)
☐ diaries (attach diary record form)
☐ participant observation
☐ participant observation (in a non-public place) without their knowledge / covert research
☒ audio-recording interviewees or events
☐ video-recording interviewees or events
☐ access to personal and/or sensitive data (i.e. student, patient, client or service-user data) without the participant's informed consent for use of these data for research purposes
☐ administration of any questions, tasks, investigations, procedures or stimuli which may be experienced by participants as physically or mentally painful, stressful or unpleasant during or after the research process
☐ performance of any acts which might diminish the self-esteem of participants or cause them to experience discomfiture, regret or any other adverse emotional or psychological reaction
☐ Themes around extremism or radicalisation
☐ investigation of participants involved in illegal or illicit activities (e.g. use of illegal drugs)
☐ procedures that involve the deception of participants
☐ administration of any substance or agent
☐ use of non-treatment of placebo control conditions
☐ participation in a clinical trial
☐ research undertaken at an off-campus location (risk assessment attached)
☐ research overseas (please ensure Section G is complete)

41. **Does the proposed research involve any specific or anticipated risks (e.g. physical, psychological, social, legal or economic) to participants that are greater than those encountered in everyday life?**

YES ☐ **NO** ☒

If **YES**, please describe below including details of precautionary measures.

N/A

42. **Where the procedures involve potential hazards and/or discomfort or distress for participants, please state what previous experience the investigator or researcher(s) have had in conducting this type of research.**

N/A

43. **Provide an explanation of any potential benefits to participants. Please ensure this is framed within the overall contribution of the proposed research to knowledge or practice. (Do not exceed 400 words)**
NOTE: Where the proposed research involves students , they should be assured that accepting the offer to participate or choosing to decline will have no impact on their assessments or learning experience. Similarly, it should be made clear to participants who are patients, service-users and/or receiving any form of treatment or medication that they are not invited to participate in the belief that participation in the research will result in some relief or improvement in their condition.

The researcher's hope is that there could be a positive impact on parents having had an opportunity to share something that has been causing some difficulty or concern with a researcher who intends to influence change in relation to provision of support. Participants may also benefit from knowing they are contributing to something that could positively impact others. The debriefing sheets will also signpost support services that are available.

44. **Provide an outline of any measures you have in place in the event of adverse or unexpected outcomes and the potential impact this may have on participants involved in the proposed research. (Do not exceed 300 words)**

If participants become distressed or concerned during the interviews

- The researcher will be sensitive to the feelings displayed by the participants throughout the interview and remind them of their right to withdraw/take a break if they would like to.

- The researcher will end the interview if they deem the interviewee to be showing signs of distress that are not resolved through taking a break, ensuring that they know how to access support following the interview
- The parents involved in this study may be sleep deprived so may be more prone to upset or distress. They will have the chance to withdraw from the study which will be made clear through the information sheet (appendix D) and consent form (appendix F).

If participants become distressed or concerned following participation in the research

- All people interviewed will be given a list of services they can access for support following the interview if needed.
- The participants will have the researcher's contact details and will be told to contact the researcher if they have any concerns

45. Provide an outline of your debriefing, support and feedback protocol for participants involved in the proposed research. This should include, for example, where participants may feel the need to discuss thoughts or feelings brought about following their participation in the research. This may involve referral to an external support or counseling service, where participation in the research has caused specific issues for participants.

Following the interviews, the participants will receive a follow up sheet signposting possible avenues to take if they feel any emotional distress, including appropriate support services for sleep difficulties for their child.

Once data analysis has been undertaken, participants will receive a summary of the findings.

46. Please provide the names and nature of any external support or counselling organisations that will be suggested to participants if participation in the research has potential to raise specific issues for participants.

The following will be provided for participants within the researcher's LA.

- Sleep Right (SCOPE)

https://www.   localoffer.co.uk/kb5/   /localoffer/service.page?id=5XzBDpSrOo8&localofferchannel=0

- Tired Out

https://www.   localoffer.co.uk/kb5/   /localoffer/service.page?id=0NL2HPMg60Q

47. Where medical aftercare may be necessary, this should include details of the treatment available to participants. Debriefing may involve the disclosure of further information on the aims of the research, the participant's performance and/or the results of the research. (Do not exceed 500 words)

N/A

FOR RESEARCH UNDERTAKEN OUTSIDE THE UK

48. Does the proposed research involve travel outside of the UK?
☐ **YES** ☒ **NO**

If YES, please confirm:

☐ I have consulted the Foreign and Commonwealth Office website for guidance/travel advice? http://www.fco.gov.uk/en/travel-and-living-abroad/

☐ I have completed ta RISK Assessment covering all aspects of the project including consideration of the location of the data collection and risks to participants.

All overseas project data collection will need approval from the Deputy Director of Education and Training or their nominee. Normally this will be done based on the information provided in this form. All projects approved through the TREC process will be indemnified by the Trust against claims made by third parties.

If you have any queries regarding research outside the UK, please contact academicquality@tavi-port.nhs.uk:

Students are required to arrange their own travel and medical insurance to cover project work outside of the UK. Please indicate what insurance cover you have or will have in place.

49. Please evidence how compliance with all local research ethics and research governance requirements have been assessed for the country(ies) in which the research is taking place. Please also clarify how the requirements will be met:

N/A

SECTION G: PARTICIPANT CONSENT AND WITHDRAWAL

50. Have you attached a copy of your participant information sheet (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials.

YES ☒ **NO** ☐

If **NO**, please indicate what alternative arrangements are in place below:

51. **Have you attached a copy of your participant consent form (this should be in *plain English*)? Where the research involves non-English speaking participants, please include translated materials.**

YES ☒ **NO** ☐

If **NO**, please indicate what alternative arrangements are in place below:

N/A

52. **The following is a <u>participant information sheet</u> checklist covering the various points that should be included in this document.**

☒ Clear identification of the Trust as the sponsor for the research, the project title, the Researcher and Principal Investigator (your Research Supervisor) and other researchers along with relevant contact details.
☒ Details of what involvement in the proposed research will require (e.g., participation in interviews, completion of questionnaire, audio/video-recording of events), estimated time commitment and any risks involved.
☒ A statement confirming that the research has received formal approval from TREC or other ethics body.
☒ If the sample size is small, advice to participants that this may have implications for confidentiality / anonymity.
☒ A clear statement that where participants are in a dependent relationship with any of the researchers that participation in the research will have no impact on assessment / treatment / service-use or support.
☒ Assurance that involvement in the project is voluntary and that participants are free to withdraw consent at any time, and to withdraw any unprocessed data previously supplied.
☒ Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations.
☒ A statement that the data generated in the course of the research will be retained in accordance with the Trusts 's Data Protection and handling Policies.: https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/
☒ Advice that if participants have any concerns about the conduct of the investigator, researcher(s) or any other aspect of this research project, they should contact Simon Carrington, Head of Academic Governance and Quality Assurance (academicquality@tavi-port.nhs.uk)

☒ Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

53. The following is a <u>consent form</u> checklist covering the various points that should be included in this document.

☒ Trust letterhead or logo.
☒ Title of the project (with research degree projects this need not necessarily be the title of the thesis) and names of investigators.
☒ Confirmation that the research project is part of a degree
☒ Confirmation that involvement in the project is voluntary and that participants are free to withdraw at any time, or to withdraw any unprocessed data previously supplied.
☒ Confirmation of particular requirements of participants, including for example whether interviews are to be audio-/video-recorded, whether anonymised quotes will be used in publications advice of legal limitations to data confidentiality.
☒ If the sample size is small, confirmation that this may have implications for anonymity any other relevant information.
☒ The proposed method of publication or dissemination of the research findings.
☐ Details of any external contractors or partner institutions involved in the research.
☐ Details of any funding bodies or research councils supporting the research.
☒ Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

SECTION H: CONFIDENTIALITY AND ANONYMITY

54. Below is a checklist covering key points relating to the confidentiality and anonymity of participants. Please indicate where relevant to the proposed research.

☒ Participants will be completely anonymised and their identity will not be known by the investigator or researcher(s) (i.e. the participants are part of an anonymous randomised sample and return responses with no form of personal identification)?
PHASE 1
☐ The responses are anonymised or are an anonymised sample (i.e. a permanent process of coding has been carried out whereby direct and indirect identifiers have been removed from data and replaced by a code, with <u>no</u> record retained of how the code relates to the identifiers).
☒ The samples and data are de-identified (i.e. direct and indirect identifiers have been removed and replaced by a code. The investigator or researchers <u>are</u> able to link the code to the original identifiers and isolate the participant to whom the sample or data relates).
☐ Participants have the option of being identified in a publication that will arise from the research.

☒ Participants will be pseudo-anonymised in a publication that will arise from the research. (I.e. the researcher will endeavour to remove or alter details that would identify the participant.) ☐ The proposed research will make use of personal sensitive data. ☐ Participants consent to be identified in the study and subsequent dissemination of research findings and/or publication.
55. Participants must be made aware that the confidentiality of the information they provide is subject to legal limitations in data confidentiality (i.e. the data may be subject to a subpoena, a freedom of information request or mandated reporting by some professions). This only applies to named or de-identified data. If your participants are named or de-identified, please confirm that you will specifically state these limitations. **YES** ☒ **NO** ☐ If **NO**, please indicate why this is the case below:

NOTE: WHERE THE PROPOSED RESEARCH INVOLVES A SMALL SAMPLE OR FOCUS GROUP, PARTICIPANTS SHOULD BE ADVISED THAT THERE WILL BE DISTINCT LIMITATIONS IN THE LEVEL OF ANONYMITY THEY CAN BE AFFORDED.

SECTION I: DATA ACCESS, SECURITY AND MANAGEMENT

56. Will the Researcher/Principal Investigator be responsible for the security of all data collected in connection with the proposed research? YES ☒ **NO** ☐ If **NO**, please indicate what alternative arrangements are in place below:
N/A

57. In line with the 5th principle of the Data Protection Act (1998), which states that personal data shall not be kept for longer than is necessary for that purpose or those purposes for which it was collected; please state how long data will be retained for.

☐ 1-2 years ☐ 3-5 years ☒ 6-10 years ☐ 10> years

NOTE: In line with Research Councils UK (RCUK) guidance, doctoral project data should normally be stored for 10 years and Masters level data for up to 2 years

58. Below is a checklist which relates to the management, storage and secure destruction of data for the purposes of the proposed research. Please indicate where relevant to your proposed arrangements.

☐ Research data, codes and all identifying information to be kept in separate locked filing cabinets.
☐ Research data will only be stored in the University of Essex OneDrive system and no other cloud storage location.
☒ Access to computer files to be available to research team by password only.
☐ Access to computer files to be available to individuals outside the research team by password only (See **23.1**).
☒ Research data will be encrypted and transferred electronically within the UK.
☐ Research data will be encrypted and transferred electronically outside of the UK.

NOTE: Transfer of research data via third party commercial file sharing services, such as Google Docs and YouSendIt are not necessarily secure or permanent. These systems may also be located overseas and not covered by UK law. If the system is located outside the European Economic Area (EEA) or territories deemed to have sufficient standards of data protection, transfer may also breach the Data Protection Act (1998).

Essex students also have access the ‘Box’ service for file transfer: https://www.essex.ac.uk/student/it-services/box

☒ Use of personal addresses, postcodes, faxes, e-mails or telephone numbers.
☐ Collection and storage of personal sensitive data (e.g. racial or ethnic origin, political or religious beliefs or physical or mental health or condition).
☒ Use of personal data in the form of audio or video recordings.
☐ Primary data gathered on encrypted mobile devices (i.e. laptops).

NOTE: This should be transferred to secure University of Essex OneDrive at the first opportunity.

☒ All electronic data will undergo secure disposal.

NOTE: For hard drives and magnetic storage devices (HDD or SSD), deleting files does not permanently erase the data on most systems, but only deletes the reference to the file. Files can be restored when deleted in this way. Research files must be overwritten to ensure they are completely irretrievable. Software is available for the secure erasing of files from hard drives which meet recognised standards to securely scramble sensitive data. Examples of this software are BC Wipe, Wipe File, DeleteOnClick and Eraser for Windows platforms. Mac users can use the standard ‘secure empty trash’ option; an alternative is Permanent eraser software.

☒ All hardcopy data will undergo secure disposal.

NOTE: For shredding research data stored in hardcopy (i.e. paper), adopting DIN 3 ensures files are cut into 2mm strips or confetti like cross-cut particles of 4x40mm. The UK government requires a minimum standard of DIN 4 for its material, which ensures cross cut particles of at least 2x15mm.

59. **Please provide details of individuals outside the research team who will be given password protected access to encrypted data for the proposed research.**

N/A

60. **Please provide details on the regions and territories where research data will be electronically transferred that are external to the UK:**

N/A

SECTION J: PUBLICATION AND DISSEMINATION OF RESEARCH FINDINGS

35. How will the results of the research be reported and disseminated? *(Select all that apply)*

☒ Peer reviewed journal
☐ Non-peer reviewed journal
☐ Peer reviewed books
☐ Publication in media, social media or website (including Podcasts and online videos)
☒ Conference presentation
☒ Internal report
☐ Promotional report and materials
☐ Reports compiled for or on behalf of external organisations
☒ Dissertation/Thesis
☐ Other publication
☒ Written feedback to research participants
☒ Presentation to participants or relevant community groups
☐ Other (Please specify below)

SECTION K: OTHER ETHICAL ISSUES

36. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of Tavistock Research Ethics Committee (TREC)?

None

SECTION L: CHECKLIST FOR ATTACHED DOCUMENTS

37. Please check that the following documents are attached to your application.

☐ Letters of approval from any external ethical approval bodies (where relevant)
☒ Recruitment advertisement
☒ Participant information sheets (including easy-read where relevant)
☒ Consent forms (including easy-read where relevant)
☐ Assent form for children (where relevant)
☐ Letters of approval from locations for data collection
☒ Questionnaire
☒ Interview Schedule or topic guide
☐ Risk Assessment (where applicable)
☐ Overseas travel approval (where applicable)

39. Where it is not possible to attach the above materials, please provide an explanation below.

N/A

A: Online Questionnaire Questions

11) Do you feel that your child has difficulties with their sleep?

Yes / No

(If No is answered, this will end the questionnaire and the participant will be thanked for their participation)

(If Yes is answered, the participant will be moved to question 2)

12) Would you like to be able to access support in relation to the concerns you have about your child's sleep?

Yes/No

(If No is answered, this will end the questionnaire and the participant will be thanked for their participation)

(If Yes is answered, the participant will be moved to question 3)

13) What type of support would you like to access?

14) Have you sought support for your concerns about your child's sleep?

Yes/No

(If No is answered, the final question will be presented)

(If Yes is answered, the participant will be moved to question 5)

15) Please provide brief details of the support that you sought.

If you are willing to consider participating in an interview to provide more detailed information about your concerns about your child's sleep and the sort of support you would like to be able to access, please provide an email address that you can be contacted on. Further information about the interviews will be supplied to enable you to make an informed decision about whether to participate.

Thank you for your participation

B: Interview schedule

The interview schedule has yet to be developed. The aspects of parental experiences that will be explored will be limited to the following:

- The concerns parents have about their child’s sleep
- Whether they have accessed support
- Where support has been accessed, their experiences/views about what was received
- What did or would encourage/discourage them to seek help
- Whether they have been offered and decline support

C: Email to schools in researcher’s LA

Dear **[insert Headteacher and SENCo’s names here]**,

I am a trainee Educational Psychologist working in ________ Education’s educational psychology service. As part of my work with Tavistock and Portman NHS Trust Doctorate course, I am hoping to recruit parents/carers of children aged 3-11 to take part in a study about the views of parents/carers experiencing difficulties with their children’s sleep. I am emailing as I would like to invite parents/carers from your school to participate.

It is my hope that this study will help those of us working in the Local Authority to better understand:

- ***The demand/need for sleep related support for parents/carers of children aged 3-11***
- ***What sleep related support parents/carers would like***
- ***What might help or get in the way of parents accessing support that could be made available***

The aim is to try and effectively plug any gaps in provision.

In order to include parents/carers from your school, I would need the school to advertise the project. This would involve sending parents/carers an email with an Information Sheet about the project. I have attached the Information Sheet to this email for you to review. To ensure equality of opportunity, I would also ask you to follow the protocols you use in the school to support access for those parents/carers who have difficulty understanding written English.

I would welcome enquiries that would help you decide if you are happy for your school to be involved and support me in advertising this research.

Many thanks and kind regards,

Amy Tyler
Trainee Educational Psychologist
atyler@tavi-port.nhs.uk

D: Phase 1 Information sheet for the researcher's borough

The Tavistock and Portman
NHS Foundation Trust

Thank you for taking the time to read this information sheet regarding my research project about your child's sleep.

A research project will be running in your child's school soon, and this information sheet has been written to provide you with information to help you decide if you would like to participate. If, having read this information, you would like to take part, please click on the link to the questionnaire below.

Who am I?

My name is Amy Tyler. I am a Year 3 trainee Educational Psychologist at the Tavistock and Portman NHS Trust. I am studying for the professional Doctorate in Educational and Child Psychology. I am on placement in ________ Local Authority and am carrying out this research as part of my training.

What is the research about?

I am interested in hearing about parents'/carers'/guardians' views of their child/children's sleep difficulties. The study aims to identify what support local parents want and what might help or get in the way of accessing wanted support.

What am I hoping to achieve?

It is my hope that this information will help people working in the Local Authority to better understand:

- The demand/need for sleep related support for parents of children aged 3-11
- What sleep related support parents would like
- What would help or get in the way of parents accessing support that could be made available

Why are you being invited to participate?

Your child's school has agreed to send this information sheet to all parents/carers. I am hoping to include as many parents as possible.

What will taking part involve?

The study has two parts. The first involves completing a simple online questionnaire that should take no more than 10 minutes to complete. The second part involves an interview that will last a maximum of one hour.

It is possible to take part in just the questionnaire. Once the questionnaire is completed, there is an option for participants to express an interest in taking part in an interview. Should they choose to, there will be space to add their contact details to allow me to contact them about this.

If you agree to take part in the questionnaire, what happens next?

If you would like to take part, please click on the link to the questionnaire below. This will take you to a short consent form which needs to be completed. You will then automatically be connected to the questionnaire.

Do you have to take part?
Taking part is entirely voluntary and is not connected to any support your child has or will receive from the Local Authority.

Your personal information
Your participation and data in this part of the study will be anonymous. I will not receive any personally identifiable details that will enable your data to be linked to you.

Can you change your mind?
Participation in this research is voluntary and you are free to withdraw from the research at any time without giving a reason. Because your participation in this part of the research is anonymous, once you have submitted the questionnaire, I will not be able to remove the data as I will not know who the responses belong to.

What happens to the information I gather?
Information collected from the questionnaire will be analysed and written up in a document that will be held at the Tavistock and Portman library. I also hope to publish the general themes from the study in the future.

Ethical Approval
If you have any queries about the ethical approval of this research, or other aspects of this project, please contact Paru Jeram, the Tavistock and Portman NHS Trust Quality Assurance Officer, using this email address: pjeram@tavi-port.nhs.uk.

If you would like to find out more about this study, you can contact me using the following email address: atyler@tavi-port.nhs.uk.

Thank you for reading this information sheet.

If you would like to take part in the questionnaire, please click on the link below:
[link will appear here]

E: Phase 2 Information sheet

NHS
The Tavistock and Portman
NHS Foundation Trust

Thank you for your interest in my research project about your child's sleep.

I am grateful to you for volunteering to participate in this interview. Please read the information sheet below and then please complete the attached consent form. Feel free to contact me with any questions on the email address below: atyler@tavi-port.nhs.uk

Who am I?

My name is Amy Tyler. I am a Year 3 trainee Educational Psychologist at the Tavistock and Portman NHS Trust. I am studying for the professional Doctorate in Educational and Child Psychology. I am on placement in ________ Local Authority and am carrying out this research as part of my training.

What is the research about?

I am interested in hearing about parents'/carers'/guardians' views of their child/children's sleep difficulties. The study aims to identify what support local parents want and what might help or get in the way of accessing wanted support.

What am I hoping to achieve?

It is my hope that this information will help people working in the Local Authority to better understand:

- The demand/need for sleep related support for parents of children aged 3-11
- What sleep related support parents would like
- What would help or get in the way of parents accessing support that could be made available

Why are you being invited to participate?

When you completed my online questionnaire about your child's sleep, you stated that you would be willing to consider participating in an interview and provided your email address. This information sheet is being sent to you in response to that expression of interest.

What will taking part involve?

This information sheet is about participating in an interview.

The interview will last for no more than one hour. It will explore your concerns about your child's sleep, what help you feel you would like and how you would like to access this help. I will make an audio recording of the interview which I will delete once I have typed up what was said. When I do this, I will change any details that could identify you, to ensure your responses are anonymised.

The interview will be arranged at a time that is convenient to you at your child's school. Alternatively, it can take place online, via Zoom, if you prefer.

Your personal information

I will be the only person who has access to your identifiable information in this study. Any information collected will be kept following the Data Protection Act (2018) and GDPR guidance.

All records related to your participation will be handled and stored securely on an encrypted drive using password protection. Any identifying information on these records will be changed, to avoid your identification. However, due to the small sample size, there is a potential for identification. The data will be kept for a maximum of 10 years.

However, if you share any information linked to your safety or the safety of others, I have a duty of care to share this information under safeguarding procedures. I will tell you if there is information which I need to share.

Can you change your mind?

Participation in this research is voluntary and you are free to withdraw from the research at any time without giving a reason. Any information you provide (including what you say in the interviews) can be deleted and removed from the study, at your request, up until the point that the analysis has been completed and submitted for review by my supervisor.

What happens to the information I gather?

Information collected from the interview will be analysed and written up in a document that will be held at the Tavistock and Portman library. I also hope to publish the general themes from the study in the future.

Ethical Approval

If you have any queries about the ethical approval of this research, or other aspects of this project, please contact Paru Jeram, the Tavistock and Portman NHS Trust Quality Assurance Officer, using this email address: pjeram@tavi-port.nhs.uk.

If you would like to find out more about this study, you can also contact me using the following email address: atyler@tavi-port.nhs.uk.

Thank you for reading this information sheet.

F: Phase 1 Consent form

Title: Parental concerns about children’s sleep; the support parents would like to access; and how they would like to access support

Thank you for clicking on the link to the questionnaire about Children’s sleep and the support parents might like in relation to this.

Before completing the questionnaire, I need to make sure that you understand what the research involves and that you consent to participating. To do this, please complete the following:

	Yes	No
I have read and understood the information sheet about this questionnaire and have had a chance to have any questions I have about it answered		
I understand that this research is being conducted as part of a university degree that the researcher is studying for		
I understand that my participation in this research is entirely voluntary, and I am free to withdraw from it before completing the questionnaire		
I understand that my data in this questionnaire is anonymised and once I have submitted it, I will not be able to withdraw it as the researcher will not be able to identify it as belonging to me		
I understand that the findings from this research will be published in a research report and they may also be shared in other presentations or publications		
I am happy to participate in the questionnaire		

If the answers to all of the above are ‘Yes’, the respondent will automatically be linked to the questionnaire.

If the answer to any of the above is ‘No’, the respondent will not be able to access the questionnaire. Instead, they will be invited to contact the researcher to discuss their participation.

G: Phase 2 Consent form

Title: Parental concerns about children’s sleep; the support parents would like to access; and how they would like to access support

Thank you for your interest in taking part in an interview about Children’s sleep and the support parents might like in relation to this.

Before taking part in the interview, I need to make sure that you fully understand what the research involves and that you fully consent to participating. To do this, please complete the following:

	Yes	No
I have read and understood the information sheet about this interview and have had a chance to have any questions I have about it answered		
I understand that this research is being conducted as part of a university degree that the researcher is studying for		
I understand that my participation in this research is entirely voluntary and I am able to withdraw consent, and my data, up until the data analysis has been conducted		
I agree for my interview to be recorded		
I understand that my data will be anonymised so that people reading the research will not link my data to me but that due to the small sample size, there is a potential for identification.		
I understand that there are limits to confidentiality and if I share information about potential harm to myself or others, the researcher is legally required to share this information		
I understand that the findings from this research will be published in a research report and they may also be shared in other presentations or publications		
I am happy to participate in the interview		

Parent/carer/guardian’s signature:
…………………………………………………………………………………….
Parent/carer/guardian’s name (BLOCK CAPITALS):
…………………………………………………………………………………….
Relationship to the child:
……………………………………………………………………………………..
Contact Email:
……………………………………………………………………………………..

Date: ……………………..………………
Please return to:
Amy Tyler
atyler@tavi-port.nhs.uk

H: Email to schools in England outside of the researcher's LA

Hello,

Thank you for looking at this email regarding my research.

I am a trainee Educational Psychologist working in a London based educational psychology service. As part of my work with Tavistock and Portman NHS Trust Doctorate course, I am hoping to recruit parents/carers of children aged 3-11 to take part in a study about the views of parents/carers experiencing difficulties with their children's sleep. I am emailing as I would like to invite parents/carers from your school to participate.

Participation would involve parents completing a 5 minute questionnaire online.

It is my hope that this study will help increase understanding of:

- ***The demand/need for sleep related support for parents/carers of children aged 3-11***
- ***What sleep related support parents/carers would like***
- ***What might help or get in the way of parents accessing support that could be made available***

The aim is to try and effectively plug any gaps in knowledge of provision.

In order to include parents/carers from your school, I would need the school to advertise the project. This would involve sending parents/carers an email with an Information Sheet and/or advert about the project. I have attached these to this email for you to review. To ensure equality of opportunity, I would also ask you to follow the protocols you use in the school to support access for those parents/carers who have difficulty understanding written English.

I would welcome enquiries that would help you decide if you are happy for your school to be involved and support me in advertising this research.

Many thanks and kind regards,

Amy Tyler
Trainee Educational Psychologist
atyler@tavi-port.nhs.uk

I: Phase 1 Information sheet for schools outside of researcher's borough

NHS
The Tavistock and Portman
NHS Foundation Trust

Thank you for taking the time to read this information sheet regarding my research project about your child's sleep.

This information sheet has been written to provide you with information to help you decide if you would like to participate in this research project. If, having read this information, you would like to take part, please click on the link to the questionnaire below.

Who am I?
My name is Amy Tyler. I am a Year 3 trainee Educational Psychologist at the Tavistock and Portman NHS Trust. I am studying for the professional Doctorate in Educational and Child Psychology. I am carrying out this research as part of my training.

What is the research about?
I am interested in hearing about parents'/carers'/guardians' views of their child/children's sleep difficulties. The study aims to identify what support parents want and what might help or get in the way of accessing desired support.

What am I hoping to achieve?
It is my hope that this information will help people to better understand:

- The demand/need for sleep related support for parents of children aged 3-11
- What sleep related support parents would like
- What would help or get in the way of parents accessing support that could be made available

What will taking part involve?
The study involves completing a simple online questionnaire that should take no more than 5 minutes to complete.

If you agree to take part in the questionnaire, what happens next?
If you would like to take part, please click on the link to the questionnaire below. This will take you to a short consent form which needs to be completed. You will then automatically be connected to the questionnaire.

Do you have to take part?
Taking part is entirely voluntary and is not connected to any support your child has or will receive from their school.

Your personal information
Your participation and data in this part of the study will be anonymous. I will not receive any personally identifiable details that will enable your data to be linked to you.

Can you change your mind?

Participation in this research is voluntary and you are free to withdraw from the research at any time without giving a reason. Because your participation in this part of the research is anonymous, once you have submitted the questionnaire, I will not be able to remove the data as I will not know who the responses belong to.

What happens to the information I gather?

Information collected from the questionnaire will be analysed and written up in a document that will be held at the Tavistock and Portman library. I also hope to publish the general themes from the study in the future.

Ethical Approval

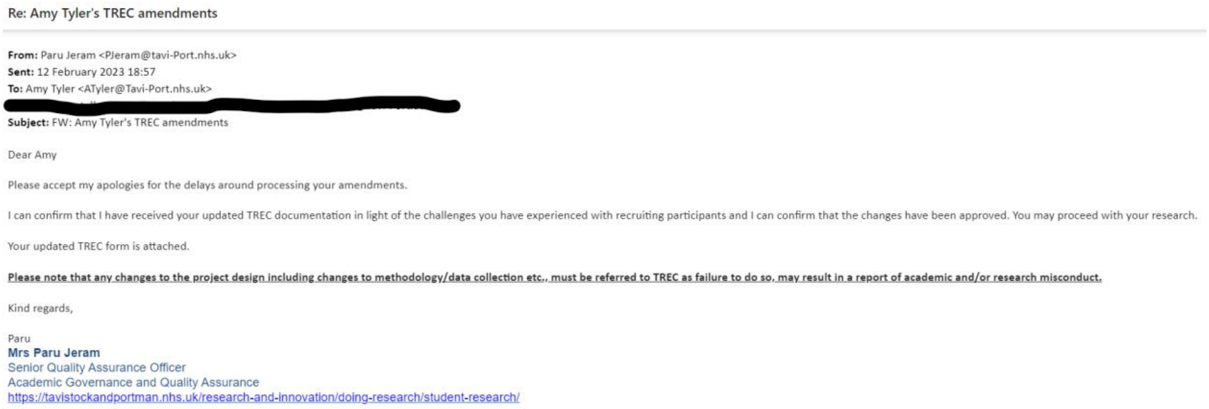
If you have any queries about the ethical approval of this research, or other aspects of this project, please contact Paru Jeram, the Tavistock and Portman NHS Trust Quality Assurance Officer, using this email address: pjeram@tavi-port.nhs.uk.

If you would like to find out more about this study, you can contact me using the following email address: atyler@tavi-port.nhs.uk.

Thank you for reading this information sheet.

If you would like to take part in the questionnaire, please click on the link below:
[link will appear here]

Appendix 14: Email Confirmation of Acceptance of Changes to TREC



Re: Amy Tyler's TREC amendments

From: Paru Jeram <PJeram@tavi-Port.nhs.uk>
Sent: 12 February 2023 18:57
To: Amy Tyler <ATyler@Tavi-Port.nhs.uk>
[redacted]
Subject: FW: Amy Tyler's TREC amendments

Dear Amy

Please accept my apologies for the delays around processing your amendments.

I can confirm that I have received your updated TREC documentation in light of the challenges you have experienced with recruiting participants and I can confirm that the changes have been approved. You may proceed with your research.

Your updated TREC form is attached.

Please note that any changes to the project design including changes to methodology/data collection etc., must be referred to TREC as failure to do so, may result in a report of academic and/or research misconduct.

Kind regards,

Paru
Mrs Paru Jeram
Senior Quality Assurance Officer
Academic Governance and Quality Assurance
https://tavistockandportman.nhs.uk/research-and-innovation/doing-research/student-research/

Appendix 15: Approval of Title Form

UNIVERSITY OF ESSEX
POSTGRADUATE RESEARCH EDUCATION TEAM

APPROVAL OF THESIS TITLE
(PARTNER INSTITUTIONS)

To be completed at least **three months prior to submission**

CANDIDATE'S DETAILS			
First name	Amy	Last name	Tyler
Department	Tavistock & Portman NHS	Registration numl	20002272
Qualification sou	M4: Child, Community and Educational Psychology		

Please note that we will use your **Essex email address** to send you important forms and notifications relating to the examination of your thesis. Please ensure that you keep your Essex email account active at all times.

THESIS TITLE

☒ I have consulted my supervisor about the submission of my thesis for the research degree indicated
above and I would like to give notice of the final title of my thesis as follows:

Please type clearly using sentence case, maximum length including spaces should not exceed 250 characters

Parents' views on their children's sleep difficulties and their approach to help seeking: An exploratory study

THIS IS THE TITLE THAT SHOULD APPEAR ON THE TITLE PAGE OF THE THESIS YOU SUBMIT FOR EXAMINATION. YOUR TITLE SHOULD NOT CHANGE FOLLOWING SUBMISSION OF THIS FORM.

☒ I confirm that I have read the Regulations regarding thesis presentation, especially those requiring a
summary of the work of up to 300 words and indicating the maximum length of the thesis.

☒ I confirm that I have the required, or do not require, University of Essex ethical approval for the research conducted as part of my research degree and contained within this thesis.

☒ I understand that the University does not guarantee that degree conferment will take place in time for attendance at the next Graduation Ceremony.

EMBARGO REQUESTS

Following successful completion of the examination process, your thesis will need to be uploaded to the University's Research Repository. In rare cases, it may be necessary to restrict access to a thesis. For example, if your thesis content may endanger study participants / authors, or you are intending to produce a novel or literary work using your thesis. If you would like to learn more about this, please visit https://www.essex.ac.uk/student/postgraduate-research/preparing-to-submit-thesis, where you will also find the Embargo Request Form. Please note that embargo requests must be submitted for approval **before** your thesis is submitted for examination, preferably together with this Approval of Title form. Post-examination requests will only be considered in exceptional cases.

My intended date of submission is:	30.09.2023		
Candidate's signature:		Date	16.02.2023

Please submit your form to your supervisor for the first stage of approval.

TO BE COMPLETED BY THE PARTNER INSTITUTION				
Has this candidate ever been a member of staff?		NO	If yes, in what capacity? *Please include dates of any positions held.*	
Is the candidate currently:	a) in debt?	No	b) registered?	YES
I confirm that: - I approve the above final title of this candidate's thesis as it reads, and that no mistakes (including spelling errors) have been made. - Both examiners have been identified and approached and that the nomination process is underway or has been completed.				
Examiners' names				
Supervisor's signature			Date	9.03.23
Graduate Director / Head of Department's signature			Date	

Following approval, please return the completed form to the PGRE Team: ***pgresearch@essex.ac.uk***

PGRE TEAM USE ONLY	
Staff check result:	☐ STAFF ☐ NOT STAFF
Registered:	☐ YES / ☐ NO
In Debt:	☐ YES / ☐ NO

Appendix 16: Participant Debrief Sheet

Thank you very much for taking part in my interview about your child's sleep difficulties

Below you will find links to information and sources that I hope will support you and your child

The **Children's Sleep Charity** offers advice to anyone whose child is not sleeping well www.thechildrenssleepcharity.org.uk
The following is a link specifically to relaxation tips
https://thesleepcharity.org.uk/information-support/children/relaxation-tips/
You can contact them on 01302 751 416

Contact (previously known as Contact a Family) provides information, particularly for children with disabilities
See their booklet on sleep at contact.org.uk/about-us/resource-library/parent-guide-helping-your-child-sleep/

Some support online from **Great Ormand Street Hospital**
https://www.gosh.nhs.uk/conditions-and-treatments/procedures-and-treatments/sleep-hygiene-children/

You can find information, advice, strategies and tips to support sleep in children and adolescents from **'action for children'**:
Sleep - Support for Parents from Action For Children

A very helpful website from **sleep foundation** containing tips, information and recent research about sleep
https://www.sleepfoundation.org/children-and-sleep

Next you will find some advice, tips and suggestions you could try

Sleep Hygiene Tips:

What is sleep hygiene?

Sleep hygiene simply means good sleep habits that may help you to get a good night's sleep. Sometimes even if you have been asleep for a long time, it is not restful sleep, so you awake still feeling tired. Good sleep hygiene can support sleep to be more restful to leave you feeling more energised in the daytime.

Daytime habits also affect sleep. You can promote restful slumber in your children by following basic sleep hygiene rules:

- ✓ Arranging a balanced schedule with interspersed periods of rest and play
- ✓ Keeping a regular bedtime
- ✓ Making the bedroom, and especially the mattress, a no-screen zone, even during the day
- ✓ Providing a healthy diet
- ✓ Having the bedroom at a slightly cooler temperature
- ✓ Using dark curtains to block out light, or a nightlight if they're scared of the dark
- ✓ Keeping the bedroom quiet, or using a white noise machine to mask outside sounds
- ✓ Avoiding caffeine, large meals, and sugary treats before bedtime, opting for a healthy bedtime snack if necessary
- ✓ It's important to give your child regular exercise, but don't fall into the trap of exhausting your child to have them sleep better at night. More often than not, this will make them overtired and actually make it harder to fall asleep. Learn to recognize the special level of hyper that means your toddler is too tired, so you can put them to bed before things turn sour.
- ✓ Sometimes, a bedtime routine is easier said than done. For two-parent households or siblings who share a room, bedtime may require extra logistics. The National Sleep Foundation has a list of additional sleep strategies if you're having trouble getting your kids sleeping.

Top tips for supporting your child with their sleep:

Create a consistent routine

Having some regularity and 'winding down' at more or the less the same time each night is helpful.

You can also be consistent with meal-times beforehand

Getting changed into bed-clothes each night

Having consistent wake up routines and times also

Saying good-night to cuddly toys etc can be another nice trigger to kick-start the sleepy feelings

Sleeping later

If someone is struggling to get to sleep and they are lying awake for a few hours, trying to go to sleep later may be more effective and less frustrating. Attempting this alongside eliminating naps would be akin to 'Sleep Restriction Therapy'. This can be an effective approach.

Bath before bed

Having a hot bath before bed will encourage bodily temperature change which naturally increases the release of melatonin. Melatonin helps to trigger sleep.

Avoid screens

Research tells us that sleep is significantly impacted if we view 'screens' within the hour before we go to sleep. This is especially true for the 30 mins before bed.

Leave phones and tablets away from the bedroom.

Set aside time to finish phone or tablet activities well before planned sleeping time.

Comfortable environment

It's worth thinking about what the preferred environment is for the sleeper. Levels of light can be changed by curtain thickness or plug in night lights. Levels of sound can be adapted. Relaxation apps can block out disturbing sounds. White noise, fans and audiobooks, can be helpful. Predictable and constant noises are easier to sleep to than the sound of speech or

fluctuating noises from the street or from neighbours. Ear-plugs can be effective for some people.
Temperature - think about duvet thickness, fabrics and breezes. Ideally the bedroom should be cool and dark.

Relaxation and Meditation
There are many relaxation and meditation apps or sound links out there which can help with sleep.
The techniques ‘progressive muscle relaxation’ or ‘belly breathing’ can help to encourage sleep inducing mind states. There are videos and support links online for these techniques that can be helpful for children to follow. These will need to be tried more than once as the novelty factor may keep someone awake initially.

Rules
Enforcing some parameters, boundaries and expectations in relation to bedtime routine is likely to be necessary with younger children and with teenagers who may prefer to fall into the social media time warp.

Resilience
Keep trying. Healthy sleeping patterns do not appear overnight. It will take patience and consistency.

Psycho-education
Talk to young people about the benefits they will see and feel if they have good sleep hygiene. For example, more energy in the day, feeling better generally and finding it easier to get up each morning.

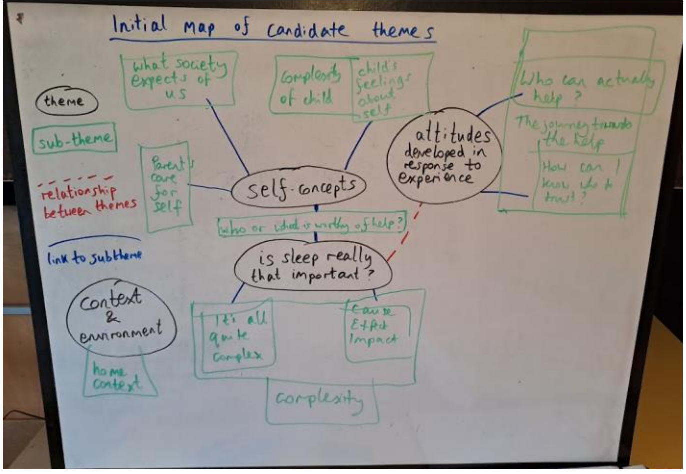
Appendix 17: Expanded Content Analysis Table

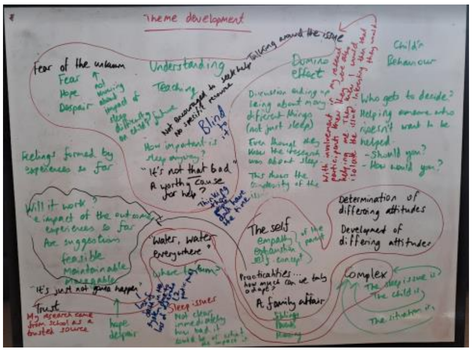
Category	Quotes
Specific individual professional sought	I went to school nurse who told me to see GP. GP referred me to a specialist to get Melatonin to try. After 6 weeks wait I got a letter telling me the department who specialise in sleep in [location name] is now closed and they could not help. Went back to GP who literally just shrugged and said there was nothing they could do as they couldn't prescribe melatonin as a GP. Tried to contact GP but no help as such Saw gp was told everything is fine and he doesn't need to see anyone or any help because he will sleep for 4/5 hours a night even though that's broken sleep When he was much younger with health visitor / healthy families team When he was younger support from h/v which is typical support control crying etc. Some time ago through a children's support worker it's the result of trauma we all went through (dv)
A group or organisation sought	Believe sleep difficulties were as a result of significant anxiety. GP was no help at all, just referred us to CAMHS who turned us down twice. Eventually got accepted by CAMHS but had to wait over a year until we managed to speak to anyone. Entire family suffered for almost two years from lack of sleep. Medical but was told that it was part of upper airway infection CAMHS support as son was on adhd pathway

	CAMHS sent useful documentation None. Just said to teacher was hard to get child to go bed.- sleep is possibly seen as something that is just a general conversation piece rather than seeking help.
Medical or other procedure or intervention sought	Sleep apnea and sleep talking and walking and breathing during sleep. Had tonsils and adenoids removed, now no concerns under the paedetrician and their answer was to give my child medication which caused nightmares and greater anxiety
Independent support sought	Bought an online sleep course but it was rubbish Of the internet how to relax them

Appendix 18: Examples of Reflexive Notes

10.04.23
From the following photos, I am beginning to define (what I think will be) my themes





I think I have decided that my 'findings' write up will be illustrative rather than analytical.
"If the researcher were aiming to produce a more illustrative write-up of the analysis, relating the results to the available literature would tend to be held until the 'discussion' section of the report."
(see page 18 of Byrne's worked TA example)

06.04.23
Talking to a course friend about maxQDA and thematic analysis
I started to talk to her about the process I have gone through in terms of analysing the data and she reminded me that all of the process needs to be written down in terms of my researcher reflexivity
I printed and cut all of the codes
Spread them out over huge surface area
Read them and split them up into very initial themes
Did not look at their 'buckets'
Then put them in envelopes
Then put the envelopes on to clipboards
I had some that were not seeming to fit into a theme so they went into envelopes that were either blank, with question mark or with post-it saying 'go through these and sort them into potential themes'

I then took all of this downstairs
Started in attic
With whiteboard and more pens I drew maps which I photographed
I wrote out potential organising concepts

Refamiliarised self with interviews by listening again and highlighting

The next day I went to cafes and library to write organising concepts in prose for each candidate theme
Next day I got out all codes in envelopes and took out all codes without a theme
It was surprisingly easy to move them all into the themes that I had already created

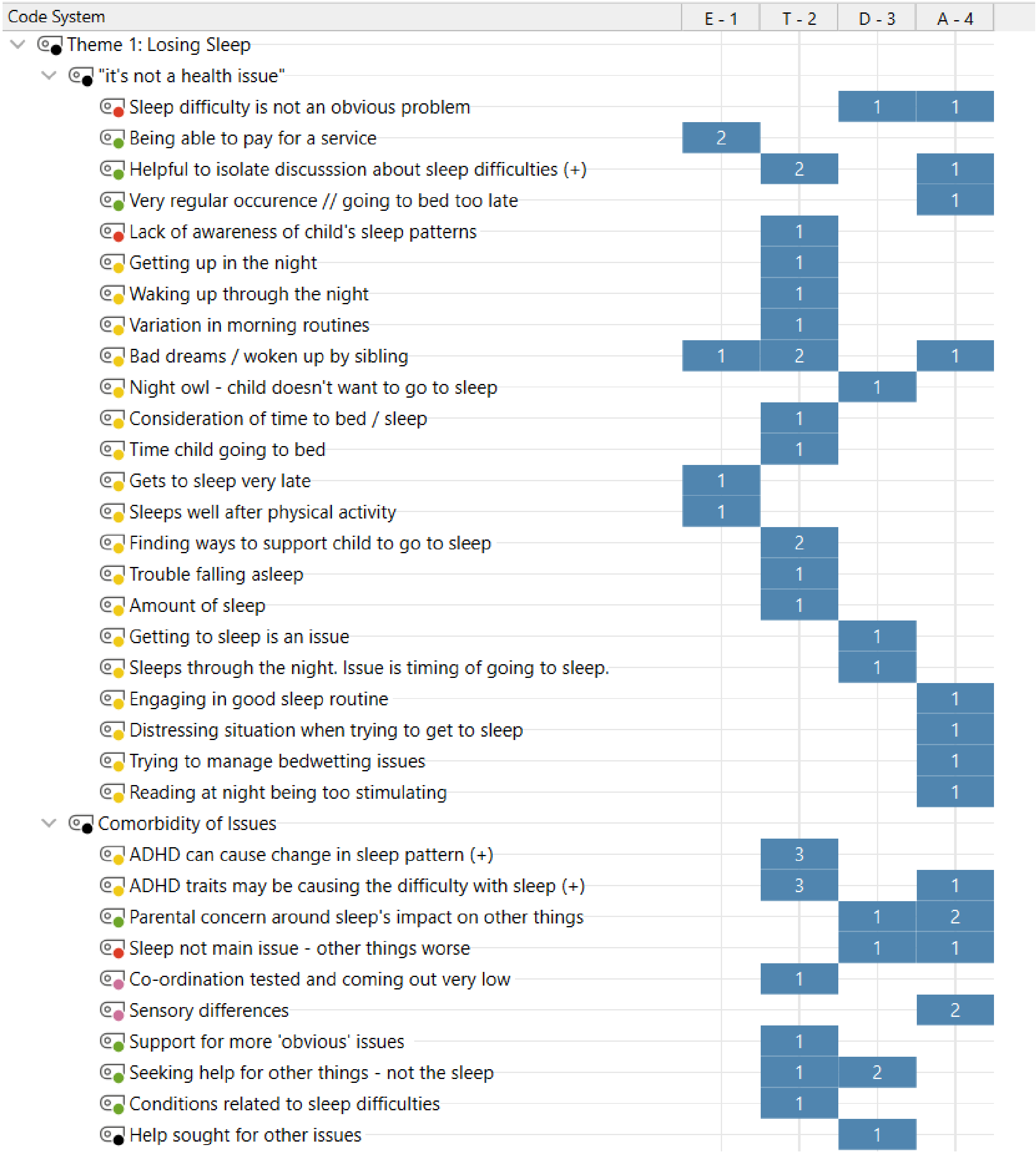
This day I also drew out thematic map of candidate themes

27th March 2023
First day working in Lake District at Dad's
Feel fresh and feel able to write Findings chapter in next 2 weeks
Currently finishing coding of final interview and then preparing codes ready to do thematic analysis
Trying to decide the best way to develop themes
Should I use software or printed cut outs?
I would prefer printed cut outs, but I'm not sure if I will need mind maps and diagrams ready to put into the thesis to show the process
I will have a short play around with this when I am back onto maxQDA and I'll also have a look at Miro for mind map ideas

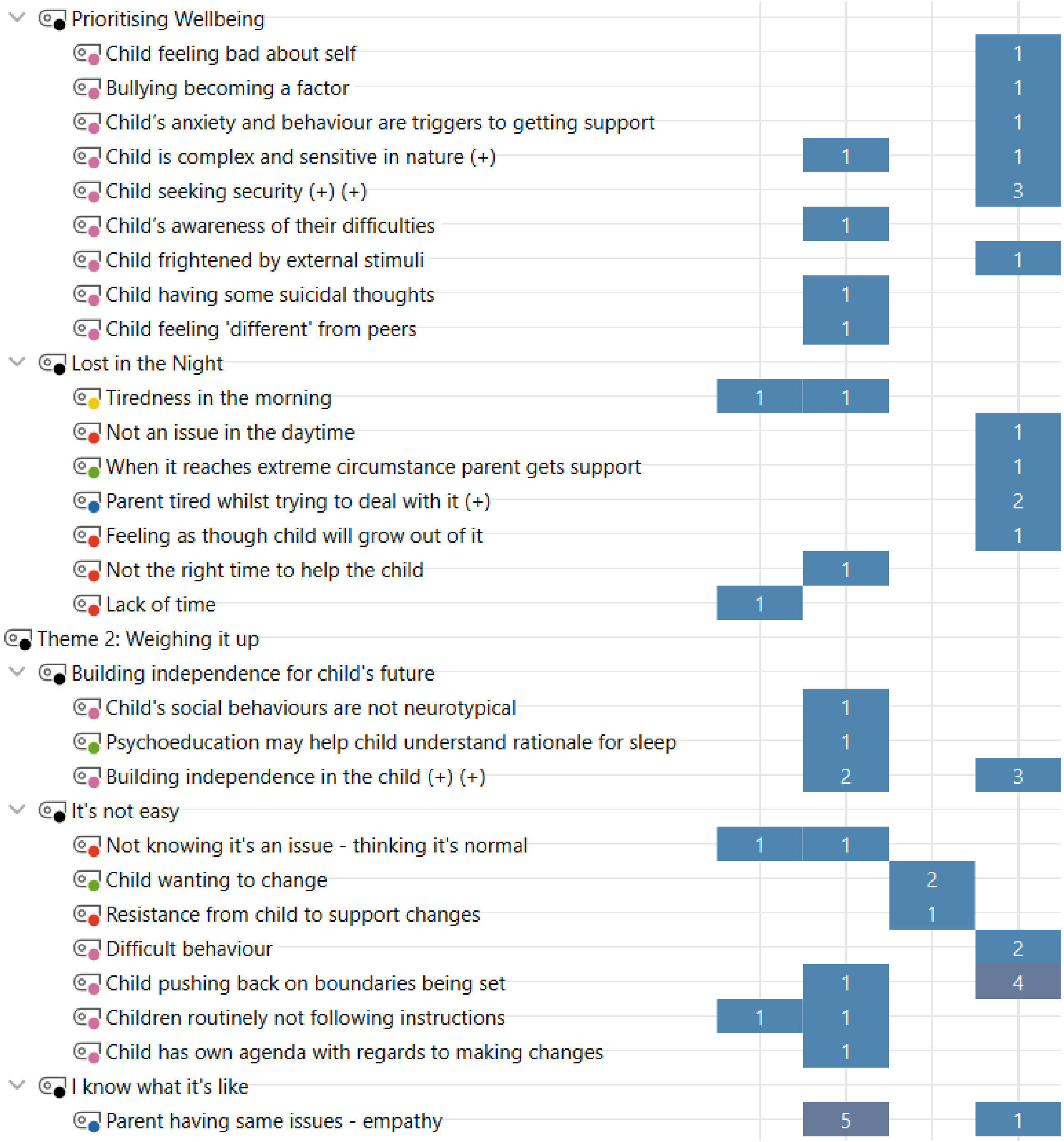
16th March 2023
I am currently analysing my data and I am finding it really interesting and enjoying it
I have coded 3 out of 4 interviews and it is just the right time to go through all of the codes I have created so far to make sure I start to develop a feel for overarching themes coming through
I am doing this when I have just coded about 10% of the final interview
This will help me to have more of a focus on what has come up already
And also this will help me to be sure I don't create a harder job for myself by creating too many new codes rather than utilising the ones I have already created

What I have noticed as I have been coding is that I have been created similar codes to those already created because I have used a very slightly different wording and can't seem to find the one that I have created before

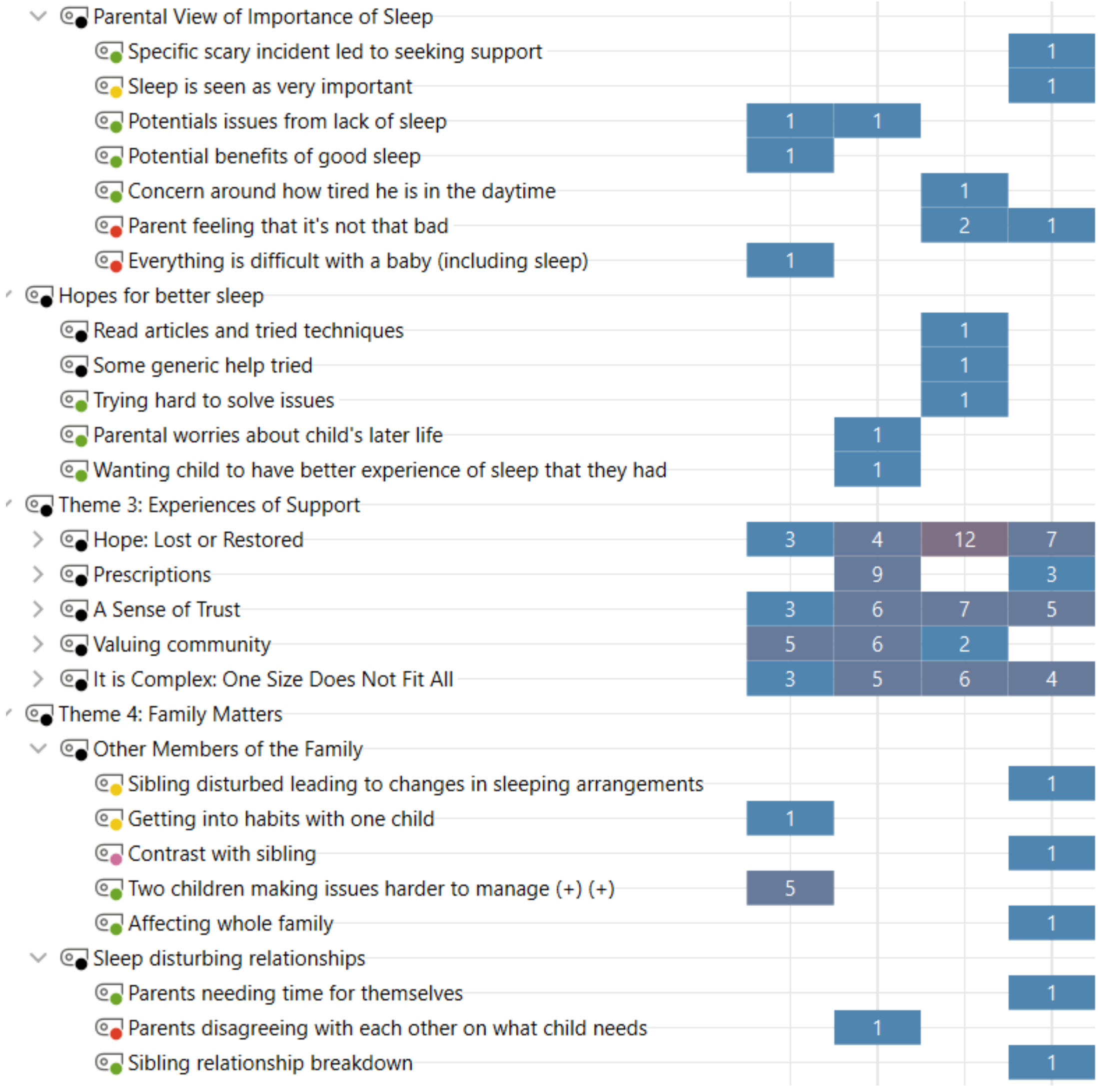
Appendix 19: Codes and Participants Represented by Subthemes



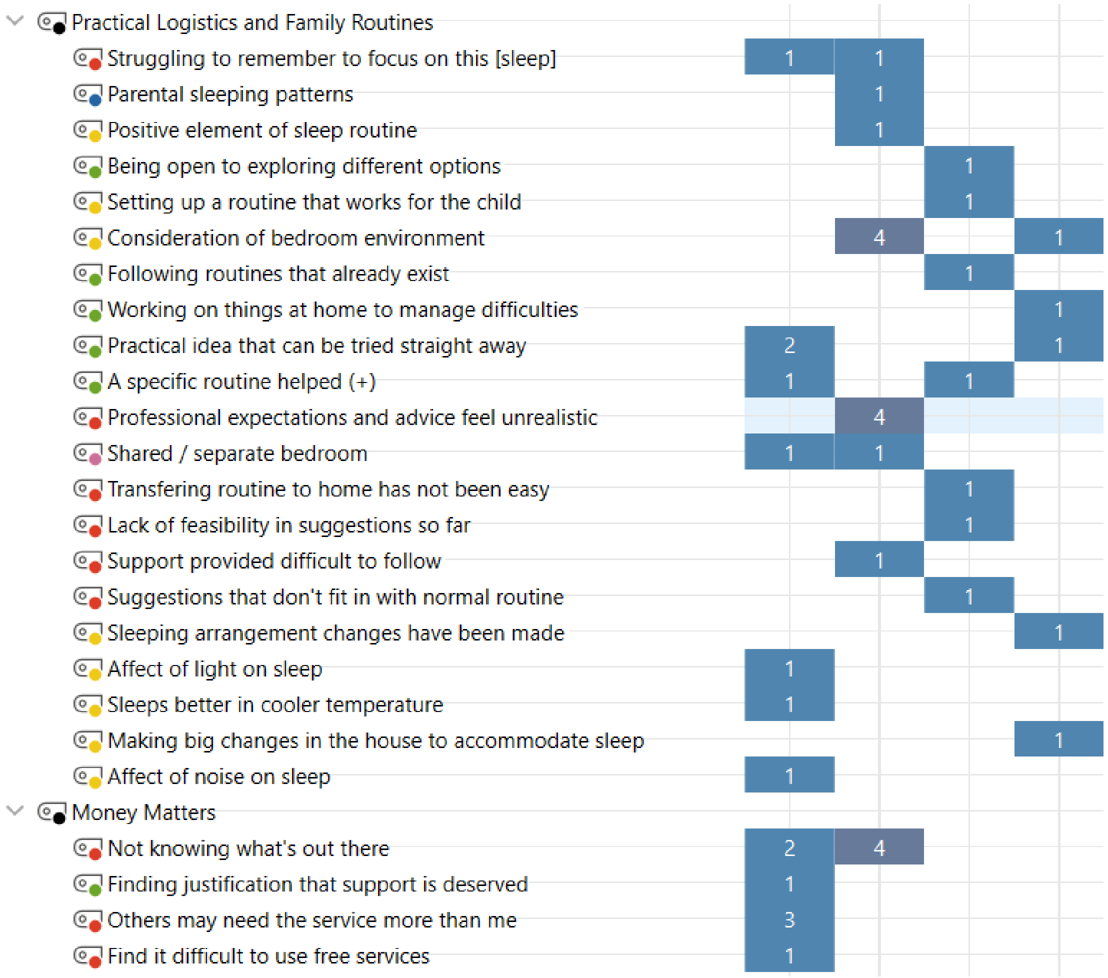
Code System	E - 1	T - 2	D - 3	A - 4
Theme 1: Losing Sleep				
"it's not a health issue"				
Sleep difficulty is not an obvious problem			1	1
Being able to pay for a service	2			
Helpful to isolate discusssion about sleep difficulties (+)		2		1
Very regular occurence // going to bed too late				1
Lack of awareness of child's sleep patterns		1		
Getting up in the night		1		
Waking up through the night		1		
Variation in morning routines		1		
Bad dreams / woken up by sibling	1	2		1
Night owl - child doesn't want to go to sleep			1	
Consideration of time to bed / sleep		1		
Time child going to bed		1		
Gets to sleep very late	1			
Sleeps well after physical activity	1			
Finding ways to support child to go to sleep		2		
Trouble falling asleep		1		
Amount of sleep		1		
Getting to sleep is an issue			1	
Sleeps through the night. Issue is timing of going to sleep.			1	
Engaging in good sleep routine				1
Distressing situation when trying to get to sleep				1
Trying to manage bedwetting issues				1
Reading at night being too stimulating				1
Comorbidity of Issues				
ADHD can cause change in sleep pattern (+)		3		
ADHD traits may be causing the difficulty with sleep (+)		3		1
Parental concern around sleep's impact on other things			1	2
Sleep not main issue - other things worse			1	1
Co-ordination tested and coming out very low		1		
Sensory differences				2
Support for more 'obvious' issues		1		
Seeking help for other things - not the sleep		1	2	
Conditions related to sleep difficulties		1		
Help sought for other issues			1	



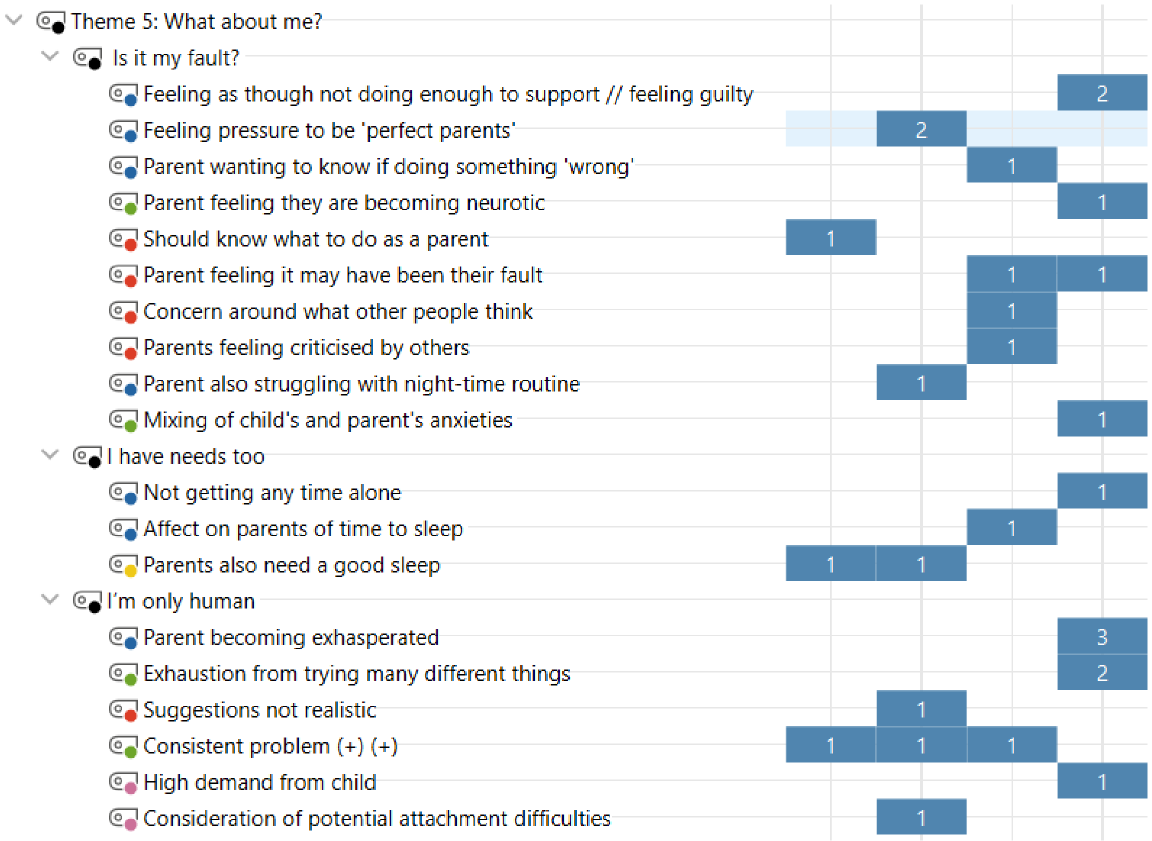
Prioritising Wellbeing				
Child feeling bad about self				1
Bullying becoming a factor				1
Child’s anxiety and behaviour are triggers to getting support				1
Child is complex and sensitive in nature (+)		1		1
Child seeking security (+) (+)				3
Child’s awareness of their difficulties		1		
Child frightened by external stimuli				1
Child having some suicidal thoughts		1		
Child feeling 'different' from peers		1		
Lost in the Night				
Tiredness in the morning	1	1		
Not an issue in the daytime				1
When it reaches extreme circumstance parent gets support				1
Parent tired whilst trying to deal with it (+)				2
Feeling as though child will grow out of it				1
Not the right time to help the child		1		
Lack of time	1			
Theme 2: Weighing it up				
Building independence for child's future				
Child's social behaviours are not neurotypical		1		
Psychoeducation may help child understand rationale for sleep		1		
Building independence in the child (+) (+)		2		3
It's not easy				
Not knowing it's an issue - thinking it's normal	1	1		
Child wanting to change			2	
Resistance from child to support changes			1	
Difficult behaviour				2
Child pushing back on boundaries being set		1		4
Children routinely not following instructions	1	1		
Child has own agenda with regards to making changes		1		
I know what it's like				
Parent having same issues - empathy		5		1



Parental View of Importance of Sleep				
Specific scary incident led to seeking support				1
Sleep is seen as very important				1
Potentials issues from lack of sleep	1	1		
Potential benefits of good sleep	1			
Concern around how tired he is in the daytime			1	
Parent feeling that it's not that bad			2	1
Everything is difficult with a baby (including sleep)	1			
Hopes for better sleep				
Read articles and tried techniques			1	
Some generic help tried			1	
Trying hard to solve issues			1	
Parental worries about child's later life		1		
Wanting child to have better experience of sleep that they had		1		
Theme 3: Experiences of Support				
Hope: Lost or Restored	3	4	12	7
Prescriptions		9		3
A Sense of Trust	3	6	7	5
Valuing community	5	6	2	
It is Complex: One Size Does Not Fit All	3	5	6	4
Theme 4: Family Matters				
Other Members of the Family				
Sibling disturbed leading to changes in sleeping arrangements				1
Getting into habits with one child	1			
Contrast with sibling				1
Two children making issues harder to manage (+) (+)	5			
Affecting whole family				1
Sleep disturbing relationships				
Parents needing time for themselves				1
Parents disagreeing with each other on what child needs		1		
Sibling relationship breakdown				1

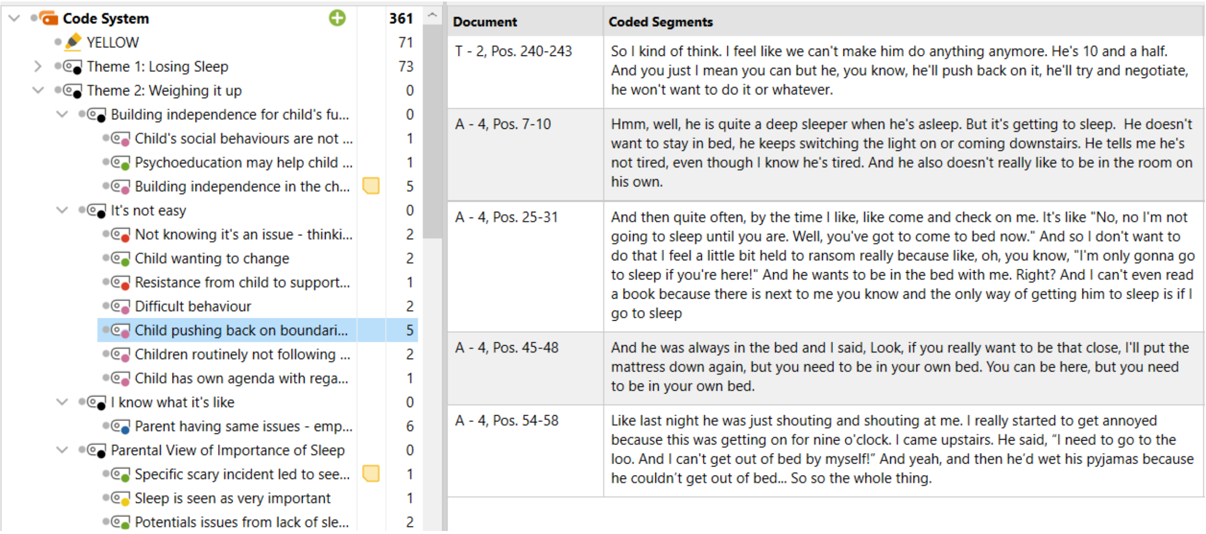


Practical Logistics and Family Routines				
Struggling to remember to focus on this [sleep]	1	1		
Parental sleeping patterns		1		
Positive element of sleep routine		1		
Being open to exploring different options			1	
Setting up a routine that works for the child			1	
Consideration of bedroom environment		4		1
Following routines that already exist			1	
Working on things at home to manage difficulties				1
Practical idea that can be tried straight away	2			1
A specific routine helped (+)	1		1	
Professional expectations and advice feel unrealistic		4		
Shared / separate bedroom	1	1		
Transfering routine to home has not been easy			1	
Lack of feasibility in suggestions so far			1	
Support provided difficult to follow		1		
Suggestions that don't fit in with normal routine			1	
Sleeping arrangement changes have been made				1
Affect of light on sleep	1			
Sleeps better in cooler temperature	1			
Making big changes in the house to accommodate sleep				1
Affect of noise on sleep	1			
Money Matters				
Not knowing what's out there	2	4		
Finding justification that support is deserved	1			
Others may need the service more than me	3			
Find it difficult to use free services	1			



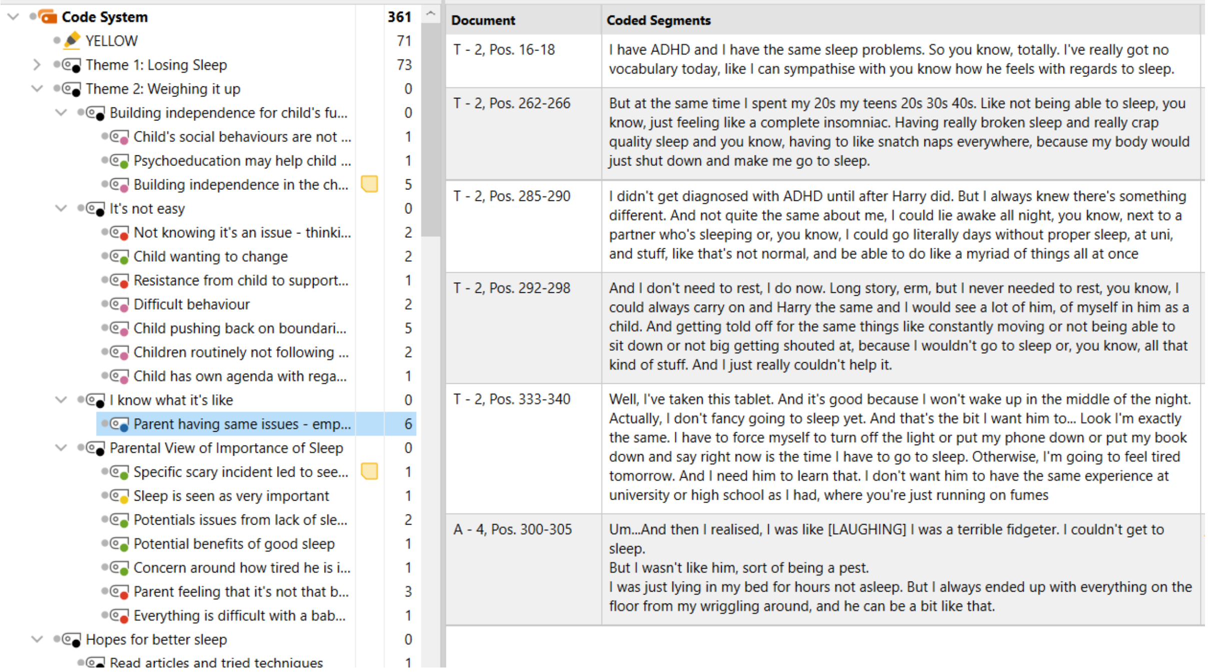
Theme 5: What about me?				
Is it my fault?				
Feeling as though not doing enough to support // feeling guilty				2
Feeling pressure to be 'perfect parents'		2		
Parent wanting to know if doing something 'wrong'			1	
Parent feeling they are becoming neurotic				1
Should know what to do as a parent	1			
Parent feeling it may have been their fault			1	1
Concern around what other people think			1	
Parents feeling criticised by others			1	
Parent also struggling with night-time routine		1		
Mixing of child's and parent's anxieties				1
I have needs too				
Not getting any time alone				1
Affect on parents of time to sleep			1	
Parents also need a good sleep	1	1		
I'm only human				
Parent becoming exhasperated				3
Exhaustion from trying many different things				2
Suggestions not realistic		1		
Consistent problem (+) (+)	1	1	1	
High demand from child				1
Consideration of potential attachment difficulties		1		

Appendix 20: Extracts from Codes following Thematic Analysis



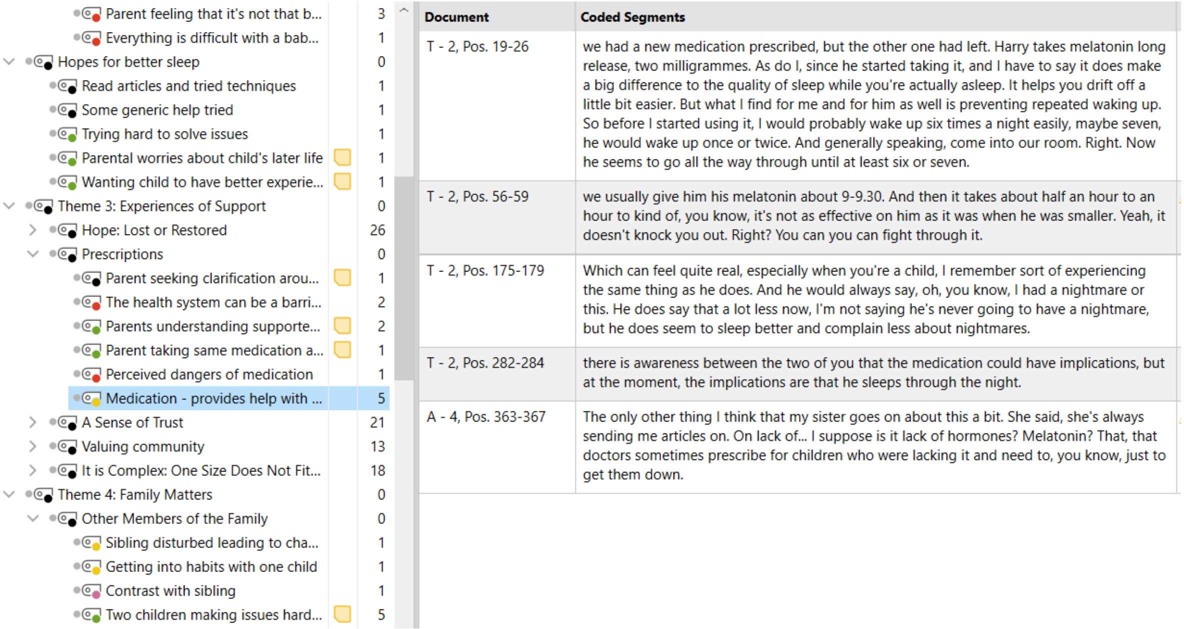
Code System	361
YELLOW	71
Theme 1: Losing Sleep	73
Theme 2: Weighing it up	0
Building independence for child's fu...	0
Child's social behaviours are not ...	1
Psychoeducation may help child ...	1
Building independence in the ch...	5
It's not easy	0
Not knowing it's an issue - thinki...	2
Child wanting to change	2
Resistance from child to support...	1
Difficult behaviour	2
Child pushing back on boundari...	5
Children routinely not following ...	2
Child has own agenda with rega...	1
I know what it's like	0
Parent having same issues - emp...	6
Parental View of Importance of Sleep	0
Specific scary incident led to see...	1
Sleep is seen as very important	1
Potentials issues from lack of sle...	2

Document	Coded Segments
T - 2, Pos. 240-243	So I kind of think. I feel like we can't make him do anything anymore. He's 10 and a half. And you just I mean you can but he, you know, he'll push back on it, he'll try and negotiate, he won't want to do it or whatever.
A - 4, Pos. 7-10	Hmm, well, he is quite a deep sleeper when he's asleep. But it's getting to sleep. He doesn't want to stay in bed, he keeps switching the light on or coming downstairs. He tells me he's not tired, even though I know he's tired. And he also doesn't really like to be in the room on his own.
A - 4, Pos. 25-31	And then quite often, by the time I like, like come and check on me. It's like "No, no I'm not going to sleep until you are. Well, you've got to come to bed now." And so I don't want to do that I feel a little bit held to ransom really because like, oh, you know, "I'm only gonna go to sleep if you're here!" And he wants to be in the bed with me. Right? And I can't even read a book because there is next to me you know and the only way of getting him to sleep is if I go to sleep
A - 4, Pos. 45-48	And he was always in the bed and I said, Look, if you really want to be that close, I'll put the mattress down again, but you need to be in your own bed. You can be here, but you need to be in your own bed.
A - 4, Pos. 54-58	Like last night he was just shouting and shouting at me. I really started to get annoyed because this was getting on for nine o'clock. I came upstairs. He said, "I need to go to the loo. And I can't get out of bed by myself!" And yeah, and then he'd wet his pyjamas because he couldn't get out of bed... So so the whole thing.



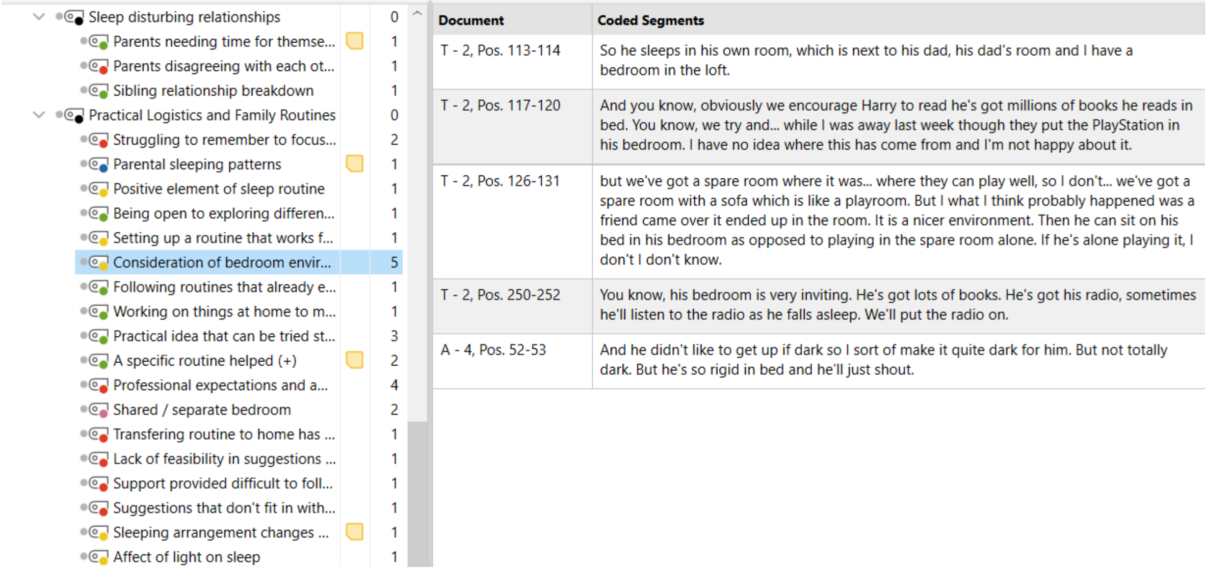
Code System	361
YELLOW	71
Theme 1: Losing Sleep	73
Theme 2: Weighing it up	0
Building independence for child's fu...	0
Child's social behaviours are not ...	1
Psychoeducation may help child ...	1
Building independence in the ch...	5
It's not easy	0
Not knowing it's an issue - thinki...	2
Child wanting to change	2
Resistance from child to support...	1
Difficult behaviour	2
Child pushing back on boundari...	5
Children routinely not following ...	2
Child has own agenda with rega...	1
I know what it's like	0
Parent having same issues - emp...	6
Parental View of Importance of Sleep	0
Specific scary incident led to see...	1
Sleep is seen as very important	1
Potentials issues from lack of sle...	2
Potential benefits of good sleep	1
Concern around how tired he is i...	1
Parent feeling that it's not that b...	3
Everything is difficult with a bab...	1
Hopes for better sleep	0
Read articles and tried techniques	1

Document	Coded Segments
T - 2, Pos. 16-18	I have ADHD and I have the same sleep problems. So you know, totally. I've really got no vocabulary today, like I can sympathise with you know how he feels with regards to sleep.
T - 2, Pos. 262-266	But at the same time I spent my 20s my teens 20s 30s 40s. Like not being able to sleep, you know, just feeling like a complete insomniac. Having really broken sleep and really crap quality sleep and you know, having to like snatch naps everywhere, because my body would just shut down and make me go to sleep.
T - 2, Pos. 285-290	I didn't get diagnosed with ADHD until after Harry did. But I always knew there's something different. And not quite the same about me, I could lie awake all night, you know, next to a partner who's sleeping or, you know, I could go literally days without proper sleep, at uni, and stuff, like that's not normal, and be able to do like a myriad of things all at once
T - 2, Pos. 292-298	And I don't need to rest, I do now. Long story, erm, but I never needed to rest, you know, I could always carry on and Harry the same and I would see a lot of him, of myself in him as a child. And getting told off for the same things like constantly moving or not being able to sit down or not big getting shouted at, because I wouldn't go to sleep or, you know, all that kind of stuff. And I just really couldn't help it.
T - 2, Pos. 333-340	Well, I've taken this tablet. And it's good because I won't wake up in the middle of the night. Actually, I don't fancy going to sleep yet. And that's the bit I want him to... Look I'm exactly the same. I have to force myself to turn off the light or put my phone down or put my book down and say right now is the time I have to go to sleep. Otherwise, I'm going to feel tired tomorrow. And I need him to learn that. I don't want him to have the same experience at university or high school as I had, where you're just running on fumes
A - 4, Pos. 300-305	Um...And then I realised, I was like [LAUGHING] I was a terrible fidgeter. I couldn't get to sleep. But I wasn't like him, sort of being a pest. I was just lying in my bed for hours not asleep. But I always ended up with everything on the floor from my wriggling around, and he can be a bit like that.



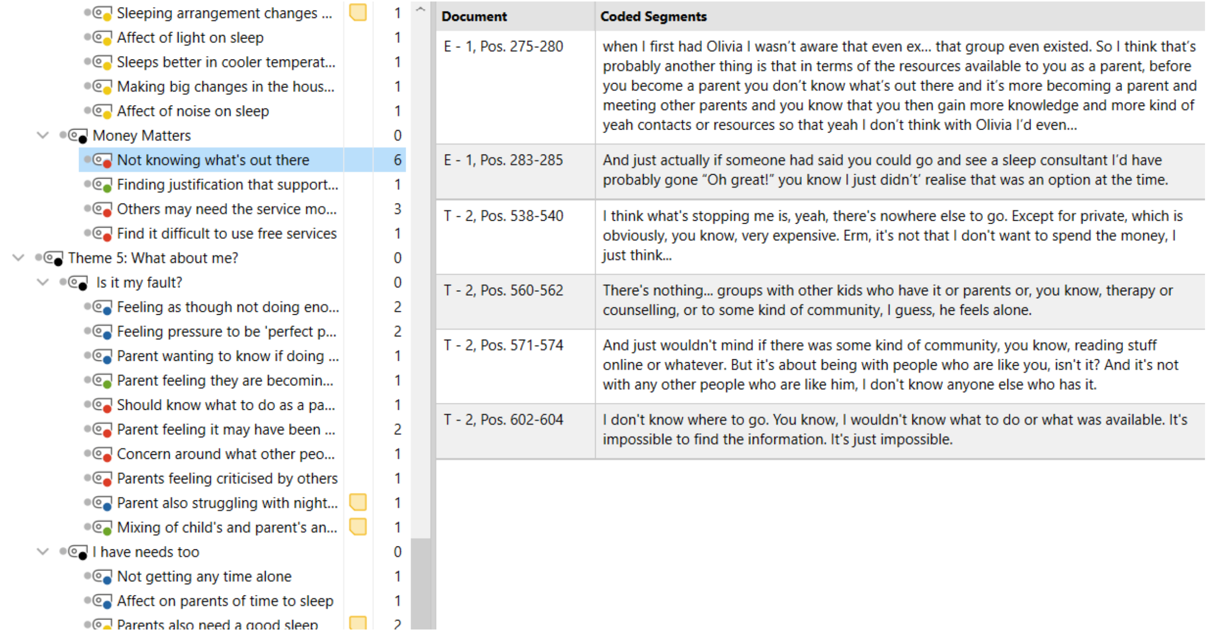
Parent feeling that it's not that b...	3
Everything is difficult with a bab...	1
Hopes for better sleep	0
Read articles and tried techniques	1
Some generic help tried	1
Trying hard to solve issues	1
Parental worries about child's later life	1
Wanting child to have better experie...	1
Theme 3: Experiences of Support	0
Hope: Lost or Restored	26
Prescriptions	0
Parent seeking clarification arou...	1
The health system can be a barri...	2
Parents understanding supporte...	2
Parent taking same medication a...	1
Perceived dangers of medication	1
Medication - provides help with ...	5
A Sense of Trust	21
Valuing community	13
It is Complex: One Size Does Not Fit...	18
Theme 4: Family Matters	0
Other Members of the Family	0
Sibling disturbed leading to cha...	1
Getting into habits with one child	1
Contrast with sibling	1
Two children making issues hard...	5

Document	Coded Segments
T - 2, Pos. 19-26	we had a new medication prescribed, but the other one had left. Harry takes melatonin long release, two milligrammes. As do I, since he started taking it, and I have to say it does make a big difference to the quality of sleep while you're actually asleep. It helps you drift off a little bit easier. But what I find for me and for him as well is preventing repeated waking up. So before I started using it, I would probably wake up six times a night easily, maybe seven, he would wake up once or twice. And generally speaking, come into our room. Right. Now he seems to go all the way through until at least six or seven.
T - 2, Pos. 56-59	we usually give him his melatonin about 9-9.30. And then it takes about half an hour to an hour to kind of, you know, it's not as effective on him as it was when he was smaller. Yeah, it doesn't knock you out. Right? You can you can fight through it.
T - 2, Pos. 175-179	Which can feel quite real, especially when you're a child, I remember sort of experiencing the same thing as he does. And he would always say, oh, you know, I had a nightmare or this. He does say that a lot less now, I'm not saying he's never going to have a nightmare, but he does seem to sleep better and complain less about nightmares.
T - 2, Pos. 282-284	there is awareness between the two of you that the medication could have implications, but at the moment, the implications are that he sleeps through the night.
A - 4, Pos. 363-367	The only other thing I think that my sister goes on about this a bit. She said, she's always sending me articles on. On lack of... I suppose is it lack of hormones? Melatonin? That, that doctors sometimes prescribe for children who were lacking it and need to, you know, just to get them down.



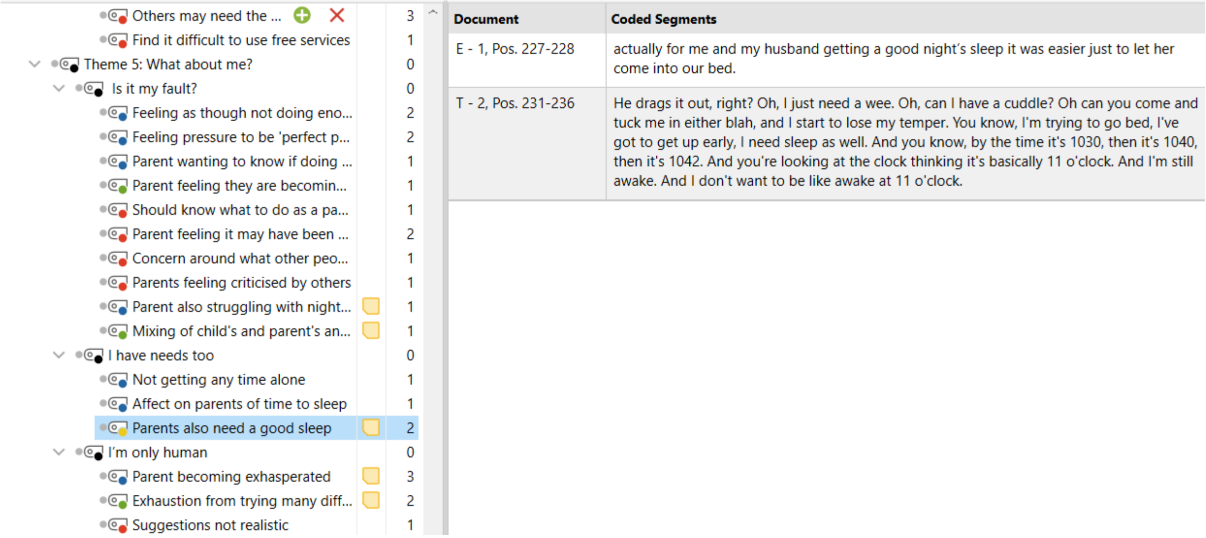
Sleep disturbing relationships	0
Parents needing time for themse...	1
Parents disagreeing with each ot...	1
Sibling relationship breakdown	1
Practical Logistics and Family Routines	0
Struggling to remember to focus...	2
Parental sleeping patterns	1
Positive element of sleep routine	1
Being open to exploring differen...	1
Setting up a routine that works f...	1
Consideration of bedroom envir...	5
Following routines that already e...	1
Working on things at home to m...	1
Practical idea that can be tried st...	3
A specific routine helped (+)	2
Professional expectations and a...	4
Shared / separate bedroom	2
Transfering routine to home has ...	1
Lack of feasibility in suggestions ...	1
Support provided difficult to foll...	1
Suggestions that don't fit in with...	1
Sleeping arrangement changes ...	1
Affect of light on sleep	1

Document	Coded Segments
T - 2, Pos. 113-114	So he sleeps in his own room, which is next to his dad, his dad's room and I have a bedroom in the loft.
T - 2, Pos. 117-120	And you know, obviously we encourage Harry to read he's got millions of books he reads in bed. You know, we try and... while I was away last week though they put the PlayStation in his bedroom. I have no idea where this has come from and I'm not happy about it.
T - 2, Pos. 126-131	but we've got a spare room where it was... where they can play well, so I don't... we've got a spare room with a sofa which is like a playroom. But I what I think probably happened was a friend came over it ended up in the room. It is a nicer environment. Then he can sit on his bed in his bedroom as opposed to playing in the spare room alone. If he's alone playing it, I don't I don't know.
T - 2, Pos. 250-252	You know, his bedroom is very inviting. He's got lots of books. He's got his radio, sometimes he'll listen to the radio as he falls asleep. We'll put the radio on.
A - 4, Pos. 52-53	And he didn't like to get up if dark so I sort of make it quite dark for him. But not totally dark. But he's so rigid in bed and he'll just shout.



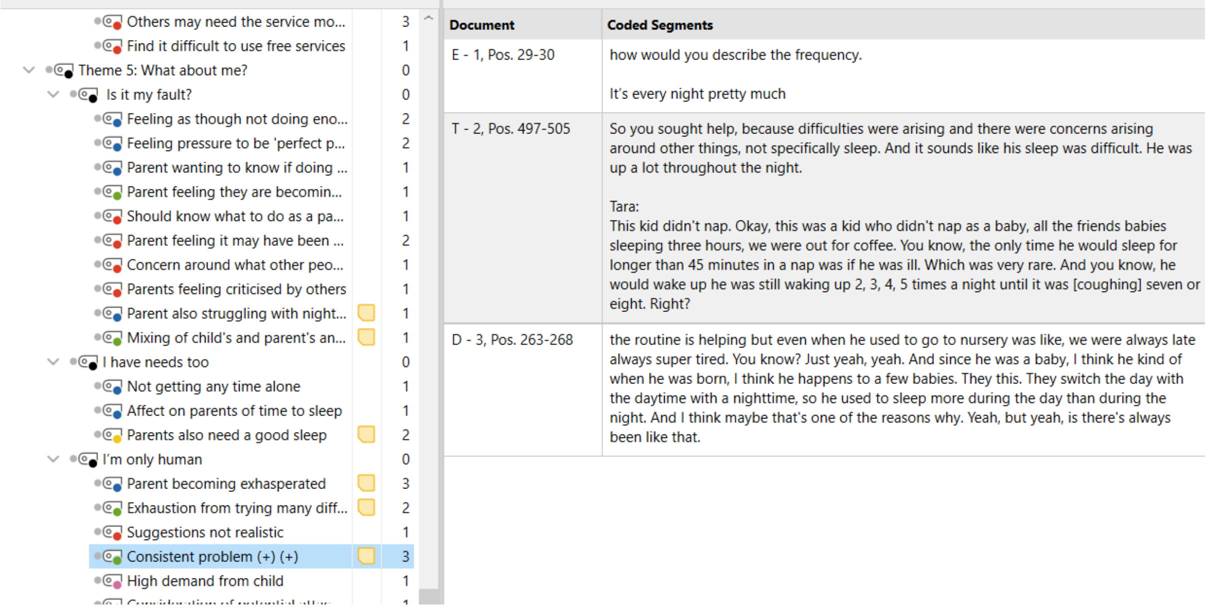
- Sleeping arrangement changes ... 1
- Affect of light on sleep 1
- Sleeps better in cooler temperat... 1
- Making big changes in the hous... 1
- Affect of noise on sleep 1
- Money Matters 0
  - Not knowing what's out there 6
  - Finding justification that support... 1
  - Others may need the service mo... 3
  - Find it difficult to use free services 1
- Theme 5: What about me? 0
  - Is it my fault? 0
    - Feeling as though not doing eno... 2
    - Feeling pressure to be 'perfect p... 2
    - Parent wanting to know if doing ... 1
    - Parent feeling they are becomin... 1
    - Should know what to do as a pa... 1
    - Parent feeling it may have been ... 2
    - Concern around what other peo... 1
    - Parents feeling criticised by others 1
    - Parent also struggling with night... 1
    - Mixing of child's and parent's an... 1
  - I have needs too 0
    - Not getting any time alone 1
    - Affect on parents of time to sleep 1
    - Parents also need a good sleep 2

Document	Coded Segments
E - 1, Pos. 275-280	when I first had Olivia I wasn't aware that even ex... that group even existed. So I think that's probably another thing is that in terms of the resources available to you as a parent, before you become a parent you don't know what's out there and it's more becoming a parent and meeting other parents and you know that you then gain more knowledge and more kind of yeah contacts or resources so that yeah I don't think with Olivia I'd even...
E - 1, Pos. 283-285	And just actually if someone had said you could go and see a sleep consultant I'd have probably gone "Oh great!" you know I just didn't' realise that was an option at the time.
T - 2, Pos. 538-540	I think what's stopping me is, yeah, there's nowhere else to go. Except for private, which is obviously, you know, very expensive. Erm, it's not that I don't want to spend the money, I just think...
T - 2, Pos. 560-562	There's nothing... groups with other kids who have it or parents or, you know, therapy or counselling, or to some kind of community, I guess, he feels alone.
T - 2, Pos. 571-574	And just wouldn't mind if there was some kind of community, you know, reading stuff online or whatever. But it's about being with people who are like you, isn't it? And it's not with any other people who are like him, I don't know anyone else who has it.
T - 2, Pos. 602-604	I don't know where to go. You know, I wouldn't know what to do or what was available. It's impossible to find the information. It's just impossible.



- Others may need the ... 3
- Find it difficult to use free services 1
- Theme 5: What about me? 0
  - Is it my fault? 0
    - Feeling as though not doing eno... 2
    - Feeling pressure to be 'perfect p... 2
    - Parent wanting to know if doing ... 1
    - Parent feeling they are becomin... 1
    - Should know what to do as a pa... 1
    - Parent feeling it may have been ... 2
    - Concern around what other peo... 1
    - Parents feeling criticised by others 1
    - Parent also struggling with night... 1
    - Mixing of child's and parent's an... 1
  - I have needs too 0
    - Not getting any time alone 1
    - Affect on parents of time to sleep 1
    - Parents also need a good sleep 2
  - I'm only human 0
    - Parent becoming exhasperated 3
    - Exhaustion from trying many diff... 2
    - Suggestions not realistic 1

Document	Coded Segments
E - 1, Pos. 227-228	actually for me and my husband getting a good night's sleep it was easier just to let her come into our bed.
T - 2, Pos. 231-236	He drags it out, right? Oh, I just need a wee. Oh, can I have a cuddle? Oh can you come and tuck me in either blah, and I start to lose my temper. You know, I'm trying to go bed, I've got to get up early, I need sleep as well. And you know, by the time it's 1030, then it's 1040, then it's 1042. And you're looking at the clock thinking it's basically 11 o'clock. And I'm still awake. And I don't want to be like awake at 11 o'clock.



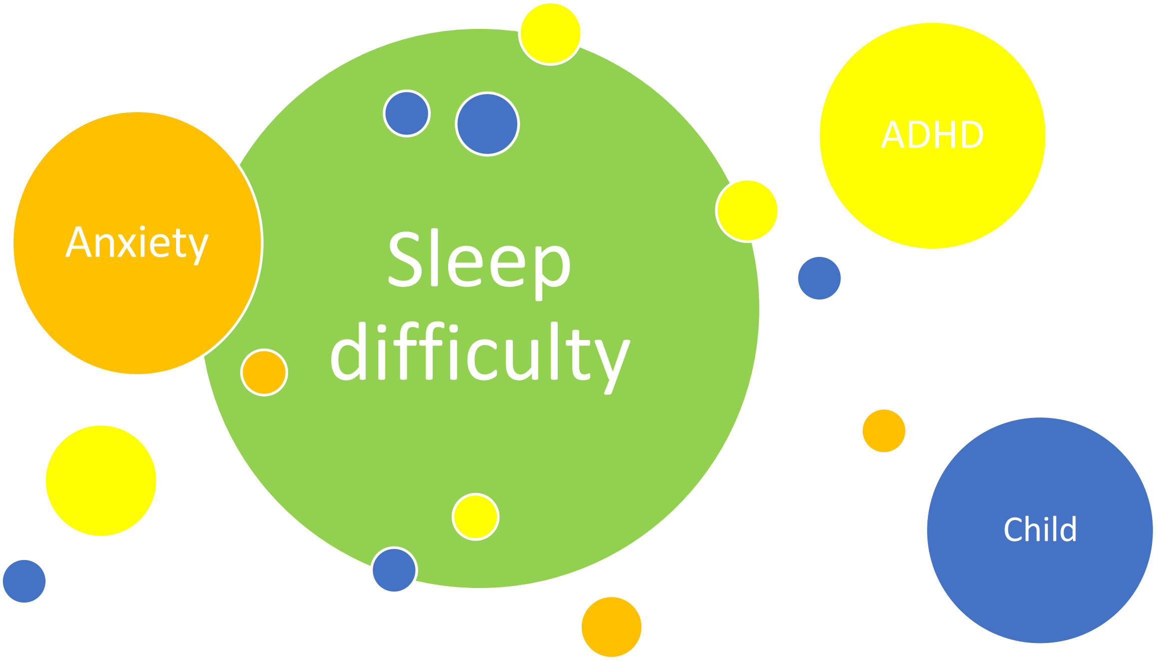
- Others may need the service mo... 3
- Find it difficult to use free services 1
- Theme 5: What about me? 0
  - Is it my fault? 0
    - Feeling as though not doing eno... 2
    - Feeling pressure to be 'perfect p... 2
    - Parent wanting to know if doing ... 1
    - Parent feeling they are becomin... 1
    - Should know what to do as a pa... 1
    - Parent feeling it may have been ... 2
    - Concern around what other peo... 1
    - Parents feeling criticised by others 1
    - Parent also struggling with night... 1
    - Mixing of child's and parent's an... 1
  - I have needs too 0
    - Not getting any time alone 1
    - Affect on parents of time to sleep 1
    - Parents also need a good sleep 2
  - I'm only human 0
    - Parent becoming exhasperated 3
    - Exhaustion from trying many diff... 2
    - Suggestions not realistic 1
    - Consistent problem (+) (+) 3
    - High demand from child 1

Document	Coded Segments
E - 1, Pos. 29-30	how would you describe the frequency. It's every night pretty much
T - 2, Pos. 497-505	So you sought help, because difficulties were arising and there were concerns arising around other things, not specifically sleep. And it sounds like his sleep was difficult. He was up a lot throughout the night. Tara: This kid didn't nap. Okay, this was a kid who didn't nap as a baby, all the friends babies sleeping three hours, we were out for coffee. You know, the only time he would sleep for longer than 45 minutes in a nap was if he was ill. Which was very rare. And you know, he would wake up he was still waking up 2, 3, 4, 5 times a night until it was [coughing] seven or eight. Right?
D - 3, Pos. 263-268	the routine is helping but even when he used to go to nursery was like, we were always late always super tired. You know? Just yeah, yeah. And since he was a baby, I think he kind of when he was born, I think he happens to a few babies. They this. They switch the day with the daytime with a nighttime, so he used to sleep more during the day than during the night. And I think maybe that's one of the reasons why. Yeah, but yeah, is there's always been like that.

Appendix 21: ***Depiction of the Author's Reflections within Research Journal of How Child Can Become Separated from or Lost Within the Issues they Experience.***

The image presented in this appendix shows a visual representation of the way in which the author had a sense of the child becoming separated from their difficulties during decision making processes. This seemed to make it hard to know how to manage the situation. Rather than from data analysis, this came from the author's reflections in their research journal:

I felt a sense that the parent was losing their child amongst everything else, and that the diagnoses or issues were leading to a loss of focus on the child themselves.



A lack of sleep can impact children in a number of ways, and so if we can focus on the sleep as something that all people need for their general health and wellbeing, all other things are likely to be better supported and managed.