

**BEDTIME STORIES:
AN EXPLORATORY STUDY OF THE REASONS FOR,
EXPERIENCE AND IMPACT OF, SLEEP
DISTURBANCE FOR CHILDREN WITH CEREBRAL
PALSY AND THEIR PARENTS**

*A thesis submitted in fulfilment of the requirements of the degree of
Doctor of Philosophy*

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ABSTRACT

TITLE:

Bedtime Stories: An Exploratory Study of the Reasons for, Experience and Impact of, Sleep Disturbance for Children with Cerebral Palsy and their Parents

BACKGROUND:

Cerebral palsy (CP) is a motor disorder associated with many comorbidities. Published evidence to date suggests that sleep problems are common in children with CP. Chronic sleep problems are often reported in the clinical setting. However, they are often poorly understood and therefore not well managed. This study aimed to explore the frequency and type of sleep problems in children with CP, the experiences of the children and their parents regarding sleep problems, and the impact of those sleep problems on the children and their parents.

METHODS:

An exploratory mixed methods sequential design was chosen. Critical social theory was used as a theoretical framework. This qualitatively driven study had three phases: qualitative scoping interviews, a quantitative survey that included the use of validated sleep assessment tools, and follow up qualitative interviews. Participants were parents or caregivers of children aged six to twelve years with CP from Victoria, Australia. The data derived from thematic analysis in Phase One was used to inform the design of Phases Two and Three.

RESULTS:

Phase One consisted of qualitative semi-structured interviews of nine parents. Thematic analysis identified two major themes: *Seeking Solutions* and *Having to Survive*. The key finding of this phase was that parents were asking for help with sleep problems, but often did not receive effective advice or treatment.

Phase Two involved an online quantitative survey using the REDCap platform, which collected 126 complete data sets. Sleep problems were reported by 46% of the cohort. The parents of children with a high score on a sleep assessment tool (indicating a sleep problem) had a higher mean score than parents of children without sleep problems (mean difference:12.1 (95%CI:9.2-15.0) ($p<0.005$)). This indicates that parent sleep is affected by child sleep. Parents found finding effective sleep solutions challenging.

Phase Three involved qualitative semi-structured interviews of 19 parents. The thematic analysis identified seven major themes: 1) *My Child Doesn't Fit into the Box*, 2) *A Mother's Ears are Always On*, 3) *Sleep Disturbance is like Water Torture*, 4) *Sleep is One of Many Spot Fires, I Put it on the Backburner*, 5) *Luck, Money or Jumping Up and Down*, 6) *There is Never One Silver Bullet* and 7) *Help: The Earlier the Better*. The key finding for this phase was that parents of children with CP often described their child's needs being different to what is provided for by systems and services. This difference created significant challenges when seeking health solutions.

DISCUSSION:

The mixed methods interpretation of the three phases of research resulted in six main findings: 1) finding effective sleep solutions can be challenging, 2) sleep problems are prevalent and persistent but are often untreated, and sleep is not a priority, 3) sleep problems have a significant negative impact on parent sleep and daily life, 4) sleep problems are often complex, 5) sleep problems can improve, and 6) overnight care is often the responsibility of mothers.

Clinical recommendations arising from this research include: 1) adopting an individualised approach to addressing sleep problems, 2) elevating sleep as a clinical priority for both parents and clinicians, and 3) incorporating nurses and allied health professionals to be both advocates and providers of sleep health care, for children and families. Where sleep problems are refractory to treatment, respite from overnight care needs to be prioritised urgently. Applying a critical social theory lens to the data revealed two dominant

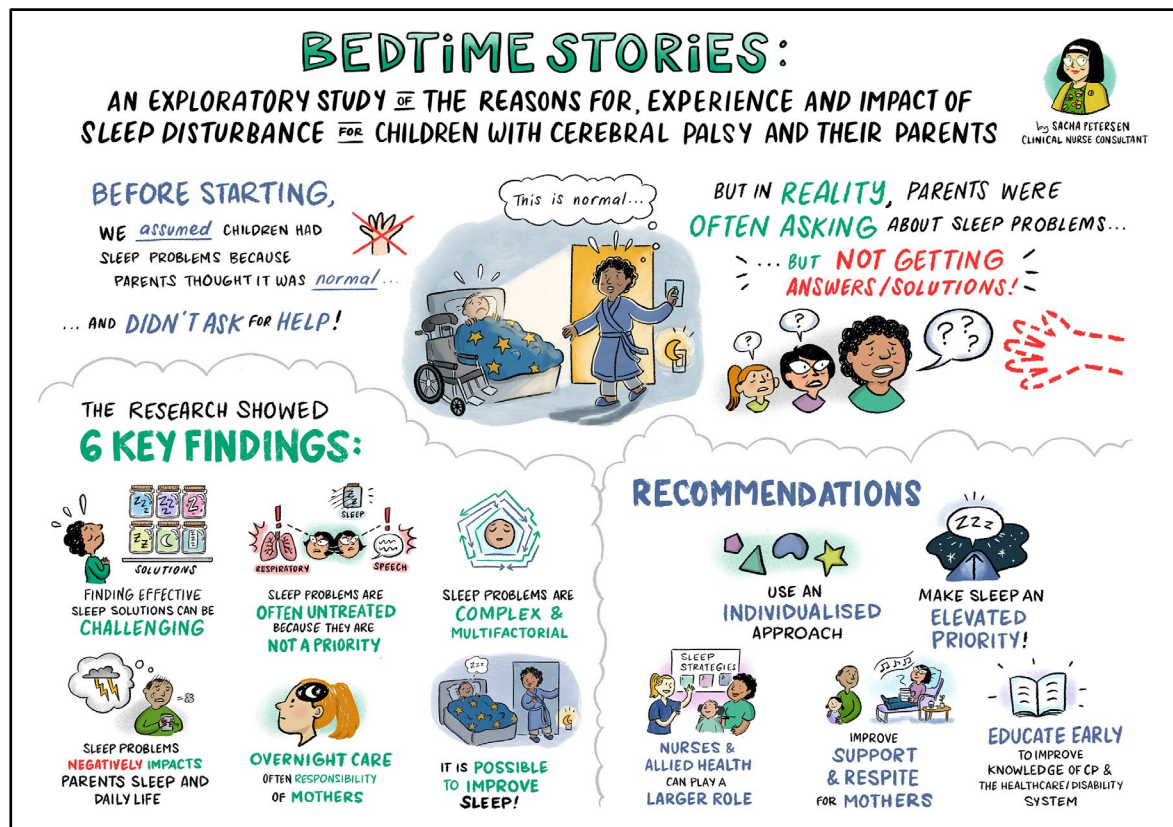
ideologies that may contribute to the persistent presence of sleep problems for children with CP: 1) the dominance of the biomedical model and 2) dominant ideologies around motherhood.

This research thesis applied an innovative approach to answering the research questions, which resulted in novel findings. This study has addressed a significant gap in the literature and will be used to make transformative clinical change and likely improve sleep for children with CP and their parents.

VISUAL ABSTRACT

The following illustration is an info-graphic drawn by graphic recorder Zahra Zainal (<https://zahrazainal.com/>). This commissioned artwork was funded by a scholarship from The Windermere Foundation. The Researcher provided the artist with a two-page dot point summary of the research findings and recommendations of this thesis. This was followed by a teleconference meeting between the artist and the Researcher. This discussion informed the design of a draft illustration, which was then revised by the Researcher and alterations were made through several email conversations.

The aim of this visual abstract is to present a one-page graphic summary of the study that is understandable by parents, healthcare providers and academics alike. This graphic will be used as a knowledge translation tool.



DECLARATION

This thesis comprises only my original work towards the degree of Doctor of Philosophy, except where indicated in the Preface. Due acknowledgement has been made in the text to all other material used. This thesis is fewer than 100,000 words, exclusive of tables, maps, bibliographies and appendices.

Sacha Petersen

29 August 2019

PREFACE

Chapter Ten is the unpublished manuscript of a journal article submitted to the *Journal of Paediatrics and Child Health* on August 26, 2019. This paper is in revision, pending peer review.

The contribution of all authors involved is detailed in Appendix J, which includes the *Declaration for a Thesis with Publication* form and *Co-author Authorisation* form.

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THIRD PARTY COPYRIGHT MATERIAL

Citation Information for Third Party Copyright Material	Location of Item in Thesis	Permission Granted Y/N
Percentiles for total sleep duration per 24 hours from infancy to adolescence Iglowstein I, Jenni OG, Molinari L, Largo RH. Sleep duration from infancy to adolescence: reference values and generational trends. <i>Pediatrics</i>. 2003;111(2):302-307.	Figure 1-1 page 14	N Author contacted via email but email address no longer valid
Conceptual model of the relationships among cultural and culture-related factors, sleep and medical factors Boergers J, Koinis-Mitchell D. Sleep and culture in children with medical conditions. <i>J Pediatr Psychol</i>. 2010;35(9):915-926.	Figure 1-2 page 16	Y
Phases of Thematic Analysis Braun V, Clarke V. Using thematic analysis in psychology. <i>Qual Res Psychol</i>. 2006;3(2):77-110.	Table 6-2 page 94	Y
Appendix B – GMFCS Descriptors and Illustrations Reid B, Willoughby K, Harvey A, Graham, K. GMFCS E & R between 6th and 12th birthday: descriptors and illustrations. The Royal Children’s Hospital Melbourne. Available at: https://canchild.ca/system/tenon/assets/attachments/000/001/399/original/GMFCS_English_Illustrations.pdf	Appendix B	Y

CONFERENCE PAPER AND ABSTRACTS ARISING FROM THIS THESIS

Petersen S, Harvey A, Reddihough D, Lima S, Newall F. Mixed methods sequential exploratory design through a lens of critical social theory: exposing key issues to create clinical change. Paper presented at the International Institute for Qualitative Methodology 2019 Qualitative Methods Conference; Brisbane (QLD); 2019 May 1-3.

Petersen S, Harvey A, Reddihough D, Lima S, Newall F. The experience and impact of sleep problems for parents of children with cerebral palsy: a qualitative study. *Dev Med Child Neurol*. 2018;60 Suppl 1:4-60.

Petersen S, Harvey A, Reddihough D, Lima S, Newall F. Proxy quality of life surveys; parental perceptions and impressions. *Dev Med Child Neurol*. 2017;59 Suppl 2:4-45.

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Just because you find that life is not fair it doesn't mean that you just have to grin and bear it if you always take it on the chin and wear it nothing will change.

Even if you're little you can do a lot you mustn't let a little thing like little stop you if you sit around and let them stop you, you might as well be saying you think that its ok and that not right! And if it's not right, You have to put it right.

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She believed she could and so she did.

DEDICATION

This thesis is dedicated to the sleepless mothers. My only aim for this work was for it to make positive change for you. Wishing you many good nights.

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LIST OF ABBREVIATIONS

ASD	Autism Spectrum Disorder
AUD	Australian Dollar
CCHUB	Complex Care Hub
CP	Cerebral Palsy
CSHQ	Children's Sleep Habit Questionnaire
CST	Critical Social Theory
DA	Disorders of Arousal
DIMS	Disorders of Initiating and Maintaining Sleep
DOES	Disorders of Excessive Somnolence
ESS	Epworth Sleepiness Scale
GMFCS	Gross Motor Function Classification System
GP	General Practitioner
HELLP	Haemolysis, Elevated Liver Enzymes, Low Platelet Count
HILDA	Household Income and Labour Dynamics in Australia
ID	Intellectual Disability
MCHN	Maternal and Child Health Nurse
NDD	Neurodevelopment and Disability
NDIS	National Disability Insurance Scheme
NREM	Non-Rapid Eye Movement
PICF	Participant Information and Consent Form
PSQI	Pittsburgh Sleep Quality Index
PSQ	Paediatric Sleep Questionnaire
RCH	Royal Children's Hospital
REM	Rapid Eye Movement
SAT	Sleep Assessment Tool
SBD	Sleep Breathing Disorder
SCN	Suprachiasmatic Nucleus
SDSC	Sleep Disturbance Scale for Children
TD	Typically Developing
TUD	Time Use Diary
USD	United States Dollar
VCPR	Victorian Cerebral Palsy Register

1 CONTEXT AND BACKGROUND

I just want you to be successful, to help us. Because we are struggling and lots of people don't understand. They know we have kids with disabilities. It's not just physical torture. It's mental. Mental torture. I put my head to the wall four or five times this morning. I cry. I scream. Maybe we are very brave in the class... But at home we are drowning.

– Astra, mother of a child with cerebral palsy*

INTRODUCTION

Sleep is an essential, but malleable, biological need. It might be argued that no research is required to explain the impact of a lack of sleep; all humans have experienced the need for sleep. Despite sleep deprivation and disturbance being a universally negative experience, sleep problems are often endured. This thesis explores the type, frequency, impact and experience of sleep problems for

* Participant interviewed in Phase One. Pseudonym used.

children with cerebral palsy (CP)[†] and their parents. This chapter describes the context and setting of the research project, and provides a background to the physiology of sleep and pathophysiology of CP. The chapter then explains the intersection between sleep and CP. To conclude, the chapter provides a brief explanation of the format of the thesis.

1.1 Context of the Research Project

The PhD candidate, who will be referred to as the Researcher, is a Clinical Nurse Consultant. The Researcher has provided clinical care, via an advance practice nurse role, to children with CP since 2006. Within her clinical role, the Researcher observed that first-time attenders to the outpatient clinic, run by a neurodevelopmental paediatrician and the Researcher, would be asked about sleep as part of the clinical assessment. Frequently, parents of school-aged children with CP would report that their child had longstanding sleep problems. Typically, they would remark: *“Of course, sleep is bad, it’s always been bad, they’ve got CP.”*

During the first appointment and subsequent appointments, the paediatrician in the clinic would implement relatively simple interventions that would improve the child’s comfort and ease of care, and subsequently their sleep. The parents would return to clinic feeling recharged. They would exclaim amazement and gratitude that the paediatrician’s interventions had improved sleep for their child and, in turn, the whole family.

In 2012, the Researcher attended the Australasian Academy of Cerebral Palsy and Developmental Medicine conference in Brisbane, Australia. At that conference, Doctor Helen Bourke Taylor, an occupational therapist, presented her research on mothers of children with disability who had sleep problems. Doctor Bourke Taylor reported a higher incidence of sleep problems for these

[†] The Researcher recognises the debate and writings within academic and activist communities in regard to language around disability. Throughout this thesis, person first language will be used to describe people with a disability, e.g. child with a disability rather than disabled child.

children and the negative impact this sleep disturbance has on mothers.⁽¹⁾ This research outcome resonated with the clinical experience of the Researcher. The Researcher recognised this as an important clinical issue that required an evidence-based solution. The Researcher conducted and published a small pilot study in 2014⁽²⁾ (see Appendix A) and the PhD project commenced in 2015.

1.1.1 Research setting

The Researcher is based at the Royal Children's Hospital (RCH). This tertiary paediatric hospital is located in Parkville, Melbourne, Victoria. Over 50,000 children are admitted to RCH each year and over 3,338,000 ambulatory appointments are scheduled.⁽³⁾ The RCH is one of two paediatric hospitals in Victoria. The RCH is considered the major provider of paediatric healthcare in Victoria and also provides clinical care to children from the neighbouring states of Tasmania, South Australia and New South Wales. Victoria is a state of Australia with a population of over 6.5 million.⁽⁴⁾ All participants of this study were residents of Victoria.

The Researcher works within the department of Neurodevelopment and Disability (NDD). This department provides both inpatient and ambulatory care to children (aged 0-18 years) with developmental disability including CP, autism spectrum disorder (ASD), intellectual disability (ID), spina bifida and other neurodisabilities.

1.1.2 The research problem

Clinical experience and research suggest that children with CP and their parents experience sleep problems are frequently unrecognised and therefore untreated. This research explores the experience of sleep problems for children with CP and their parents, based on parent report. This research is positioned at the intersection between a clinical problem and parent experience.

1.2 Background: Cerebral Palsy

Cerebral palsy has been recognized as a clinical condition since the mid-nineteenth century. Orthopaedic surgeon William Little has been credited with identifying the causal pathway between spasticity (muscle stiffness) and birth complications.⁽⁵⁾ Sigmund Freud, a neuropathologist (better known for his work as a psychiatrist), was the first to use the words (translated from German) “*infantile cerebral paralysis*”, which was later shortened to cerebral palsy to describe infants with a motor disorder linked to a brain origin.⁽⁵⁾ Freud was the first to use CP as a descriptor for a group of heterogeneous motor disorders. Freud’s nomenclature continues to be used today. Cerebral palsy as a diagnosis or descriptor has been extensively debated since the 1800s and the nuances of its definition are constantly evolving. Today, CP is considered an umbrella term for many movement disorders, as opposed to a diagnostic description,⁽⁶⁾ and is useful for describing and designing interventions for this heterogeneous cohort. The current International Consensus definition of CP states:

Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder and by secondary musculoskeletal disorders.^{(6)p572}

Reported rates of CP are 1.4 per 1000 live births in Australia⁽⁷⁾ and the overall prevalence of CP, based on published studies from CP registers, is 2.11 per 1000 live births.⁽⁸⁾ Known risk factors are maternal health conditions during pregnancy, premature birth and neonatal encephalopathy.⁽⁹⁾ The Australian CP Register Group⁽¹⁰⁾ reported that among children with CP born between 1993-2006, 94.4% of all cases were associated with an event occurring during the prenatal and perinatal period. The remaining 5.6% of children incurred their brain injury more than 28 days after birth.⁽¹⁰⁾

1.2.1 Basic science of cerebral palsy

Fluid motor movement is a complex, highly ordered neurological process. Sensory input, including vision and balance as well as adaptive systems and equilibrium, all synchronise to create the movement of a typically developing child.⁽¹¹⁾ When injury, insult or structural abnormalities occur to the central nervous system, the neural pathways can falter, and the fluidity of these movements can be impacted. Voluntary motor movement is initiated in the primary motor cortex of the cerebrum. It is within the primary motor cortex that upper motor neurons form the proximal end of the corticospinal tracts; these tracts then descend through the medulla in the brain stem, to the ventral horn of the spinal cord.⁽¹²⁾ To initiate movement, the primary motor cortex generates a neural impulse which descends the corticospinal tract to the ventral horn, which then sends innervation to the individual muscles.⁽¹²⁾

The development of the central nervous system is initiated at conception and continues to grow until five months post birth,⁽¹¹⁾ and during this time, it is particularly susceptible to damage, malformation and infection.⁽¹¹⁾ The motor cortex is most vulnerable to damage during brain formation because of the manner in which the blood circulation develops in utero. The periventricular zone of the motor cortex is the area furthest from large blood vessels, making this area, which is crucial for coordinated motor control, vulnerable to damage.⁽¹¹⁾ Lesions occurring within the motor cortex lead to the clinical presentation of a movement disorder. The heterogeneous causes of injury and the variety of locations affected in the individual's central nervous system leads to the heterogeneous clinical presentation of CP.

1.2.2 Identification and management of cerebral palsy

Within the state of Victoria, when an infant fails to meet their motor milestones, they may be referred to a specialist for advice. This specialist may be a neurologist, an orthopaedic surgeon, a paediatrician or a rehabilitation specialist. The identification of CP is often made over time; antenatal and birth

history is collected, neuroimaging obtained, genetic testing is conducted, family history explored, and possibly a metabolic review is undertaken.⁽¹¹⁾ There is considerable variation in how, where and by whom a child is recognised as having CP. Once CP is identified, the child and their family generally require life-long care, both in the form of primary healthcare and surveillance from a multidisciplinary team, usually coordinated by one primary physician. Depending on the level of severity, this may be a general practitioner (GP), a general or developmental paediatrician, a rehabilitation paediatrician, an orthopaedic surgeon or a neurologist. Each of these specialists have a different scope of care; this effectively means that not only are children with CP a heterogeneous group, but the care of children with CP is also diverse and dependent on the views and the skillset of their primary clinician. In regard to the management of sleep problems for children with CP within the state of Victoria, there are no services specifically for school aged children with CP. Typically, sleep problems are managed by the child's paediatrician or rehabilitation specialist.

There is no effective cure for CP,⁽¹¹⁾ rather, treatment aims to manage symptoms and maximise participation.⁽⁹⁾ With regard to the motor disorder, the most common movement disorder is hypertonicity (high tone), and many of the treatment options focus on reducing this. Treatments specifically to reduce tone include oral medication, intramuscular medications, orthopaedic surgeries, implantable devices and neurosurgery (of the spine). Allied health professionals, including physiotherapists, occupational therapists and speech pathologists, also treat CP. The aim of this treatment is to maximise function, promote rehabilitation and to provide appropriately timed early intervention. Social workers and psychologists are also essential members of the team.

1.2.3 Describing cerebral palsy

The heterogeneity of CP has created difficulty in describing CP within the clinical setting, as each child's movement disorder is as individual as the child. Cerebral palsy is described by the type of movement disorder that the child

experiences: spasticity, dyskinesia or ataxia. With regard to the origin of injury, spasticity is primarily a disorder of the motor cortex, whereas dyskinesia and ataxia are caused by damage to the basal ganglia.⁽¹³⁾ Cerebral palsy can also be described by topography (the location of the affected limbs). Traditionally, this was done using one of the following terms: quadriplegia – all four limbs involved; diplegia – mainly lower limbs involved; or hemiplegia – unilateral limb involvement.⁽⁹⁾ More recently, in an attempt to improve the reliability of topographical classification, the terms bilateral and unilateral spasticity, as described in the Surveillance of Cerebral Palsy in Europe Classification tree,⁽¹⁴⁾ are preferred.

Just as the causes of CP are many and varied, there is a very broad spectrum of CP severity. Children range from being very mildly to very severely affected. A classification system that enables a clinician to describe the severity of the child's motor disorder has been devised and widely adopted by CP researchers and clinicians: the Gross Motor Function Classification System (GMFCS).⁽¹⁵⁾ This is an internationally recognised method of describing a child's gross motor function using one of five levels. This system, first validated in 1997, has been used in more than 700 research studies. Children classified within GMFCS level I can walk independently with mild gait disturbance, whilst children with CP classified within GMFCS level V experience severe motor impairment, are unable to independently ambulate or have poor head control.⁽¹⁶⁾ Full descriptions of GMFCS levels can be seen in Appendix B.

The GMFCS is also used within research contexts to group children with CP according to their severity level. Research outcomes and associated risk factors are often grouped according to GMFCS level. For example, the incidence of hip migration has been directly related to gross motor function and can be classified according to the GMFCS levels. Children classified within GMFCS level V have a 90% likelihood of experiencing hip displacement, whereas a child with GMFCS level I CP has little likelihood.⁽¹⁷⁾ Although CP is primarily a motor

disorder, there are often comorbidities, particularly in those with severe motor impairment.

1.2.4 The impact of cerebral palsy

The impact of CP on the individual and the family can have major consequences for health, financial status, quality of life and family relationships. A parent who has been told their child has CP may expect this to impact their life in a variety of ways, depending on the extent and severity of the condition. The motor impairment may result in mild difficulties with walking through to an inability to sit, stand or walk, therefore requiring the use of a wheelchair for all mobility.⁽⁹⁾ The child may have very few limitations in their activity and be as able as their typically developing peers, or they may require the assistance of another person for all tasks, including self-care, eating and communication. The child with CP may be very robust, rarely ill and require only minimal assistance in activities of daily living. Alternatively, they may experience a range of comorbidities (listed below), with frequent hospital visits for treatment. Children with CP often require the use of aids and equipment, including orthotics, splints, crutches, walking frames, feeding tubes, wheelchairs, communication devices, beds with adjustable heights, modified bathrooms and cars, lifting hoists, pressure mattresses, oxygen therapy and equipment for naso-oral suctioning. Alternatively, they may only require someone to assist with their zips and laces. Thus, the phenotype of CP will vary depending on the severity of the CP and any additional comorbidities.

The comorbidities of CP can be divided into three categories according to the associated problems:

- i. Associated disabilities, such as hearing and visual impairment, intellectual disability
- ii. Health issues, such as respiratory disease, gastro-oesophageal reflux, epilepsy

- iii. Consequences of the motor disorders, such as contractures, hip displacement and poor saliva control.

The incidence of the most common comorbidities can be seen in table below.

Comorbidity	Incidence in CP
Associated Disabilities	
Intellectual disability	Mild/probable 26.5% ⁽¹⁸⁾ Moderate severe 22.7% ⁽¹⁸⁾
Visual impairment	Some impairment 30.3% ⁽¹⁸⁾ Functionally blind 5.5% ⁽¹⁸⁾
Hearing impairment	Some impairment 8.9% ⁽¹⁸⁾ Bilateral deafness 3.4% ⁽¹⁸⁾
Communication difficulties	Some impairment 36.9% ⁽¹⁸⁾ Non-verbal 23.8% ⁽¹⁸⁾
Health Issues	
Pain	75% ⁽⁹⁾
Constipation	59% ⁽⁹⁾
Respiratory illness causing hospitalisation	12% ⁽¹⁹⁾
Gastro-oesophageal reflux	32% ⁽²⁰⁾
Urinary incontinence	25% ⁽⁹⁾
Epilepsy	27.8% ⁽¹⁸⁾
Consequences of Motor Disorder	
Oromotor dysfunction requiring non-oral feeding	5% ⁽⁹⁾
Scoliosis	50% of GMFCS IV-V ⁽²¹⁾
Hip dysplasia	33% ⁽⁹⁾
Poor Saliva control/drooling	40% ⁽²²⁾

Table 1-1 Incidence of the Most Common Comorbidities of CP

Families of children with CP are impacted by their child's disability in a number of ways, such as the ability to earn an income due to the care requirements of their child, the ability to participate in home and community life, and the opportunity to undertake health-promoting activities.⁽¹⁾

In a 2011 report⁽²³⁾ from the Longitudinal Study of Australian Children, which followed Australian children (n=4720) and their families, 267 of these families had a child with a disability. These families were twice as likely to experience financial hardships; they were more likely to be unable to pay their bills, to go without meals and to be unable to heat or cool their home.⁽²³⁾ The impact of this

financial stress may affect many aspects of the parent's life. The current structure of the Australian healthcare and funding system means that parenting a child with a disability puts significant financial pressure on a family. If a child has high healthcare needs, one parent is usually required to provide full-time care for that child, reducing the family to a single income or no income, if it is a single parent family. The cost of equipment for a child with disability is significant. A father recounts the personal financial cost of having a child with a physical disability in a parenting magazine:

Another thing I was ignorant about was that specialised equipment for a child with a disability is not readily accessible. We have been waiting for over a year to get a new wheelchair for Marcus (at a cost to us of \$8,000-\$10,000). In addition, he needs a disability stroller (\$2,500-\$3,000) because he loves to jet off in the opposite direction, which makes simple tasks like grocery shopping in his wheelchair a logistical nightmare. He also needs a gait trainer (\$3500-\$5,000), a specialised walker designed to build leg strength.⁽²⁴⁾_{p18}

Parents or caregivers of children with CP may also experience negative psychosocial impact. When compared to families without a child with disability, parents of children with CP have significantly higher anxiety scores, depressed mood and lower life satisfaction scores.⁽²⁵⁾ Parents of children with CP are more likely to experience physical and psychosocial health problems and to have lower incomes, despite having equivalent education to other families.⁽²⁶⁾

Thus, it is evident that parents of children with disability may be significantly impacted by the extra care needs and a substantial financial burden. This impact needs to be considered and addressed by researchers, clinicians and service providers alike. Future interventions to improve outcomes for children with disability also need to address the impact for parents and caregivers in order to achieve optimal health for the child and their family.⁽²⁶⁾

1.3 Sleep

Sleep may be defined as a rapidly reversible state of reduced mobility and sensory awareness that is not simply a loss of consciousness, but an actively generated state.^{(27)p964}

Sleep is a biological function that is essential to health and wellbeing. Sleep comprises a significant portion of a human's life, as much as one third. Sleep medicine and the effects of sleep quality on health are rapidly growing areas of research. Sleep is particularly important for parents; the newborn period brings with it significant and frequent sleep disruption and the majority of parents aim to return to a diurnal pattern of sleeping as soon as possible after the baby is born. Parents seek solutions to achieve the ultimate goal of their new baby sleeping through the night. Indeed, whether or not children are getting enough sleep has been an ever-present issue for parents. A recent historical review of the literature revealed that for over 100 years, parents and professionals have been concerned with the busyness of modern life and the amount of sleep children achieve.⁽²⁸⁾ Sleep is an essential biological function, imperative to health, cognition and daytime functioning and is also an integral part of everyday life.

The need for sleep has been explored extensively. There are three main theories that attempt to explain the need for sleep. First, sleep is restorative.⁽²⁹⁾ Wakefulness depletes biological and physical processes. The second theory of the need for sleep is that sleep conserves energy.⁽²⁹⁾ The reduction in energy requirements while asleep reduces the energy requirement over a 24-hour period. However, as described by Kotegal,⁽²⁹⁾ this theory is often discredited; while sleep reduces metabolic drive, the reduction is small. Sleep is not hibernation. The third and final theory on the need for sleep is that sleep assists learning and memory. There is increasing evidence that sleep is a phase in which memory consolidation occurs; it is thought that information processing of the day's events occurs during sleep, supporting the consolidation of memory and enabling communication between the prefrontal cortex and

hippocampus.⁽³⁰⁾ The following sections shall briefly describe the basic science of sleep, sleep architecture, typical sleep requirements, sleep hygiene, the culture and social determinants of sleep, sleep disorders and the impact of sleep problems.

1.3.1 Basic science of sleep

The biological and physiological processes of sleep are complex, with multiple neurological regions synchronising to create the states of sleeping and wakefulness.⁽²⁹⁾ The circadian rhythms are set by the suprachiasmatic nucleus (SCN), which is triggered by light receptors on the retina.⁽³¹⁾ When light is present, the SCN signals the pineal gland and inhibits the production of melatonin, an inhibitory neurotransmitter. The production of melatonin reduces the alert signal of wakefulness and induces sleep.⁽²⁹⁾ There are also complex wake generating and sleep generating systems that are either suppressed or stimulated to create the sleep-wake cycle. These systems are complex and require great coordination, but sleep is still possible if there is injury to one of these systems.⁽²⁹⁾ As sleep is initiated through these complex neurological systems, there are also physiological changes that occur: brain activity, blood pressure, heart rate, respiration, temperature and sympathetic nerve activity all decrease.⁽³²⁾

1.3.2 Sleep architecture

Sleep architecture is the basic structure of sleep. The sleep-wake cycle consists of a homeostatic process and a circadian process.⁽³¹⁾ There are two types of sleep: rapid eye movement (REM) and non-REM (NREM) sleep that occur in cycles. The processes, types and cycles of sleep are described below.

1.3.2.1 Two process model of sleep

A widely recognised model of sleep is that of Borbely,⁽³³⁾ who describes a homeostatic component named as Process S (for sleep) and a circadian component known as Process C (for circadian). These two processes together

regulate the sleep wake cycle. It is the balance of these two models that creates a diurnal rhythm of sleep and wake. Process S is the drive to sleep that accumulates during wakefulness and declines during sleep. That is, the longer a person is awake the sleepier they feel. Process C is controlled by clock genes and is independent of sleep or waking.⁽³¹⁾

1.3.2.2 Sleep stages and cycles

There are two sleep stages: REM sleep and NREM sleep. NREM sleep is divided into three stages: N1, N2, N3. Sleep initiates at NREM stage one and cycles through to REM sleep, then a brief rise to consciousness occurs. The development of sleep cycles is maturational⁽³⁴⁾ and changes significantly from birth to adulthood. That is, sleep cycles for a new-born are shorter and more frequent, eventually growing in length, and by the age of six months, most term infants can sleep for a period of eight hours overnight.⁽³⁵⁾ For any individual, within one night of sleeping, the sleep cycle reoccurs three to four times with very brief periods of wakefulness between each cycle.⁽³⁶⁾ By young adulthood, sleep stages occur in ultradian cycles of 90 to 110 minutes. Total sleep time is dictated by the individual's clock genes⁽³²⁾ for sleep onset and sleep wake time.

The above description briefly outlines the physiological processes that cause and maintain sleep and wakefulness. Sleep is not an innate function; sleep can be avoided and is controlled, to some extent, by social needs: the need to get up and go to work or school and to stay awake at night for social activities.

1.3.3 Typical sleep requirements

It is generally accepted that the right amount of sleep is how much the child or adult needs in order to feel rested and do what they need to do in the day (excluding some other reason for fatigue).⁽³⁶⁾ The average sleep requirements are outlined in the graph below. The ideal dose of sleep for adults is difficult to articulate. However, less than six to seven hours of sleep is thought to have detrimental effects on health and wellbeing.⁽³⁷⁾ Figure 1-1 below presents

percentiles for total sleep duration over a 24 hour period ranging from infancy to adolescence.⁽³⁸⁾

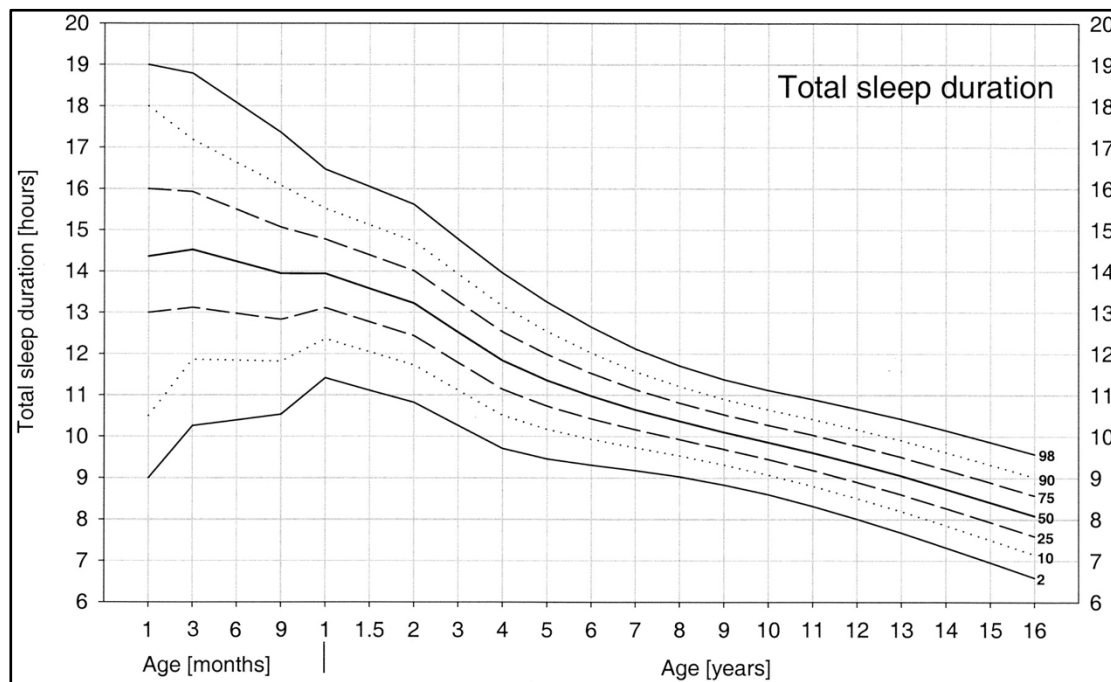


Figure 1-1 Percentiles for Total Sleep Duration per 24 Hours from Infancy to Adolescence

1.3.4 Sleep hygiene

Sleep hygiene is a term that describes the behaviours and habits around sleep.⁽³⁶⁾ Good sleep hygiene will optimise sleep quality and quantity and reduce the risk of behavioural sleep disorders developing. Good sleep hygiene is the establishment of a bedtime routine, in a low/no stimulus environment and maximised personal comfort. Sleep experts often describe the ideal sleeping environment as nest-like, comfortable, dark and warm. Sleep hygiene also requires consistent bedtime routines, with quiet relaxed time before initiating sleep. For children, this is often a simple routine of bath time, a bedtime story and lights out. It is thought that sleep hygiene is effective in inducing sleep as the routine entrains the circadian rhythm to the external environment.⁽³⁹⁾ Poor sleep hygiene may contribute to the development of sleep disorders.⁽³⁶⁾

1.3.5 Culture and social determinants of sleep

The need for sleep is inherent in all humans and sleep time is factored into a 24-hour period for every culture. However, how sleep is scheduled and prioritised is very culturally sensitive. Culture has been defined as *“all aspects of human nature that are not biologically inherited, that is anything that is socially constructed and learned is a part of culture.”*^{(40)p205} One’s culture, combined with biology, will determine what is a normal bed time, normal wake time, if one takes a nap, where one sleeps, who one sleeps with and even if whether a sleep disturbance is considered problematic.

Sadeh et al.⁽⁴¹⁾ conducted a study whereby they surveyed large numbers of parents from 17 countries about their infant’s sleep, and their perception of that sleep. Parents from predominantly Asian countries were more likely to define their child’s sleep as problematic than parents from predominately Caucasian countries. This study and others⁽⁴²⁾ affirm that the perception of sleep problems is influenced by cultural factors.

Figure 1-2 below is a conceptual model that was created by Boergers and Koinis-Mitchell^{(43)p917} as part of a systematic review to determine the interrelationships between sleep, culture and children’s health. It illustrates the relationships between culture, sleep and medical factors.

It is also important to recognise the social determinants of health and their potential impact on sleep. Hale and Hale⁽⁴⁴⁾ present a valid and important argument that the basic need to achieve good sleep hygiene requires autonomy and privilege; a person needs to have a safe, warm, quiet home, sufficient food, to feel safe, and to be free of mental health and physical issues that may impact on sleep. Hence, those with a lower socioeconomic status, and those with physical or mental health issues may be significantly challenged to adhere to health recommendations for sleep hygiene.

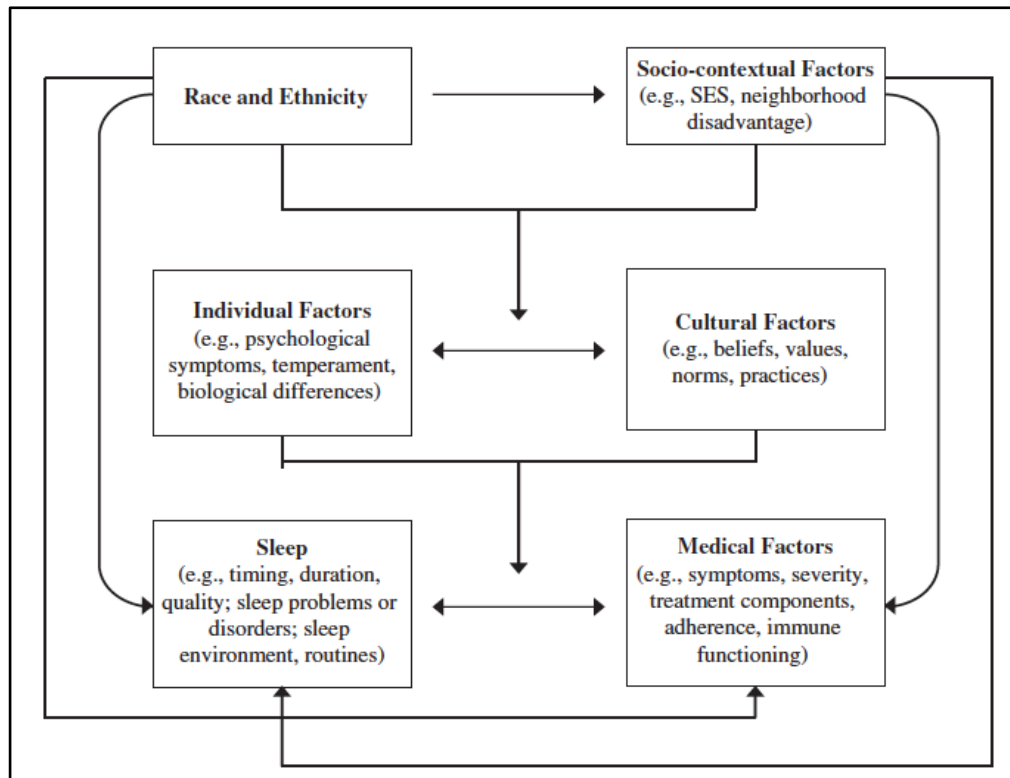


Figure 1-2 Boergers and Koinis-Mitchell's Conceptual Model of the Relationships among Cultural and Culture-Related Factors, Sleep and Medical Factors

1.3.6 Sleep disorders

Mindell and Owens⁽³⁶⁾ describe childhood sleep problems as being conceptualised into one or more mechanisms: insufficient sleep, fragmented sleep, primary disorders of excessive daytime sleepiness and circadian rhythm disorders. Sleep disorders can be described as intrinsic (from within the body) or extrinsic (as a result of an external factor). There are numerous intrinsic sleep disorders that are directly related to pathophysiology of one of the normal sleep processes, such as obstructive sleep apnoea, central hypoventilation or disorders of melatonin production (for example, as is associated with autism spectrum disorders).⁽⁴⁵⁾ Sleep, especially in children, can also be associated with extrinsic factors. The majority of sleep disorders in typically developing children are related to behaviour.⁽³⁵⁾ Behavioural problems include sleep associations, bedtime resistance and separation anxiety.⁽³⁶⁾ The key aspects

that are considered when assessing a child's sleep are reflected in a frequently used and recommended paediatric sleep evaluation: the BEARS (Bedtime problems, Excessive daytime sleepiness, Awakenings in the night, Regularity and duration of sleep and Sleep disordered breathing). This assessment aims to screen children for the major domains of possible sleep problems.⁽³⁶⁾

1.3.7 The impact of sleep problems

There are vast amounts of research investigating the impact of sleep deprivation for adults, in particular, fatigue-related risk in the workplace. It is well recognised that sleep deprivation increases the risk for workplace error due to reduced concentration, cognition and decision making.⁽⁴⁶⁾ There is also substantial evidence that sleep deprivation correlates with poorer mental health. Sleep deprivation has been linked to depression⁽⁴⁷⁾ and a number of comorbid diseases, including hypertension, diabetes, respiratory disease, musculoskeletal disease and gastrointestinal disease.⁽⁴⁸⁾ Sleep deprivation causes the slowing of most aspects of cognitive function,⁽⁴⁹⁾ and the consequences of this slowing may impact daily living, ability to safely drive a motor vehicle and decision making.⁽⁴⁹⁾

The impact of sleep deprivation for typically developing children has also been investigated. Poor sleep quality and quantity for children has been linked to poorer school performance⁽⁵⁰⁾ and neurobehavioral function.⁽⁵¹⁾ Hill, Hogan and Karmiloff-Smith⁽⁵²⁾ argue that good sleep is a precondition for learning and consolidates memory. In the case of children with neurodisability, the importance of optimising learning needs to be considered.

There is a small body of research that explores the impact of sleep problems in children with neurodisability on their parents. This research focuses on the experience of parents of children with neurodisability, the additional care needs required for their child with a disability and the sleep of the parent.^(1, 53, 54) None of this research focuses on the CP group specifically, but mothers of children with CP were a portion of larger study cohorts. These studies have suggested

parents of children with a disability report poor sleep^(1, 54, 55) and that chronic sleep disturbance has a negative impact on the parent.^(1, 53, 55) Those impacts include reduced subjective health,⁽¹⁾ reduced participation in healthcare activities,⁽¹⁾ stress,^(54, 55) depression,⁽⁵⁵⁾ anxiety⁽⁵⁵⁾ and affected quality of life.⁽⁵³⁾ Conclusively, the impact of sleep problems can be significant and further research is required in this area.

1.4 Where Sleep and CP Intersect and Where this Study is Placed

Children with CP have the same risks of paediatric sleep disorders as typically developing children. However, children with CP are more likely to experience additional sleep disturbance related to the comorbidities of CP. Due to abnormalities in upper airway tone and structure, children with CP, especially those with global involvement, are more likely to experience issues with sleep disordered breathing, such as obstructive sleep apnoea.⁽⁴⁵⁾ It has also been hypothesised that for children with CP, normal sleep architecture may be altered by pathological factors associated with neurodevelopmental impairment. For example, epilepsy, visual impairment and intellectual disabilities may interrupt the typical sleep processes and cause disordered sleep.⁽⁴⁵⁾ These pathological sleep factors are likely to impact on sleep, are difficult to address and are not the focus of this research.

Other intrinsic factors that have been identified as impacting on sleep are those related to movement, abnormal muscle tone and associated comorbidities. Hypertonicity can cause involuntary uncomfortable postures that are often associated with spasms and pain. Indeed, many of the most common comorbidities of CP are triggers for pain that can directly impact on sleep. According to one study, children with CP were the most common attenders at a paediatric chronic pain clinic and these children experienced more sleep disturbance than children without CP.⁽⁵⁶⁾ The comorbidities can result in children requiring frequent and intense care including, but not limited to, pain,

repositioning, hygiene needs, seizure management, feeding and medication administration. This care is often required overnight. Additionally, a child with a neurodisability, such as CP, is at risk for intellectual disability and associated behavioural problems.⁽⁵⁷⁾ This may lead to different challenges in regard to behavioural management of sleep. The impact of comorbidities on sleep in children is increasingly recognised, however much more research is required.⁽⁵⁸⁾

Finally, as described above, CP is often identified early in life, and this can often be associated with some level of medical trauma and vulnerability. Pierrehumbert⁽⁵⁹⁾ examined the association between sleep problems in premature infants and maternal posttraumatic reactions. This study⁽⁵⁹⁾ found a linear relation between a premature child's sleep problems and the mother's posttraumatic reactions. Whilst this study acknowledges the many confounding factors that may influence this relationship, this finding suggests that the impact of a traumatic premature birth and of parenting a child that is medically vulnerable need to be considered.

One reason a parent may choose to sleep with their child is to maintain vigilance. Children with CP, especially those with epilepsy or respiratory problems, may require parental attention overnight to keep the child safe. It is not uncommon for a child with CP to pass away in their sleep⁽⁶⁰⁾ and this may contribute to the sense of vigilance a parent feels towards their child overnight. Often parents choose to share a bed with their child so they can ensure their safety. McCann⁽⁶¹⁾ discusses how vigilance is a common issue for parents of children with disability. They feel they must keep watch overnight to ensure their safety. A 2012 report by the Victorian Equal Opportunities commission highlighted that vigilance is a risk factor for surrendering a child with disability into care.⁽⁶²⁾ A child with severe CP has complex healthcare needs and is medically vulnerable. The impact of this vulnerability, especially at night, needs to be taken into account.

Thus, the malleable nature of sleep, the impact of motor dysfunction and comorbidities associated with CP, behavioural problems and parental vigilance for a vulnerable child, can all be reasons for sleep disturbance and deprivation for children with CP and their parents. The intersection is illustrated in Figure 1-3 below.

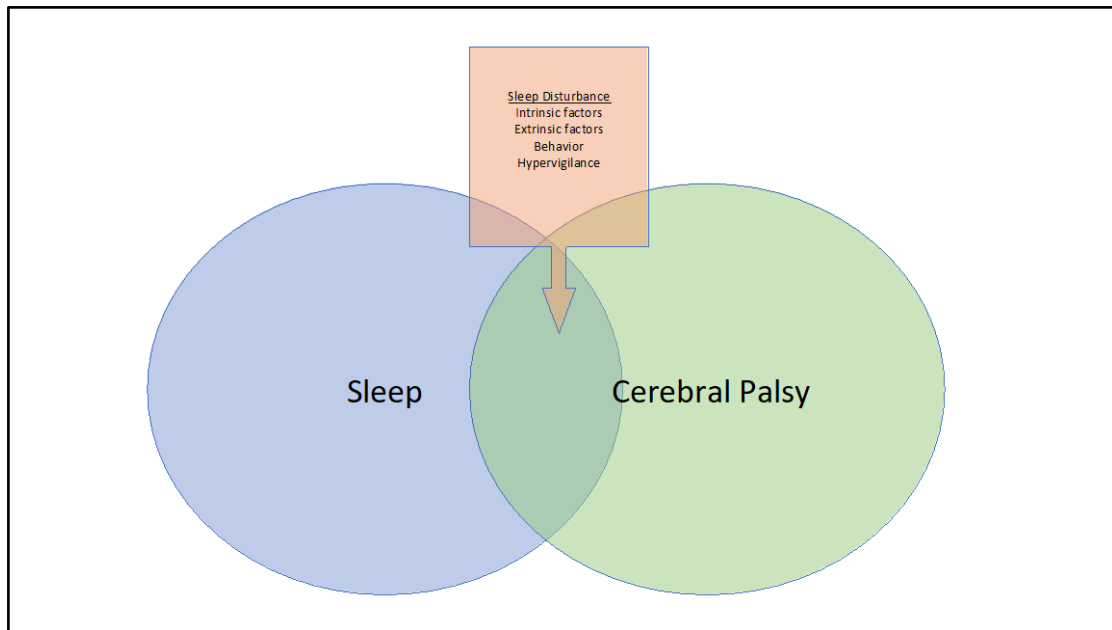


Figure 1-3 The Intersection between Sleep and CP where Sleep Problems Occur

This thesis focuses on the intersection between CP and sleep. This intersection occurs where the intrinsic and extrinsic factors of CP and sleep combine with aspects of parenting, environment and culture. It is the aim of this thesis to explore the type, frequency, causes, impact and experience of sleep problems for children with CP and their families. There is little published evidence in regard to sleep and CP, and even less research in regard to clinical interventions for sleep. The broad aim of this study is to gather more evidence about sleep problems in the context of CP. This evidence will be the scaffolding for possible interventions and future research. The aims and research design for the study will now be explained.

1.5 Study Aims and Research Questions

The primary aim of this study is to understand the frequency of, reasons for, and the impact of sleep disturbance for children with CP and their parents.

The secondary aim of the study is to develop recommendations for a possible sleep intervention for this cohort.

The research questions are:

- i. What are the reasons for and frequency of sleep disturbance for children with CP and their parents?
- ii. What is the experience and impact of sleep disturbance for parents of children with CP?

An exploratory mixed methods sequential design, as described by Creswell,⁽⁶³⁾ was chosen for the research study. The study methods, theoretical framework and rationale for the research design are discussed in Chapter Five of the thesis.

1.6 Structure of the Thesis

This introductory chapter has described the evolution of this research project and the broad aims, context and background of the study. The physiology of both sleep and CP have been explained. This chapter concluded with a description of how sleep and CP intersect to contribute to sleep problems. The position of this thesis within that body of knowledge has been described.

Chapter Two provides a critical review of the published literature on sleep and cerebral palsy for children. A synthesis and critique of the small number (less than 25) of current studies is described. The chapter concludes with a summary of the knowledge gap that this thesis has aimed to address.

Chapter Three introduces critical social theory, which was chosen as the theoretical framework for the study. The chapter also describes the rationale

for choosing an exploratory sequential mixed methods design and explains how critical social theory has been applied to the research design.

Chapters Four and Five provide a brief synopsis of the historical discourse around disability and sleep. Chapter Four explains key policy and legislation changes in Australia, and the transformation of disability as a stigmatised affliction to the present day, where legislation and public funding seeks to normalise disability. Chapter Five summarises the available sleep resources, the value of sleep in western societies and the subsequent sleep industry that has emerged.

Chapters Six and Seven describe Phase One methods procedure and results. The research setting, recruitment process, data collection, data management and analysis, study rigour and ethical considerations are articulated. The results of the thematic analysis are presented in the form of a concept map and key quotes are provided to illustrate each theme.

Chapter Eight describes how the findings from Phase One were applied to the design of Phase Two (quantitative) and Phase Three (qualitative). This chapter serves as a clear explanation of how the three phases of this research were linked to create a truly mixed methods thesis.

Chapter Nine presents a detailed description of the methods used in Phase Two and Phase Three of the study. The research setting, data collection, ethical considerations and methods for data analysis are presented.

Chapter Ten presents the Phase Two results. Phase Two results have been submitted as a manuscript to the *Journal of Paediatrics and Child Health*. At the time of submitting this thesis, the manuscript is awaiting editorial decision. The manuscript, as it has been submitted to the journal, is presented as the chapter. The methods are described and analysis presented followed by a discussion. Chapter Ten also includes a supplemental section of relevant data presented as tables in the section following the published paper.

Chapter Eleven is the final findings chapter of the thesis. It presents the qualitative findings of Phase Three. The results of the thematic analysis are presented in the concept map. The themes are explained, and key quotes are used to illustrate each theme.

The thesis concludes with Chapter Twelve. This chapter provides a synthesis of all three phases of the research project. This synthesis is presented in the form of a joint display table, and six meta-themes have been identified. The meta-themes are explored in the context of existing literature. This chapter then applies critical social theory to the study findings; two dominant ideologies are identified and how they may have influenced the experience of sleep problems in CP are discussed. Following this, the limitations of the study are described. The clinical and research recommendations of the study are then presented. These demonstrate the potential uses of this body of work. This chapter ends with a final conclusion and a brief summary of the study.

CONCLUSION

This chapter has presented the context for this thesis, including an explanation of how the study evolved. A brief explanation of the physiology of both sleep and CP has been provided. How sleep problems and the comorbidities of CP may intersect to contribute to sleep problems has been explained in detail. The position of this study in the wider sphere of knowledge has been articulated. Finally, this chapter has explained the aims and purpose of this study and the knowledge gap it aims to address. The following chapter will describe, in detail, current published literature that quantifies sleep problems and their impact for children with CP and their parents.

2 LITERATURE REVIEW

INTRODUCTION

The preceding chapter explained how sleep and cerebral palsy (CP) intersect and included a brief introduction to the scope of this research project. This chapter aims to locate the thesis within the sphere of existing literature, up until the time when data collection commenced (February 2016); literature published after this time is presented in Chapter Twelve. This chapter begins with a brief explanation of the literature search methodology and the criteria for inclusion and exclusion. Following this, literature that addresses the frequency, type and impact of sleep problems for children with CP is presented, synthesised and critiqued. Only studies that explored sleep and children with CP or sleep and children and parents with CP were included in this review. Finally, this chapter concludes with a summary of the identified gap in published literature and how this thesis plans to address that literature gap.

2.1 Literature Search: Methods, Inclusions and Omissions

In early 2016, a critical review of the current literature was conducted to determine what is known about sleep problems for children with CP. The aim of the review was to reveal gaps in the current literature and highlight the relevance of the proposed PhD thesis. As discussed in Chapter One, Section

1.4, sleep problems for children with CP can be pathological, behavioural or due to care needs or comorbidities. The focus of this thesis, and subsequently the literature review, is the non-pathological, non-respiratory causes of sleep disturbance. Additionally, this thesis does not include an exploration of the specific use of medication in the management of sleep problems.

2.1.1 Search methods and inclusion criteria

Papers were included in the review if they presented original data about the type, frequency, impact or experience of sleep for children with CP or their parents.[‡] The following search terms were used: sleep and cerebral palsy or disability or neurodisability or developmental disability. Due to the known paucity of research on CP and sleep, search terms were broad to maximise search results. Medline, CINAHL, Psychinfo and Embase databases were searched. Studies with mixed diagnosis sample groups were included if children with CP were part of that sample. The search strategy for each database can be found in Appendix C. The reference lists of relevant papers were also searched to find additional papers. The search was conducted in February 2016 and papers published from 1980 up until this time were included. Papers published after February 2016 that fit the inclusion criteria will be discussed in Chapter Twelve, Section 12.4.2. The literature search results will now be summarised, synthesised and critiqued.

2.2 Summary of Literature that Quantifies Sleep Problems in Cerebral Palsy: Frequency, Type and Impact

At the time of the review, 21 studies were found that quantify the type and frequency of sleep problems in CP. Some of these studies also explore the causes of sleep disturbance, and the impact of sleeplessness in terms of mental health

[‡] There is a small body of published work that explores the sleep of parents of children with CP in isolation, that is, their child's sleep is not examined. These studies have been presented in Chapter One, Section 1.3.7.

or quality of life for the child or their caregiver. Table 2-1 provides a summative representation of the 21 papers. Following this table, the included papers will be critiqued, compared and contrasted under four themes: the incidence of sleep problems, the causes of sleep problems, the impact of sleep problems, and how sleep problems in children impact the quality of life and mental health of parents and sleep interventions in CP. This review will provide a detailed and comprehensive understanding of the existing research on sleep and CP. A legend is provided at the end of the table to explain the abbreviations used in the table.

Table 2-1 Review of Current Literature that Quantifies Sleep in Cerebral Palsy

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
Adiga, Gupta, Khanna, Taly, Thennarasu, 2014, India ⁽⁶⁴⁾	Questionnaires Child: SDSC (PR) Parent: PSQI	Total n=50 children with CP Age range: 6-15	GMFCS I n=20 (40%) GMFCS II n=14 (28%) GMFCS III n=6 (12%) GMFCS IV n=1 (2%) GMFCS V n=9 (18%) Spastic CP n=42 (84%) Dyskinetic CP n=3 (6%) Mixed CP n=5 (10%)	DIMS n=17 with pathological score	Not assessed	36% of cohort had pathological total sleep scores No correlation between GMFCS and sleep disturbance	50% of mothers had sleep disturbance measured by PSQI score 70% bed sharing with mothers 92% of the bed-sharing parents had disturbed sleep	Small study numbers Participants recruited from clinics. Potential total population not described
Atmawidjaja, Wong, Yang, Ong, 2014, Malaysia ⁽⁶⁵⁾	Questionnaire Child: SDSC (PR) Parent: Sleep duration and latency recorded	Total n=109 children with CP Total n=TD children (siblings) control Age range: 4-18	GMFCS I n=15 (14%) GMFCS II n=19 (17%) GMFCS III n=10 (9%) GMFCS IV n=52 (48%) GMFCS V n=24 (22%)	Child: DIMS (37%) SWTD (19%) SBD (12%)	Not assessed	30% of CP cohort had a pathological total sleep score compared to 5% TD cohort	Co-sleeping 48% Reduced sleep duration and sleep latency of parents associated with higher sleep scores in child	Limited to SAT Sample population higher proportion of children with GMFCS level IV CP Participants recruited from clinics

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
								Potential total population not described
Blankenberg, Tietze, Hechler, Hirschfeld, Michel, Koh, Zerinkow, 2013, Germany ⁽⁶⁶⁾	Questionnaire SNAKE (PR) – study to develop and validate the tool	Total n=224 children with severe psychomotor impairment CP n=62 (27.68%) Mean age: 10.5 Age range: 1-25	CP not described	N/A	Passive position changes (25%) Epileptic seizures (12%) Pain (12%) Medical measures (8%)	As this was a validation study, key findings were discussed in regard to the validity and psychometrics of the tool	Discussed in study below (Tietze 2014)	Limited to severe psychomotor impairment (GMFCS IV, V equivalent) CP population not well described
Hemmingsson, Stenhammar, Paulsson, 2008, Sweden ⁽⁶⁷⁾	Questionnaire Child: researcher design (PR) RS (not validated) Parent: Not assessed	Total n=505 children with physical disability n=216 (42.77%) children with CP n=59 (11.68%) children with spina bifida n=27 (5.35%) children with muscular dystrophy n=203 (40.2%) children with other diagnosis Age range: 1-16 Mean age: 9.25	Not reported	SAT not used	CP cohort: Sleep problems: Difficulty relaxing n=54 (25%) Nightmares n=45 (20.8%) Pain n=41 (19%)	48% of the children had sleep problems 23% of those problems were considered serious by the parents	37% of the children needed parental attention every night 10% needed help 5 times or more Reasons for support from parents: Repositioning n=95 (44%) Toileting / continence n=8 (37.1%) Restless sleep n=107 (49.5%) Pain n=39 (18.1%)	Unknown/not validated SAT used CP population not described, GMFCS not used

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
Ikeda, Nagai, Kato-Nishimura, Mohri, Taniike, 2012, Japan ⁽⁶⁸⁾	Questionnaires Child: RS – authors own questionnaire (not validated) (PR) Parent: J-ZBI PSQI	Total n=100 children with physical disability N = 62 (62%) children with CP Age range: 1-17	Can sit up n=35 Cannot sit up n=65	Problems initiating and maintaining sleep (57%) Problems with sleep related movement (52%) Flings legs around (46%) Wakes up during night several nights per week (34%)	Not assessed	88% of cohort had one sleep problem 67% had two sleep problems	34% of caregivers had a pathological score on PSQI Poor caregiver sleep correlated with perceived caregiver burden Sleep problems in physically disabled children strong influence sleep quality of caregivers	Unknown/not validated SAT used
McCabe, Blackmore, Abbiss, Langdon, Elliott, 2015, Australia ⁽⁶⁹⁾	Retrospective review of clinical notes	Total n = 154 children with CP Age range: 1-18 Age Mean: 7.8	GMFCS I n=20 (13%) GMFCS II n=13 (8%) GMFCS III n=17 (11%) GMFCS IV n=28 (18%) GMFCS V n=76 (49%)	N/A	For children aged 6-12 years (n=39) Body position (69%) Movement (36%) Breathing (68%) Reflux/digestion (31%) Settling routine (51%) Sleep environment (28%) Pain (18%)	Sleep problems evident across every GMFCS level, not just GMFCS IV and V	N/A	Retrospective study limited to information recorded in case files Sample population higher proportion of children with GMFCS level V CP

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
Ming, Pak, Mulvey, O'Sullivan, Reddy, Schwab, Pecor, 2014, United States of America ⁽⁷⁰⁾	Quantitative interviews Using validated questionnaires Child: PSQ (PR) SDBS (PR)	Total n=227 n=23 (10.13%) children with CP n=106 (46.7%) children with epilepsy n=29 (12.78%) children with CP and comorbid epilepsy n=69 (30.4%) TD children Age range: 2-18	Hemiplegia Diplegia Quadriplegia Choreoathetoid Ataxic (% not described)	SDB: 100% of children with CP 76% of children with CP and comorbid epilepsy Insomnia: 83% of children with CP 76% of children with CP and comorbid epilepsy Excessive Daytime Sleepiness: 91% of children with CP 41% of children with CP and comorbid epilepsy	Not assessed	Sleep disorders higher in CP cohort than TD cohort Children with CP and epilepsy were not more likely to have sleep disturbance than children with CP alone	N/A	CP population not well described. GMFCS not used Participants recruited from clinics. Potential total population not described
Mörelus, Hemmingsson, 2014, Sweden ⁽⁷¹⁾	Questionnaires RS (not validated) (PR) Included child sleep and parent report of own health	Total n=375 children with physical disabilities n= 161 (42.93%) children with CP Mean Age: 9 (range not stated)	Not described	N/A	n=147 (47%) were reported to have sleep problems Minor 51% Moderate 30% Severe 19%	Problems relaxing n= 86 Nightmares n=79 Pain n= 70 Convulsion n=67	n= 187 (50%) required night-time attention from parents 47% of children had sleep problems 17.5% bed sharing. Mothers reported poorer perceived health than fathers Reasons for parents to attend to child:	Unknown/not validated SAT used CP population not described. GMFCS not used. Participants recruited from clinics. Potential total population not described

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
							Restless sleep n=164 Toileting n=148 Repositioning n=142	
Newman, O'Regan, Hensey, 2006, Ireland ⁽⁷²⁾	Questionnaires Child: SDSC (PR) With additional researcher designed questions	Total n=173 children with CP Age range: 6-11	n=83 (48%) spastic diplegia n=59 (34.1%) hemiplegia n=18(10.4%) spastic quadriplegia n=13(17.5%) dystonic/dysinetic CP GMFCS I n=73 (42.2%) GMFCS II n=33 (19.1%) GMFCS III n=30 (17.3%) GMFCS IV n=23 (13.3%) GMFCS V n=14 (8.1%)	DIMS (24.3%) SWTD (17.9%) SBD (14.5%)	Not reported	CP pathological sleep score 22.5% TD 5% A pathological sleep score was associated with presence of active epilepsy, as single parent family, and sleeping with parents GMFCS level was not associated with an increase in sleeplessness	Bed sharing at least one night per week in 22.5% families, 9.2% shared bed every night	Limited to SAT
Petersen, Reddihough, Newall, 2015, Australia ⁽²⁾	Prospective survey Child: CSHQ (PR) TUD (PR)	Total n = 8 children with CP Age range: 6-10	GMFCS IV n= 7 (87.5%) GMFCS V n=1 (12.5%)	All children had a pathological total sleep score on CSHQ (specific domains not presented)	Body positioning n=3 Movement/restlessness	Qualitative methods may enrich data collection	3 of the 8 children shared a bed with their parent	Very small study numbers Limited to GMFCS IV or V

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
	RS (not validated)				Requires comfort n=4 Pain n= 1 Hygiene n=1			Descriptive statistics only
Quine, 1991, England ⁽⁷³⁾	Longitudinal study using diagnostic assessments and clinical interviews. 1982 and 1984 Behaviour Screening Questionnaire	Total group: Children with severe disability n=166 CP n=100/166 Age range: 0-18	Not reported	Night settling n=62 (37%) Night waking n=84 (51%) Co-sleeping n=49 (29%)	Not reported	71% (n=71) of CP cohort had sleep problem. Night settling problems associated with problems of daytime behaviour Night settling problems associated with night waking problems Sleep problems associated with maternal stress Severity of disability not associated with sleep problems Communication skills associated with sleep problems	Child behaviour problems may impact maternal irritability, stress, quality of marriage, which may influence sleeping problems	CP group not well described GMFCS not used
Richdale, Francis, Gavidai-Payne, Cotton, 2000, Australia ⁽⁷⁴⁾	Researcher designed questionnaire about child sleep and behaviour	Total n=52 children with intellectual disability	Not reported	Frequent night waking (68.9%) Sleeps in others bed (42.3%) Snoring (38.5%)	Not reported	Percentage of total cohort with current sleep problem=57.7%	Severe ID and sleep problems associated with more stress and hassle (on	Small percentage of total study population

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
	(not evidence if validated)	Total CP n=12 (23%) Total TD n=25 Age range: 1.8-19 Mean age: 7.7		Yelling at night (34.6%)		Percentage of total cohort with current sleep problem=66.7% Children with ID current sleep problems=57.7 % Control group: 16% Children with ID past sleep problems=66.7 % Control group: 33% Sleep problem associated with behaviour problem Sleep problems had been present for more than 2 years in 56% of children with ID	hassle index) for mothers	were children with CP CP population not described. GMFCS not used. Unknown/not validated SAT used
Robinson, Richdale, 2004, Australia ⁽⁷⁵⁾ <i>Two questionnaire studies (1999 and</i>	Researcher designed questionnaire about child sleep (not evident if validated)	Total n=243 children with intellectual disability Total CP: 16 (16.5%)	Not reported	Early waking n=84 (35.1%) Night settling n=62 (25.9%) Night waking n=84 (35.1%)	Not reported	36.2% prevalence of sleep problems Average duration of 6-9 years	62.3% of parents of children who had settling problems reported this	Small percentage of total study population were children with CP

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
<i>2001) – only study 2 included children with CP. Only study 2 reported in this table.</i>	Yes/no question about child sleep affected parent sleep	Age range: 3.1-18.7 Age mean: 10.6					affected their own sleep 86.6% of parents of children who had night waking reported this affected their own sleep	CP group not described. GMFCS not used. Unknown/not validated SAT used
Romeo, Brogna, Quintiliani, Baranello, Pagliano, Casalino, Sacco, Ricci, Malladi, Musto, Sivo, Cota, Battaglia, Bruni, Mercuri, 2014, Italy ⁽⁷⁶⁾	Questionnaires SDSC (PR) GMFCS WIC CBC	Total n=165 children with CP Age range: 6-16	GMFCS I n= 68 (41%) GMFCS II n= 20 (12%) GMFCS III n=19 (12%) GMFCS IV n=17 (10%) GMFCS V n=41 (25%) Diplegia n= 38 (23%) Hemiplegia n= 34% Quadriplegia n=64 (39%) Dyskinesia n=7 (4%)	DIMS (22%) SBD (14%) SWD (15%) DA (10%)	Not assessed	19% of cohort abnormal total sleep score 42% of cohort had at least one sleep disorder Strong association between SDSC scores and epilepsy = OR (95% CI) 3.500 1.385–8.688 P<0.05 77% of children with abnormal SDSC had an intellectual disability Behavioural problems associated with abnormal SDSC total score	N/A	Limited to SAT Participants recruited from clinics. Potential total population not described.

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
Sandella, O'Brien, Shank, Warschausky, 2011, United States of America ⁽⁶⁷⁾	Questionnaire Child: PedsQL 4.0 (PR) PSQ (PR)	Total n=132 n=41 (31.06%) children with CP n=91 TD children control Age range: 8-12 Mean age: 9.8	GMFCS I (51.2%) GMFCS II (7.3%) GMFCS III (19.5%) GMFCS IV (7.3%) GMFCS V (4.9%) (n= not provided)	Not quantified CP group had higher scores on PSQ for SRBD and EDS	Not assessed	Insomnia, daytime sleepiness and functional motor abilities were associated with lower QOL in children with CP	N/A	Small percentage of total study population were children with CP Sample population higher proportion of children with GMFCS level I CP
Svedberg, Englund, Malker, Stener-Victorin, 2008, Sweden ⁽⁷⁷⁾	Questionnaire Child: Researcher designed questionnaire (PR) Parent: Not assessed	Total n=107 children with CP Age range: 5-13 Mean age: 11.8	GMFCS I n=40 (37%) GMFCS II n=20 (19%) GMFCS III n=4 (4%) GMFCS IV n=23 (21%) GMFCS V n=20 (19%)	SAT not used	Difficulty relaxing, presence of hypertonicity, anxiety, epilepsy, pain, restless sleep (statistics not provided)	51% of cohort had sleep disorder 54% of children with sleep disorders had not been offered treatment 44% of mothers and 35% of fathers said their health was influenced by child's sleep problems	N/A	Unknown/not validated questionnaire used
Tietze, Zernikow, Michel, Blankenberg, 2014, Germany ⁽⁷⁸⁾	Questionnaires Child: HOST (PR) Parent: PSQI	Total n=214 children with severe psychomotor impairment CP n=61 (28.5%) Age range: 0-25	CP not described	N/A	Not presented (child sleep details presented in Blankenburg 2013 paper.	Bed sharing = 24% Strong correlation between sleep disturbance of	71% of parents significant sleep impairment on PSQI	Limited to severe psychomotor impairment (GMFCS IV, V equivalent)

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
	ESS Sf-36					child with sleep disturbance of parent Poor parental sleep linked to decreased physical, and mental, health of parents	50% of parents showed prolonged sleep latency	CP population not well described
Wayte, McCaughey, Holley, Annaz, Hill, 2012, England ⁽⁷⁹⁾	Questionnaires Child: CSHQ (PR) Parent PSQI MDI	Total n=142 n= 40 children with CP n=102 TD children control Age range: 4-12 Mean age: 7.8	Quadriplegic (35%) Hemiplegic (27%) Diplegic (22%) Ataxic (8%) Athetoid (8%) (only % provided)	Higher scores than TD children for: anxiety, night waking, parasomnias, sleep disordered breathing	Not assessed	Children with CP had significantly higher total CSHQ than typically developing children	CP cohort significantly higher CSHQ scores than TD Sleep disturbance in children correlated with sleep disturbance in mother Parents of children with sleep disorder scored higher on PSQI, 44% of those with high PSQI scores had high MDI scores	Small sample size CP population not described, GMFCS not used
Wiggs, Stores, 1996, England ⁽⁸⁰⁾	Researcher designed questionnaire for parent and child (not evident if validated)	Total n=269 children with severe learning disabilities CP n=16 (6%)	Not reported	Settling n=24 (26%) Night waking n=20 (22%) Settling and waking n=18 (19%)	Not reported	Percentage of total cohort with sleep problems: 44% Children with sleep problems	64% of parents of child with sleep problems felt they were not getting enough sleep compared to	Small percentage of total study population were children with CP

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
		Age range: not reported Mean age: 10.01				demonstrate more challenging behaviour than those without sleep problems Children with sleep problems scored higher on: Daytime irritability: mean score (95% CI) 8.87 vs 4.79 P-value <0.01 Lethargy: mean score (95% CI) 5.38 vs 3.58 P-value <0.01	21% of parents whose children did not have a sleep problem	CP group not described. GMFCS not used 43% response rate
Wright, Tancredi, Yundt, Larin, 2006, Canada ⁽⁸¹⁾	Mixed methods Focus groups (4) with caregivers of children with CP or physiotherapists and occupational therapists. Focus groups informed the design of the questionnaires Postal questionnaires: Parent, Child, Sibling	Total n=178 children with physical disability n=68 (38%) children with CP n=13 (7%) children with spina bifida n=8 (5%) children with muscular dystrophy n=52 (29%) children with developmental delay	CP not described	SAT not used	Pain (n=51) 19.4 x rate in TD (p<0.001), swallowing or digestive problems (n=46) 14.2 x rate in TD (p<0.001) Behavioural problems (n=41) 18.9 x rate in TD (p<0.001)	History of Sleep problems n=125 35.8 x rate of TD (p<0.001) Toss, turn or thrash in sleep n=40 (TD n=1) Night wakening n=118 16.5 x rate of TD (p<0.001)	Caregivers of PD children more likely to report daytime sleepiness, feeling irritable, feeling stressed, worry about the sleep of other family members	CP population not described, GMFCS not used 26% recruitment rate (n=184 of possible n=705) Methods for focus group and qualitative analysis not described

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT) (child)	Cause of Sleep Disturbance (child)	Key Results (child)	Key Results (parent)	Limitations
		n=35 (20%) children with CP n=69 TD children (control) Age range: 0-13 Caregivers of PD child: n=177 Caregivers of TD child: n=64 Siblings of PD child: n=102 Siblings of TD: n=34						
Zuculo, Knap, Pinato, 2014, Brazil ⁽⁸²⁾	Questionnaires SHQ SDSC (PR) Sleep Diary RS (not validated) SD AUQUEI CHQPF50	Total n=43 children with CP Total n=35 children with TD Age range: 4-18	Hemiparetic n=2 (4.6%) Diaparetic n=16 (37.2%) Diplegic n=6 (13.9%) Tetraparetic n=9 (20.2%) Tetraplegic n=10 (23.2%)	RSD (25.6%) SH (34.9%)	N/A	60.4% of CP cohort presented with sleep disorders 23.2% woke up overnight Negative correlation between sleep disorders and quality of life Mean SDSC score for children with CP was higher (5.27 SD 0.54) than the control group (3.28 SD 0.31)	N/A	Small sample size Participants recruited from clinics Potential total population not described GMFCS not used to describe population

Table Legend

AD – Arousal Disorders

CBC – Child Behaviour Checklist

CHQPF50 – Child Health Questionnaire

CSHQ – Child Sleep Habits Questionnaire

DA – Disorders of Arousal/Nightmares

DIMS – Difficulty Initiating or Maintaining
Sleep

DOES – Disorders of Excessive Somnolence

ESS – Epworth Sleepiness Scale

GMFCS – Gross Motor Function
Classification SystemHOST – Holistic Assessment of Sleep and
Daily Troubles

JZBI – Japanese Burden Index

MDI – Major Depression inventory

N – No

PD – Physical Disability

PR – Assessment by proxy (parent) report

PEDSQL 4.0 – Paediatric Quality of Life
Inventory

PSQ – Paediatric Sleep Questionnaire

PSQI – Pittsburgh Sleep Quality Index

RSD – Respiratory Sleep Disorders

RS – Researcher Designed Survey

SDBC – Sleep Disordered Breathing Scale

SBD – Sleep Breathing Disorders

SD – Sleep Diary

SDSC – Sleep Disturbance Scale for Children

SH – Sleep Hyperhidrosis

SHQ – Sleeping Habits Questionnaire

SPMI – Severe Psychomotor Impairment

SAT – Sleep Assessment Tool

TD – Typically Developing

TUD – Time Use Diary

U – Unknown

WIC – Wechsler Intelligence Scale for
Children

Y – Yes

2.2.1 Table 2.2 summary

The 21 papers included in this review were relatively similar in design, with the majority using prospective questionnaires as their method of data collection.^(2, 64-68, 70-72, 74-83) These questionnaire-based studies used either survey tools designed by the researcher^(68, 71, 74, 75, 77, 80, 83) or previously validated (in research with typically developing children) sleep assessment tools.^(2, 64, 65, 67, 70, 72, 76, 78, 79, 82). Blankenberg's⁽⁶⁶⁾ paper was a study to develop and validate the design of a sleep assessment tool for use in children with severe psychomotor impairment. Only Wright et al.⁽⁸¹⁾ conducted qualitative focus groups prior to designing their own survey. McCabe⁽⁶⁹⁾ completed a retrospective review of patient clinical notes and Quine⁽⁷³⁾ used assessments and quantitative interviews (survey tools were read out to participants who answered verbally). These were the only studies that did not use a questionnaire-based approach. Whilst the study design, for the majority of the papers, appears relatively similar between the studies, there was great variation between the tools selected and any extra information that was collected. Indeed, within the 21 studies there is so much variation in tools used and data collected that no two papers could be easily compared. This highlights the infancy of sleep research within the area of CP and the need for more studies to explore, and attempt to replicate, key studies. The quality of the research papers varied. The majority were small cross-sectional studies that had small sample sizes, many used un-validated sleep assessment tools, and confounding variables were rarely considered.

Notably, there is great diversity in the countries of origin of these 21 studies. Four papers originated from Australia. Others were from England (3), Sweden (3), Germany (2), USA (2), Brazil (1), Canada (1), India (1), Ireland (1), Italy (1), Japan (1) and Malaysia (1). This diversity in origin is significant as it highlights that sleep is an issue for children with CP and their parents internationally. It also highlights the need for more local studies, given the cultural and health service differences in each country. The time range over which the studies were published is also noteworthy; eight of the 21 studies were published in the two years prior to this review (2014 or 2015). This signifies the increasing awareness of sleep as an

issue for children with CP and demonstrates how well placed and timed this PhD research is within the current sphere of CP research.

In all but one of the studies, the research methods were designed by the researchers without consultation with the potential participants. The one study that did consult participants used qualitative focus groups to ask both parents and therapists (physiotherapists and occupational therapists) about sleep issues, and used these qualitative data to design a survey tool.⁽⁸¹⁾ This study revealed very detailed data about why parents are awake with their children with physical disabilities. This suggests that engaging participants in the research design may result in richer data and more meaningful outcomes. Creswell⁽⁶³⁾ argues that using qualitative findings to inform the design of a quantitative tool enables the research tool to be grounded in the experience of the participants. This may be particularly relevant when thinking about how these data may be applied to the design of any intervention that may improve sleep.

The sample size of the reviewed papers varied greatly, from Petersen,⁽²⁾ who conducted a small pilot study of eight children, to the study of Hemmingsson et al.,⁽⁸³⁾ which included 216 children with CP. Within the studies, the participant groups varied. Nine studies examined only a CP cohort.^(64, 67, 69, 72, 77, 79, 84) Zuculo et al.⁽⁸²⁾ and Atmawidjaja et al.⁽⁶⁵⁾ compared a CP group to a typically developing group. Four studies examined children with physical disability, including CP, and other diagnoses including muscular dystrophy, spina bifida and acquired brain injury.^(68, 71, 78, 83) Notably, four studies were designed with a focus on intellectual disability (ID) and behavioural problems.^(73-75, 80) These studies provide relevant insight into the impact of ID and behavioural problems in relation to CP, but their application is limited as it does not include how physical disability and associated comorbidities may impact on sleep. One similarity between all of these papers was the consistently high frequency of sleep problems in groups of children with CP. This shall now be explored.

2.3 Overall Incidence of Sleep Problems in CP

Research suggests that at least 30% of typically developing children have sleep problems.⁽³⁵⁾ The results from the reviewed studies for this thesis showed that between 19 and 88% of children with CP/physical disability experienced sleep problems. Eight of the 21 papers compared the sleep of children with CP to their typically developing peers.^(65, 67, 70, 74, 79-82) These eight studies all revealed that compared to typically developing children, the incidence of sleep problems is significantly higher for children with CP. One study of Malaysian children⁽⁶⁵⁾ compared children with CP to their typically developing siblings. The results of this study are particularly important as surveying siblings removes the variance of cultural and social situation and parenting style when making comparisons between a cohort of CP and typically developing children. This Malaysian study⁽⁶⁵⁾ showed only 5% of the typically developing children had a pathological sleep score, while 30% of their siblings with CP scored within the pathological range on a sleep-screening tool. Similarly, Wright,⁽⁸¹⁾ Newman,⁽⁷²⁾ Wayte,⁽⁷⁹⁾ and Zuculo⁽⁸²⁾ all found that children with CP reported a higher frequency of sleep problems than their typically developing peers. It can be suggested that this consistently repeated finding in school-aged children suggests that sleep problems in CP are often chronic and pervasive, and that they occur across the globe, regardless of culture or parenting styles. This reiterates the need for further research in this area and, perhaps, that the challenges of treating sleep problems in CP are universal.

2.4 Causes of Sleep Disturbance

Seven^(2, 69, 71, 77, 78, 81, 83) of the twenty papers sought to quantify the frequency and reason for night time wakings. That is, the researchers focussed on what causes a child with CP to wake at night, or what care or comfort requirements overnight required the attention of the parents. The reviewed papers suggest that positioning, pain, seizures and continence are the most commonly reported care and comfort reasons for sleep disturbance. McCabe⁽⁶⁹⁾ used a retrospective audit to assess why children with CP presented to a sleep assessment clinic. This method revealed 23 sleep concerns, whereas the sleep screening tools merely

capture the type of sleep disturbance as a broader domain, rather than the reasons for it. Wright⁽⁸¹⁾ and Hemmingsson⁽⁸³⁾ also used surveys that captured a greater breadth of answers in their data. Wright⁽⁸¹⁾ listed 39 health related associations for sleep disturbance and Hemmingsson⁽⁸³⁾ revealed 17. That is, the studies that not only examined if sleep was disturbed, but also why it was disturbed, obtained more detailed data. This detail provides greater insight into the reasons for sleep problems and in turn, insight into possible solutions. The figure below shows a list of reasons for waking and the number of papers that found this to be a cause of sleep disturbance.

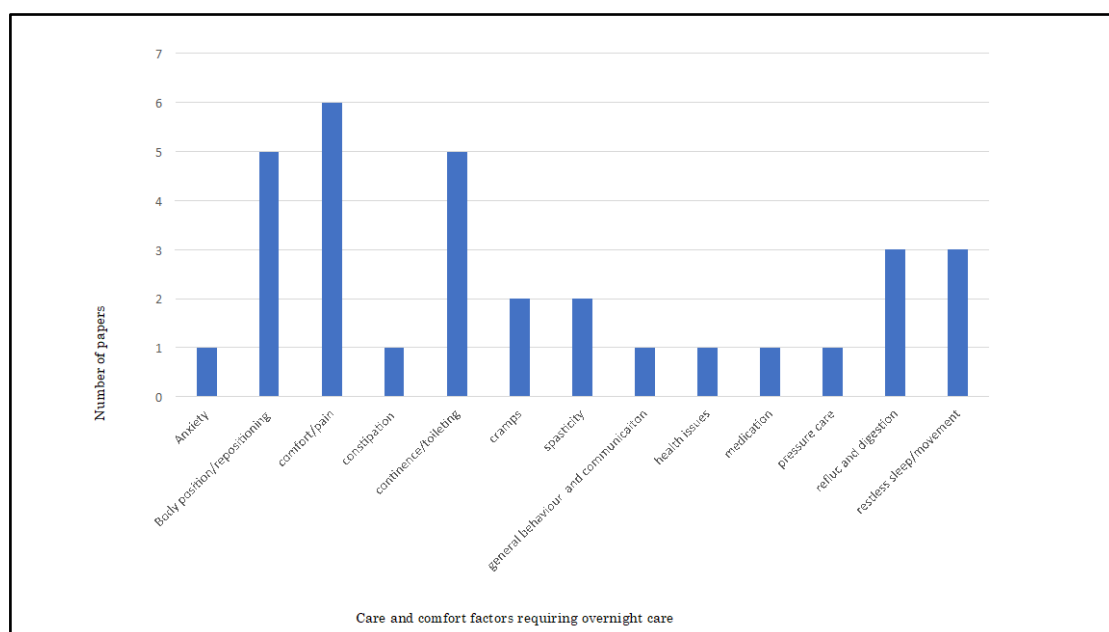


Figure 2-1 Current Literature: Care Need Linked to Sleep Concern

It is important to recognise that studies which limit their data collection to the commonly used validated sleep assessment tools, such as the Children's Sleep Habit Questionnaire (CSHQ)⁽⁸⁵⁾ and the Sleep Disturbance Scale for Children (SDSC),⁽⁷⁶⁾ will produce results that align with those tools. These results are broad descriptors of sleep problems. For example, on the CSHQ the broad descriptors are defined as the domains of: night-time waking, anxiety, parasomnias, sleep disorder breathing and bedtime resistance. This can be seen in the findings of the eight^(64, 65, 67, 70, 72, 76, 79, 82) studies that used validated sleep assessment tools alone. This highlights the need for research designs to consider the complexity of sleep

problems in CP, and the benefit of a multi-modal approach to research. This reinforces the mixed methods approach used in this thesis.

2.5 The Impact of Sleep Problems on the Caregivers (Parents) of Children with CP

Within all of the studies included in the review, the sleep of the child was the main focus. However, eleven^(64, 65, 68, 72-75, 78-81) of the 21 studies measured at least one aspect of how sleep problems may impact on the sleep of parents or caregivers of a child with CP. These studies provide insight into overnight care requirements. It is assumed and has been supported by these studies^(2, 64, 65, 68, 71, 73, 75, 78-80, 83, 86) that when a child is awake so is the parent. One study suggested⁽⁸³⁾ that some parents of children with physical disability are awake with their child even when their child is asleep. This highlights the importance of assessing the parent's sleep within research. Measuring the child's sleep alone may underestimate the impact of the sleep disturbance in the family. These studies also suggest that the impact of poor sleep on a parent can influence the parent's perception of their own health, increasing the likelihood of them reporting their own health as poor^(71, 81). Indeed, one study suggested this sleep disturbance may contribute to a parent's perception of the care of their child as burdensome.⁽⁶⁸⁾ These studies suggest that the sleep of parents is significantly affected by the poor sleep of the child. Indeed, Tietze⁽⁷⁸⁾ found that 71% of the parents of children with physical disabilities had a clinically significant sleep problem. The extent of night-time attention required is also high. Hemingsson et al.⁽⁸³⁾ found that almost 40% of their physically disabled cohort needed parental attention overnight and a staggering 10% needed support five times a night or more. The data captured in these studies emphasise the fact that the sleep of parents of children with CP is affected by the sleep of their child, and that this is an area that requires much greater exploration.

2.5.1 Bed sharing

Within the papers reviewed, six^(2, 64, 65, 71, 72, 78) specifically examined how many children with CP share a bed with a family member. The proportion of co-sleeping in these studies was significant. Newman⁽⁷²⁾ reported 9.2% of their cohort shared

a bed with their parents. This number jumps to 70% in the study by Adiga,⁽⁶⁴⁾ where 92% of the co-sleeping parents also reported disturbed sleep on the Pittsburgh Sleep Quality Index (PSQI), an adult sleep screening tool. The theory behind why the parents co-sleep with their child can be likened to a chicken and an egg theory. That is, it is unclear whether parents are sleeping with their children because their children sleep badly, or if the children are sleeping badly because their parents are sharing a bed with them. As previously discussed, children with CP often require attention overnight for repositioning. Sometimes a parent may choose to co-sleep with their child to minimise the disruption to their own sleep by repeatedly having to get up to their child. However, the reasons for bed sharing have not been investigated within any of the reviewed papers, which highlights a significant gap in the literature.

This section has demonstrated the small body of published research that quantifies the impact of a child's sleep problems and overall care needs on parents' sleep. It is important to understand how this reduction in sleep quality and quantity impacts on the quality of life and physical and mental health of the parents. The current evidence for this impact will now be presented.

2.5.2 Parent quality of life and mental health

Three^(78, 79, 82) of the 21 studies quantified the impact of sleep disturbance for parents of children with CP. Wayte⁽⁷⁹⁾ established that there was a correlation between poor sleep of mothers and higher depression scores. Tietze⁽⁷⁸⁾ found that the quality of sleep and quality of life for parents of children with severe psychomotor impairment were profoundly affected. Zuculo⁽⁸²⁾ specifically focussed on the relationship between quality of life and sleep disturbance, and found that low sleep quality negatively affects the physical and emotional wellbeing of these parents. Studies also reported that a child's sleep problem impacted on maternal irritability⁽⁷³⁾ and stress ^(73, 74). Whilst it is widely acknowledged that poor sleep has detrimental effects on physical and mental health, there are little data on what this means for parents of children with CP. Given the extra time demands for these parents, the impact of poor sleep may have a more significant impact. Once again, the small sample of published research that examines the effects of

sleep disturbance for parents of children with CP supports the Researcher's position that this area requires greater exploration.

2.5.3 The impact of sleep problems on the child with CP

Interestingly, within these 20 papers there are very little data that describe the impact of sleep problems on the child with CP. One study⁽⁷⁴⁾ found that sleep problems were associated with behavioural problems, and another⁽⁷³⁾ reported an association with irritability and lethargy. It is apparent that there are insufficient data about the impact of sleep problems for children with CP.

2.5.4 GMFCS and likelihood of sleep problems

The heterogeneity of the aims, method and analysis of the studies included in the review makes comparisons difficult, as each study used the GMFCS in slightly different ways. Eight^(2, 64, 65, 67, 69, 72, 76) of the 21 studies used GMFCS levels to classify the children. Nine of the studies that used the GMFCS used it to compare sleep between levels. Two studies^(64, 72) found no relationship between GMFCS level and sleep problems, which may be due to smaller sample size⁽⁶⁴⁾ and samples with uneven distribution of GMFCS level.⁽⁷²⁾

GMFCS levels IV and V describe greater severity of motor disability and it might be assumed that sleep problems would also be worse for children with more severe motor impairment. This assumption has been supported by several studies. A higher GMFCS has been associated with insomnia and sleep disordered breathing,⁽⁸⁴⁾ lower physical quality of life⁽⁶⁷⁾ and a higher total score on the sleep disturbance scale for children.⁽⁷⁶⁾ Svedberg et al.⁽⁷⁷⁾ found that 36% of the children within GMFCS level I-III had sleeping disorders, compared with 76% of those within GMFCS IV-V.

Perhaps the most detailed data in regards to GMFCS and sleep problems come from McCabe,⁽⁶⁹⁾ who performed a retrospective study of their in-home sleep clinic for children with CP. They reviewed 154 case files and matched type of sleep concern to GMFCS level. They found that 90% of children in GMFCS IV-V had issues with body positioning overnight, whereas 90% of those in GMFCS I-II had

issues with settling routines. Less than 50% of those in GMFCS IV and V had issues with settling routines and sensory responses. That is, the more ambulant children were more likely to have behavioural sleep issues, and those who were not independently mobile had more sleep problems related to physical causes. McCabe⁽⁶⁹⁾ emphasised that their cohort provided evidence that sleep problems are present across all GMFCS levels, however, the types of sleep problems differ.

2.5.5 Sleep interventions

None of the 21 studies focussed on identifying or developing interventions to improve sleep for children with CP and their parents. At the time of the review, there were no CP-focussed evidence-based interventions or published research on potential interventions.^(72, 76)

2.6 Summary

Overall, the quality of the research reviewed is poor to fair, and there is scope for larger scale, more rigorous research in this area. Importantly, there is a paucity of qualitative methods within these studies. A qualitative approach could provide greater insight into the context of sleep problems and seeking sleep solutions from healthcare providers. It can be concluded from the literature reviewed that children with CP who sleep poorly are likely to have parents who also sleep poorly. Poor sleep impacts on the quality of life and wellbeing of these parents and little is known about the impact of sleep problems on the child. Three of the 21 studies^(76, 78, 82) suggest that in order to effectively address sleep issues for children with physical disabilities, the use of in-depth interviews, rather than highly structured sleep screening tools, may capture more relevant data about the causes of sleep issues. The pilot study by Petersen⁽²⁾ suggested that qualitative data would enrich results and better inform the design of an intervention. These conclusions highlight the need for the research presented in this thesis, and the need for greater consideration of the impact of sleep problems on parents. Indeed, some studies have suggested⁽²⁶⁾ that interventions that reduce the stress experienced by caregivers of children with CP need to focus not just on the child

but also the caregivers. Decreasing the impact of the disability on the caregiver will in turn improve outcomes for the children.

CONCLUSION

Within Australia, over 8000 children born between 1995 and 2012 have been described as living with CP.⁽⁷⁾ Based on current evidence, it is likely that a significant portion of these children experience sleep problems. In order to optimise health and wellbeing, sleep needs to be of good duration and quality. The preceding review of the literature has demonstrated the correlation between CP and sleep disturbance, and that children with CP are more likely to experience sleep disturbance than their typically developing peers. The parents of children with CP also have poor sleep and are more likely to have anxiety, depression, poor health or a poor perception of their own health. There is evidence to suggest that children with CP wake because of care and comfort requirements. However, there is a lack of evidence on how sleep quality and duration might be improved for children with CP and their caregivers. The 21 papers reviewed in this chapter provide important preliminary information and have demonstrated that the causes of sleep disturbance are complex and its impact is multi-layered. This review confirms that more evidence about the causes and impact of sleep disturbance for children with CP and their parents is needed. Without this, an intervention is unlikely to adequately address the significant differences in the clinical presentation of CP. There is great variability in diagnosis, phenotype and management of CP, which may result in gaps in care for sleep problems and also creates difficulty in designing clinical interventions. This review reveals a significant clinical issue that requires greater exploration through robust research. The proposed study will address this significant gap in this very important field of research.

3 THEORETICAL FRAMEWORK AND RESEARCH DESIGN

INTRODUCTION

This chapter presents the theoretical framework for the thesis, incorporating the worldview of the Researcher, the underpinning philosophical approach and the research design. Firstly, the position of the Researcher within the study is described. A sequential exploratory multiphase mixed methods design was chosen for this study. The details and rationale for this design choice are explained. Next, this chapter provides a succinct introduction to critical social theory (CST), its history and core concepts. Finally, the chapter concludes by describing how CST was applied to the design of this study.

3.1 Position of the Researcher

Within qualitative research, it is important to understand the position of the researchers in relation to the research topic. Berger⁽⁸⁷⁾ states that many characteristics of the researcher, including race, gender, personal ideologies, politics and biases, can influence how research is conducted. That influence

may occur in one of three ways: access to the research field, the nature of the researcher-researched relationship, and the worldview and background of the researcher as the lens through which the research is conducted.

The Researcher conducting this study is a forty-year-old, Caucasian, cis female, lesbian, mother of two typically developing children, who holds a clinical role as a nurse consultant with extensive clinical experience caring for children with CP and their families, both in acute care and ambulatory care environments. The Researcher is a feminist, working class academic with politics and ideologies that closely align with socialism. The Researcher also aligns to the social model of disability, has actively campaigned for a more inclusive healthcare system, and advocates for equity and equality for all, especially those living with a disability. Creswell⁽⁶³⁾ describes that all research is underpinned by philosophical assumptions and these assumptions inform how the research is conducted, from data collection to analysis and interpretation, and it is essential for the researcher to acknowledge their worldview (synonymously known as a paradigm). Creswell⁽⁶³⁾ claims that there are four main worldviews that underpin research. The Researcher of this thesis project aligns most closely with the Transformative worldview, which values activism, empowerment and emancipatory change. Within qualitative research, researchers often articulate an epistemological approach (the relationship of knower to known⁽⁸⁸⁾) and an ontological approach (the nature of reality⁽⁸⁸⁾) approach. The Researcher of this thesis is a feminist and experienced nurse with a pragmatic approach to research, and she respectfully declines to choose one epistemological or ontologic paradigm.

3.2 Introduction to Study Design

A multiphase exploratory sequential mixed methods design was chosen for this thesis. The design was qualitatively driven, that is, the qualitative phases were prioritised. Creswell⁽⁶³⁾ presents a notation system for describing mixed methods designs. Qualitative is represented by ‘qual’, quantitative by ‘quan’, and the use of capitalisation represents the priority of the study. A ‘→’

represents that the methods occur in that sequence. According to the notation system of Creswell,⁽⁶³⁾ the mixed methods design for this study is:

$$\text{QUAL} \rightarrow \text{quan} \rightarrow \text{QUAL}$$

Phase One consisted of qualitative one-on-one interviews with parents of children with CP aged 6-12 who self-reported sleep problems for their child. The thematic analysis from this phase, and parent opinions and preferences for survey design, informed the design of the second and third phases of the study.

Phase Two of the study was a web-based quantitative survey, which included two validated sleep screening tools. The sleep screening tools, demographic questions, and questions about the parent's experience of sleep problems and accessing sleep solutions, were all chosen based on the findings of Phase One.

Phase Three of the study was a follow-up qualitative phase to Phase Two. Participants from Phase Two who consented to be contacted were invited to participate in a qualitative interview. The interview further explored parents' experiences of their child's sleep, based on survey responses and the study research questions.

The three phases of this study were then synthesised and a mixed methods interpretation was applied via a joint display table.

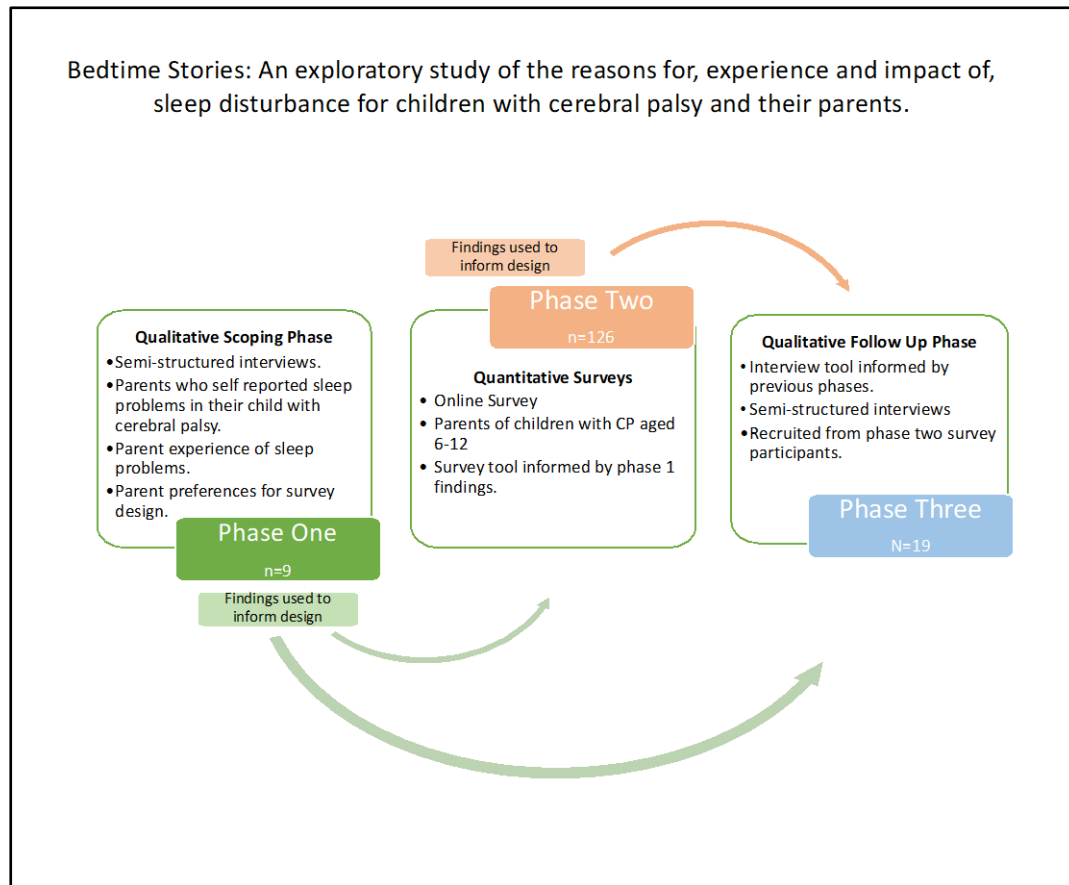


Figure 3-1 Study Research Design

3.3 Rationale for Mixed Methods Design

Johnson⁽⁸⁹⁾ describes the three research paradigms: qualitative, quantitative and mixed methods. In mixed methods research, the values of both qualitative and quantitative viewpoints are respected and incorporated when answering a research question.⁽⁸⁹⁾ Some research purists would argue that qualitative and quantitative methods are incompatible because of their respective approaches.⁽⁹⁰⁾ Alternatively, mixed methods research has been described as ‘methodological eclecticism’; selected elements of both qualitative and quantitative designs can be applied in order to appropriately answer the research question.⁽⁹⁰⁾ A mixed methods design allows for the synthesis of both qualitative and quantitative data and creates an interpretation of the research problem through this synthesis of multiple viewpoints. Within the context of a

health-based research question, a mixed methods approach considers both the health problem itself and the social and cultural context of that problem.⁽⁹⁰⁾

A mixed methods approach was used in this study to explore both the type and frequency of sleep problems in children with CP and their parents (quantitative), and the impact and experience of sleep problems and strategies used to find solutions for them (qualitative). A mixed methods approach is often used when the project is exploratory, where there is little already known about a topic.⁽⁶³⁾ Creswell⁽⁶³⁾ also highlights that mixed methods research is appropriate when complete and corroborated results are required. Qualitative data can provide a rich and in-depth understanding of the topic, in context, whilst quantitative data enables breadth and maximises potential generalisability. A key advantage of mixed methods research is that it harnesses the strengths of both qualitative and quantitative methods whilst mitigating their weaknesses.⁽⁶³⁾ As others have recognised,^{(63)p23} using both qualitative and quantitative methods of data collection enables a 'more complete' data set. Fetter and Freshwater ⁽⁹¹⁾ eloquently describe the combination of qualitative and quantitative components of mixed methods research as similar to the equation $1+1=3$. They explain that the integration of mixed methods allows for the assumptions of either method to be explored. Hence, this mixing of methods allows for a true triangulation of different types of data, and creates, in a sense, a third perspective: the sum of the two types of data merged.

3.3.1 Qualitative considerations: The experience of sleep problems and solution seeking

As previously discussed, sleep is heavily influenced by biological, sociological and socioeconomic factors. The nuances of choices around sleep, parenting, sleep routines and seeking sleep solutions for children and parents are often private and personal. There are no published data in regard to the prevalence of sleep problems in Victorian children with CP. The quantitative arm of this study allowed for the frequency of sleep problems for children with CP to be

examined. These data not only strengthen the understanding of the problem, but also provide evidence on the broader applicability of the qualitative findings of this study. Within clinical research, especially in the context of clinical care of children with CP, there is a prevailing focus on quantitative research to understand a clinical problem. This lean towards a positivist research can be reductionist and fail to recognise the complexity of poorly understood health issues, such as sleep problems. As has been outlined in previous chapters, sleep issues are a clinical/health problem but also heavily influenced by culture, parenting, behaviour and psychology. A mixed methods approach enables sleep problems and the context in which they occur, along with the impact that they have on families and the children themselves, to be explored. The deductive nature of quantitative methods limits the ability to explore these issues. The data acquired by quantitative methods alone are limited to the assumptions of the researcher or the research tools used. Consequently, the exploratory nature of this study dictated that qualitative methods should also be used. Even so, a quantitative survey was also an essential component of this study.

3.4 Design Mixing

A key component of mixed methods research design is how and where the different types of data are mixed. How this mixing occurs is debated amongst most methods researchers.⁽⁸⁹⁾ Mixing may occur at the time of data collection, data analysis or across all stages of the research.⁽⁸⁹⁾ Within this study, the mixing of qualitative and quantitative methods occurred in three main areas:

- i. The qualitative findings of Phase One were used to inform the design of Phase Two and Phase Three; findings of Phase Two were used to inform Phase Three.
- ii. The quantitative Phase Two was the source of recruitment for participants in qualitative Phase Three. Phase Three explored and expanded upon the survey answers provided in Phase Two.

- iii. The overall study findings integrated qualitative themes and quantitative results. This mixed methods interpretation generated discussion, recommendations and conclusions based on how the different data sets matched or contradicted, whilst also exposing what is absent from the study findings and the meaning of this absence.

3.5 Critical Social Theory: A Brief Introduction

Despite its name, critical social theory (CST) is not a clearly defined theory. Critical social theory is described as a collection of theories and perspectives that are adapted as needed, in order to create change.⁽⁹²⁾ It is not within the scope of this thesis to present a comprehensive summary of all iterations of CST. Rather, a succinct summary of the history and core features of CST and how it was applied to this thesis will be provided. Critical social theory was selected as the theoretical framework of this study as it enabled an understanding of how the historical and sociological factors, systems and structures of the research location (Victoria, Australia) might influence the experience of sleep problems and how sleep solutions are sought by parents of children with CP. It is the premise of CST that understanding these factors and then addressing them will enable transformative change towards the deconstruction of inequalities identified.⁽⁹³⁾ Within this thesis, CST informed the study design and was a lens through which the data were analysed. When selecting the theoretical framework for this study feminist theoretical perspectives were also considered by the Researcher. For the reasons already presented, CST was chosen as the preferred theory cluster due to its flexible and pragmatic approach.

3.5.1 History of critical social theory

Critical social theory originated in the 1920s and 1930s, and was primarily associated with academics at the Institute for Social Research in Frankfurt, Germany,⁽⁹⁴⁾ commonly referred to as the Frankfurt School. The Frankfurt School was known for being the first to use traditional research techniques,

such as surveys, in social research testing Marxist theories.⁽⁹⁵⁾ The founding theorists of the school, Horkheimer, Adorno and Marcuse, are referred to as neo-Marxists.⁽⁹⁵⁾ Marxism, a social theory developed by theorist Karl Marx, emerged in reaction to the rapid rise of capitalism, in an attempt to deconstruct capitalism and its associated inequalities.⁽⁹⁶⁾ Marxist theory focuses on class struggle and its contribution to inequality in society. It is concerned with the influence of economic systems and it particularly challenges the influence of capitalism.⁽⁹⁷⁾ Marx's theory centres around two main social classes, the 'bourgeoisie', as the smaller, wealthier class that owns and controls the means of production, and the 'proletariat', or working class who are dependent on the bourgeoisie for employment and income.⁽⁹⁶⁾ The power imbalance between these social classes, whereby the wealthy class exploits the working class for labour whilst becoming wealthier, and the consequences of this imbalance, are the central focus of Marxist theory.⁽⁹⁶⁾

Jurgen Habermas is recognised as the 'father' of contemporary CST.⁽⁹⁴⁾ Habermas, a German philosopher and a postgraduate student of the Frankfurt School, revised CST in the 1960s to ensure that it remained relevant to society as it evolved.⁽⁹⁵⁾ Habermas sought to adopt the concepts of Marx, broadening Marx's specific view that power is class based⁽⁹⁸⁾ to encompass a more varied and broad approach of analysing social, cultural, political and economic influence on equalities.⁽⁹⁴⁾ Within Habermas' theory, CST moved away from the strictly class-based and capitalist view of power ascribed to by orthodox Marxism. Kincheloe and McClaren⁽⁹²⁾ explain that CST contrasts with Marxism in that it considers all forms of power in addition to economic power, including racial, gender and sexual power. Morrow^{(95)p14} describes these founding critical theorists as the first to recognise the influence of social science when exploring a research problem, stating that "...critical theory proposed that an alternative conception of social science was required, one that could grasp the nature of society as a historical totality, rather than as an aggregate of mechanical determinants or abstract functions."

Since the work of Habermas, many social theorists have been linked to CST, including Touraine, Bourdieu and Foucault.⁽⁹⁵⁾ Today, CST is recognised as a ‘theory cluster’, with many theorists and iterations, rather than a prescriptive theory as such.⁽⁹⁵⁾ The core tenets of CST are outlined in the following section.

3.5.2 What is critical social theory?

Critical social theory recognises that there are dominant structures within cultures, systems, and society that create inequalities, and proposes that these inequalities are perceived as natural, due to the embedded nature of the dominant structures.⁽⁹⁴⁾ Critical social theory is the critical analysis of these dominant structures in order to understand what needs to be changed to address power inequalities.⁽⁹⁴⁾ Critical social theorists argue that modern societies perpetuate oppressive structures by promoting one dominant way of thinking.⁽⁹⁴⁾ Critical social theory has been described as connecting the micro-dynamics of the everyday with the macro-dynamics of structures.⁽⁹²⁾ Critical social theory attempts to understand how a person, group or society engages in these dominant structures, even though this engagement is not to their benefit or interest.⁽⁹⁴⁾ Browne^{(98)p29} synthesised the basic assumptions of CST:

- i. *No knowledge is value free, it is all known within human conscience*
- ii. *All knowledge is mediated by social and historical power relations*
- iii. *Every social order entails some forms or power domination*
- iv. *Language is central to the creation of knowledge and formation of meaning*
- v. *Mainstream research generally maintains and reproduces (however unwittingly) systems of race, class and gender oppression*
- vi. *Facts (or truth claims) can never be separated from the domain of values or forms of ideological inscriptions*
- vii. *By explaining and critiquing the social order, critical social science serves as a catalyst for enlightenment, empowerment, emancipation and social transformation*

- viii. *Critically oriented knowledge should offer cultural critiques with a view to transforming normative foundations that maintain the status quo.*

Most contemporary writings on CST include the preface that CST is not a delineated theory with prescriptive guidelines or concepts.^(92, 95, 98) As such, a definition of CST cannot be presented. Instead there are many descriptions of what constitutes CST and its core characteristics. For the purpose of this thesis, the following paragraph by Kincheloe and McLaren^{(92)p299-300} aligns most closely with this body of work's interpretation of what CST is:

...all thought is fundamentally mediated by power relations that are social and historically constituted; that facts can never be isolated from the domain of values or removed from some form of ideological inscription; that the relationship between concept and object and between signifier and signified is never stable or fixed and is often mediated by the social relations of capitalist production and consumption; that language is central to the formation of subjectivity (conscious and unconscious awareness); that certain groups in any society are privileged over others and, although the reasons for this privileging may vary widely, the oppression that characterizes contemporary societies is most forcefully reproduced when subordinates accept their social status as natural, necessary, or inevitable; that oppression has many faces and that focusing on only one at the expense of others (e.g., class oppression versus racism) often elides the interconnections among them; and, finally, that mainstream research practices are generally, although most often unwittingly, implicated in the reproduction of systems of class, race, and gender oppression.

How this interpretation of CST has been applied to this thesis will now be discussed.

3.6 Critical Social Theory as it is Applied to this Thesis

Critical social theory focuses on the complex social and historical systems and structures that contribute to power imbalances and domination.⁽⁹⁵⁾ The purpose

of the theory is to understand these factors and focus on how they may be altered or assuaged to create transformative change. Critical social theory was applied to this thesis in three key ways:

- i. The design of the research methods: data from the participants' experience were used to inform the design of subsequent phases of the study.
- ii. A lens for analysis: data obtained in this study were analysed and interpreted through the lens of the principles of CST.
- iii. The recommendations and conclusions of this thesis were designed around the research outcomes in relation to power imbalances, inequalities and structural dominations that contribute to sleep problems for children with CP and their parents.

3.6.1 Participant engagement as an aspect of applied CST

Within Phase One of this thesis (semi-structured qualitative interviews), the key aim was to compare the experience of the Researcher, as a clinical nurse consultant who works within a Victorian hospital, to the experience of the participants. The experience of the participants was used to inform the subsequent design of and lines of enquiry for Phases Two and Three of the study. Specifically, they were asked their perceptions and preferences of sleep screening tools and various questions about survey design, such as type of question and survey length. This consultation process was chosen as it reflects core concepts of CST: to engage stakeholders and to provide a voice to those for whom the research aims to service. This consultation also distributes power: research is often designed based on the knowledge and experience of the researchers alone and this didactic approach fails to consider the experience of the participants and may be perceived as a form of oppression in itself. Freeman⁽⁹⁴⁾ describes CST as often adopting a participatory approach. Stakeholders are engaged to reflect on social, economic and political systems, and these perspectives are used to develop new ways of conceiving the meanings of those systems.⁽⁹⁴⁾ Phase One of this study collected the experiences and

opinions of nine mothers who self-identified that their children had sleep problems. The data collected from these mothers were analysed through the lens of CST, power imbalances and inequities were understood, and that analysis was applied to the design of subsequent phases of the study. That is, the participants did not directly inform the study design, but an interpretation of their collective experience was applied to the study design.

An outcome of this research was to understand the system and power dynamics that may influence a parent's ability to access affective sleep solutions. This study did not assume error or blame on the part of the medical/clinical/healthcare systems. It did aim to uncover the often-unrecognised socio-cultural barriers within systems, whatever they may be, in order to instigate transformative social change. Freeman⁽⁹⁴⁾ notes that CST does not have an automatic bias towards the less powerful, but as the main purpose of CST is to achieve social justice, it inherently leans towards implementing change for those who are less powerful. Within the sphere of most clinically situated research, neutrality is a tightly held stance. However, as Kincehloe and McLaren^{(92)p300} state, critical researchers tend to *"frequently announce their partisanship in the struggle for a better world"*.

3.6.2 Creating emancipatory knowledge

Emancipation is commonly recognised as a key outcome of CST when the theory is applied to a specific social issue.⁽⁹⁸⁾ This emancipation occurs by balancing unequal power relations and reducing domination within systems.⁽⁹⁸⁾ An outcome of this thesis is the production of knowledge that could contribute to the emancipation or empowerment of the parents of children with CP who have sleep problems. A secondary outcome of this thesis is that the knowledge generated by this study could be applied to the reduction of the hypothesised power imbalances that occur for parents of children with CP. Again, emancipation as a concept in clinically based research is often avoided for fear of being labelled political. However, if the purpose is to expose the inequalities

in systems and power imbalance for vulnerable groups, this research must align itself to those aspirations and affiliations.

3.6.3 CST as a lens for data analysis

The qualitative phases of this study were analysed using the thematic analysis technique of Braun and Clarke.⁽⁹⁹⁾ During the analysis, CST was used as a lens. Specifically, the codes/nodes were considered in the context of systems – the parents/caregivers, their experience of sleep problems, accessing sleep solutions and help from their healthcare teams. The core tenets of CST were used as a guide for the formation of themes – how the systems may influence parents' experience, how they might be oppressed and how false truths may lead them to the status quo. The quantitative phase of this research was designed with the core concepts of CST applied. Survey questions included socioeconomic factors, and the parents were also asked for information about how and from whom they had accessed sleep solutions. Thus, CST was embedded within all aspects of this project design and analysis.

3.6.4 Applying the research outcomes for transformative change

As discussed, the parents' experiences of the healthcare system, in relation to seeking solutions for sleep problems or other health issues, were explored as part of this thesis. This exploration considered recognised or unrecognised dominance or oppression, false truths, and inequalities of healthcare provision for children with CP and their parents. The systems within which the participants engaged were analysed in order to understand how positive change might be made. Dant⁽⁹⁷⁾ explains that the purpose of CST is not to free people from violence or physical bondage, but to provide people with the freedom to live life to the full. This thesis aims to create knowledge that will inform an intervention that optimises sleep, which could enable parents to attain greater physical and mental resources to live a full life. Dant⁽⁹⁷⁾ goes on to argue that social transformation comes about only by changing the understanding of how societies work and changing them from within. As a clinician researcher who

works within the clinical area of care of children with CP, who will use this position to implement the intervention, it is hoped that the evidence generated from this thesis will be used as a catalyst for clinical and systems change.

CONCLUSION

This chapter has described the overall study design and provided a rationale for why a mixed methods sequential study design was chosen. It has explained the value of using mixed methods to provide context and nuance to a complex and under-researched topic of enquiry. The chapter has also described how the core tenets of CST were applied to the study design, data analysis and research outcomes. The methods of the three phases of this study are presented in Chapters Six and Nine.

4 A BRIEF HISTORY OF DISABILITY DISCOURSE, POLICY AND WELFARE IN AUSTRALIA

INTRODUCTION

This chapter provides a brief synopsis of the historical background and significant events that have contributed to the establishment of current social structures and systems that support the subjects of this thesis: children with cerebral palsy (CP) and their parents. The history of the social construct of disability in Australia from the time of the British invasion in 1788[§] will be presented. From a critical social perspective, this chapter will chronologically describe how the concept of disability has been perceived in the last two centuries, with a particular focus on the health and social welfare changes that

[§] The Researcher would like to acknowledge the traditional owners of this land and recognises that this land has an ancient, rich and complex history prior to white invasion in 1788. The scope of this chapter is limited to the time of white invasion.

have occurred in the state of Victoria. As discussed in Chapter Three, the main principle of critical social theory (CST) is to understand the events that have influenced social structures and systems in order to create positive change and address inequalities.⁽⁹⁸⁾ This chapter concludes with a description of the current systems and supports that are available for parents of children with a significant disability in Victoria today.

4.1 The Social Construct of Disability

The definition of what constitutes disability has changed over time and is heavily dependent on context. Indeed, Earl^{(100)p86} states that “*disability, like other cultural categories, is fluid and historically contingent, subject to change, resistance and contestation.*” Kudlick⁽¹⁰¹⁾ argues that disability is not a medical diagnosis but actually a social category, similar to race, gender and class.⁽¹⁰¹⁾ Culturally, the concept of disability has been ever-present. Aristotle, the ancient Greek philosopher, created an ideological concept of a perfect human body. This body type was both aspired to and admired. Disability, by not conforming to that ‘perfect’ image, was by default defined as an imperfection.⁽¹⁰¹⁾ Religion provided an alternate view: disability was often constructed as a punishment or consequence of wrongdoing. The Old Testament of the Bible, the basis of Jewish and Christian faith, suggests that disability is a blemish, meaning the person is spiritually unclean.⁽¹⁰²⁾ Conversely, the Old Testament also indicates that disability should be considered a reminder to those without disabilities to be compassionate.⁽¹⁰²⁾ Within many religions, disability has been viewed as honourable; having a disability is regarded as suffering in the name of a god, which generates a purpose for teaching others.⁽¹⁰³⁾ In Western societies and the context of healthcare, the meaning of disability can be framed within the bio-medical model. In this model, disability is viewed as a diagnosis, a variation from a ‘normal’ or healthy body. Disability has traditionally been regarded as a medical problem to be cured.⁽¹⁰³⁾

Whichever lens is used to view disability, it is frequently perceived as being outside the concept of 'normal', resulting in those with a disability being seen as 'other',⁽¹⁰³⁾ thereby leading to exclusion. Historically, this 'othering' of those with a disability has resulted in segregation from mainstream society, and the associated stigma has led to widespread discrimination. In an extreme example, the medical construct of disability as abnormal has been associated with the concept of eugenics. The eugenics ideology emerged in the early nineteenth century. It was based on the concept that the human race could be improved via encouraging those with desirable traits to reproduce, and controlling or preventing the reproduction of those with undesirable traits. In some cases, this included sterilising those with a disability against their will.⁽¹⁰⁴⁾ From this very brief synopsis of the different ways disability can be constructed, and the subsequent societal changes that occur because of these constructs, it is clear that disability as a concept is indeed fluid and contingent on many societal and cultural factors.

4.2 The History of Disability in Australia

English explorers invaded Australia on January 26, 1788, and immediately commenced the task of establishing a British colony. The newly established country of Australia inherited the British colonial perception of disability.⁽¹⁰⁴⁾ The white colonisation of Australia coincided with the dawn of the industrial age, a time when people's ability to work and earn an income was prioritised. Those with a disability were perceived as worthless as they were unable or less able to engage in paid work and as such, were viewed as unproductive and a drain on resources.⁽¹⁰⁵⁾ Consequently, the definition of disability was indivisibly linked to one's ability to work and earn a wage.⁽¹⁰⁶⁾ Indeed, Barnes⁽¹⁰⁶⁾ has noted that at the time of the industrial revolution, disability was, by definition, the inability to work and earn a living. Those who were unable to work because of

disability ('idiots' **), mental health ('lunatics'**), or illness or old age ('invalids'**), were often stigmatised and segregated.⁽¹⁰⁴⁾

Individuals with severe disabilities were segregated by being involuntarily admitted to residential institutions where they would live for their lifetime, more often than not permanently separated from their birth families. Clapton⁽¹⁰³⁾ has powerfully described this segregation as the equivalent of a 'social death', as the person with the disability no longer lived in or had contact with everyday society. The purpose of these institutions was to separate those with severe disabilities from general society, providing 'cradle to grave' care, and to free their families of the burden of looking after disabled family members. It has been reported that parents, following the birth of their disabled child, were advised to 'forget about the child' and surrender the care of the child to an institution.⁽¹⁰⁷⁾ It is likely that parents did not find this decision an easy one. However, parents had little alternative as social supports for people with a disability were extremely limited.⁽¹⁰⁷⁾

In Britain, the first institution to provide permanent care for those with a disability or severe mental health issue was the London Bethlehem Royal Hospital.⁽¹⁰⁴⁾ The hospital was built in 1337, highlighting the lengthy history associated with disability and segregation. The first such institution in Australia was the Castle Hill Lunatic Asylum, built in New South Wales in 1911.⁽¹⁰⁴⁾ In Victoria, the first institution for those with disabilities was the Yarra Bend Asylum, built in 1848. Later, in 1887 the Kew Idiot Colony (later known as Kew Cottages) was built for the care and support of children with disabilities in Melbourne. It is important to note that at this time, there was little differentiation between the mentally ill ('insane') and those with disabilities. Therefore, institutions would be homes to both groups of people. Indeed, up until 1959, young children, even infants with disabilities, were required to be diagnosed as 'insane' by two doctors in order to gain admission

** This language is stigmatising and offensive. It is only included in this thesis to for accuracy and to demonstrate historical context.

to Kew Cottages.⁽¹⁰⁸⁾ Kew Cottages (for those with a disability) and Kew Mental Hospital (for the mentally ill) separated from each other in 1952.⁽¹⁰⁸⁾ In 1959, the *Mental Health Act* was passed which allowed parents to voluntarily admit their children into permanent residential care.⁽¹⁰⁸⁾ It was not until 1986 that separate legislation, the *Intellectually Disabled Person's Services Act*, was passed by the Victorian government. These two pieces of legislation marked the recognition of the differences between individuals with mental illness and those with disabilities.

The use of institutions for the lifetime care of those with a significant disability eventually resulted in a secondary gain, in financial terms, for the institutes and their administrators.⁽¹⁰⁸⁾ With the aim of providing training and development, administrators engaged the residents of Kew Cottages to perform unpaid work, such as cleaning and gardening. Because the employment of staff to do this work was no longer required, residents were seen as a valuable and profitable resource, perhaps even making the Cottages self-supporting.⁽¹⁰⁸⁾ This boosted the sustainability of Kew Cottages and the motivation to house more residents,⁽¹⁰⁸⁾ which resulted in the significant growth of the residential population from 57, when Kew Cottages first opened, to a peak of 948 residents in 1968. At this time, it was Australia's largest institution for those with intellectual disabilities.⁽¹⁰⁸⁾

The growth of Kew Cottages was not without issue. Reports of exploitation, maltreatment and poor working conditions for the residents emerged. As early as 1937, journalists reported on what they considered was exploitation. In response, the medical superintendent stated that "the employment was necessary and desirable for the contentment of patients".⁽¹⁰⁸⁾(p90) In the late 1940s, there was increasing concern about institutional care, and parents of children with a disability began to form advocacy groups to improve conditions. The work of these parents contributed to the reframing of the construct of disability in the Australian context.⁽¹⁰⁰⁾ Motivated by the substandard level of care in residential homes, parents joined together to protest standards and to

lobby government for change.⁽¹⁰⁰⁾ At this point in time, volunteer and philanthropic groups such as Lions and Rotary Clubs emerged, and they were enlisted by parent advocacy groups to financially support their cause. This ‘new voluntarism’, as described by Earl⁽¹⁰⁰⁾, resulted in community groups and charities becoming enmeshed in the support of disability care. That is, charities and philanthropists were expected to assist in funding the provision of disability care.⁽¹⁰⁰⁾ This trend continued to the present day. Not-for-profit and non-government organisations often fill gaps in care and support not addressed by government-provided welfare or supports.⁽¹⁰⁰⁾

In the 1980s, the case of Anne McDonald and her experience of institutional care emerged. Anne was born in 1961 with severe CP. She was sent to permanently reside in St Nicholas Hospital in Carlton, Victoria. Anne was unable to communicate verbally; the staff of the hospital assumed that she had no ability to communicate at all. However, Rosemary Crossley, who worked at the hospital, discovered that Anne was capable of communication. At the age of 16, Anne launched a *habeas corpus* action in the Supreme Court of Victoria against the Health Commission in order to win the right to leave the institution. Anne went on to complete high school and graduate from university. In 1980, her life story was published as a book titled *Annie's Coming Out*,⁽¹⁰⁹⁾ which was subsequently made into a film⁽¹¹⁰⁾ in 1984. The book and film revealed the neglect and abuse Anne suffered as a resident of the St Nicholas Hospital. Anne's story was considered to be representative of the experience of children with severe physical disabilities who were committed to permanent residential care. Until her death in 2010, Anne continued to be a disability activist. The sharing of her powerful story contributed to an increasing change in the perception of disability and drew significant attention to the negative experience of living in an institution.

Another significant social change that influenced disability discourse was the United Nations' *Universal Declaration of Human Rights*.⁽¹⁰⁴⁾ This was enacted in 1948 and was the catalyst for many civil rights movements. This declaration

recognised human freedom, human potential and equality. Australia was a founding member of the United Nations and was one of eight nations involved in the drafting of the declaration. This was a significant marker of Australia's progressive approach to human rights, including disability.

By the 1970s the reputation of institutional care in Victoria was damaged. Simultaneously, Australian society began to embrace the concept of normalising disability, or enabling those with a disability to engage in everyday ordinary lives within the community, as those without disability do. This concept of normalisation, which is now mainly accredited to the work of Wolfensberger,⁽¹¹¹⁾ embraces the concept of integration rather than segregation. Essentially, it is the antithesis of institutional care. Indeed, the introduction of this concept in the 1970s is understood as the beginning of the disability rights movement.⁽¹⁰⁷⁾ Support for institutional care began to lose momentum and alternative systems were proposed. The public view of how to care for those with a disability started to shift. In 1977, the Victorian Committee on Mental Retardation^{††} recommended that care for those with intellectual disabilities move away from institutions. The concept of normalisation had grown in popularity. Thus, community attitudes and government policy shifted away from institutional care whilst institutions were struggling with damaged reputations, which created a level of risk for their administrators.

According to Soldadtic,⁽¹¹²⁾ it was not until the Whitlam government and the introduction of the *Handicapped Person's Welfare Act* in 1974 that the federal government legislated to support people with a disability. This act funded the provision of facilities and services for persons with disabilities. Prior to this, the responsibility was provided in a piecemeal approach through institutions and charities. It was around this time that the dismantling of institutional care began to be woven into policy. In 1984, St Nicholas Hospital was closed and the residents were moved into community housing. This closure was the first of its

^{††} This language is stigmatising and offensive. It is only included in this thesis to demonstrate historical context.

kind in Australia.⁽¹⁰⁸⁾ Community housing was embraced as a concept and became a new way to care for adults with disability. It was also thought that community housing would result in cost reductions compared to the running of large facilities.⁽¹⁰⁷⁾ Typically, community housing was staffed by untrained carers, as opposed to medical or nursing staff working in the larger institutions, with up to seven residents in any one house.⁽¹⁰⁷⁾

The dismantling of institutional care meant that young children with severe disability were no longer admitted to institutions for life, but were cared for at home by their parents (usually their mothers). The help of state and community services was enlisted to provide additional support and care for these children. This community engagement included educating children with a disability either within mainstream schools or at schools that specialised in the education of children with a disability, known as ‘specialist schools’. Specialist schools have become part of community care and support for children with moderate to severe disability, and often provide the children and their families with community links to allied health and nursing professionals, in addition to meeting educational and developmental needs. A 2009 report from the Australian Bureau of Statistics (ABS)⁽¹¹³⁾ revealed that in Victoria, the majority of children with a disability attend a mainstream school (65.9%), some attend special classes within a mainstream school (24%), and others attend a separate specialist school for children with a disability (9.9%). These statistics indicate how Victorian children with disabilities are educated, with most being integrated.

It is also important to recognise that the move away from medically run institutions removed some elements of the medicalisation of disability. That is, the move from institutional care to community care removed responsibility for care from an exclusively medical role, distributing the responsibility to many agents throughout the community.⁽¹⁰⁷⁾ However, the medical system, especially the role of doctors in diagnosis and as gatekeepers to many disability services, remained.

In the 1990s, two significant disability policies were introduced. In 1992, the *Disability Discrimination Act* was passed. This act legislated against discrimination based on a disability and provided the framework for complaints and conciliation for disability discrimination.⁽¹⁰⁵⁾ This was a momentous move by the Federal government, representing a significant change in the perception of disability in Australia. The *Commonwealth Disability Strategy* was introduced in 1994. This strategy aimed to empower persons with disabilities to achieve economic and social participation.⁽¹⁰⁵⁾ These policies highlight the government's shift towards the social model of disability and away from a purely medical focus on disability. Thus, throughout the 1980s and 1990s, more and more legislation was written to support the autonomy and equality of persons with disabilities and the enactment of this legislation represented a significant change in attitudes towards disability.

4.3 Social Construct of Disability Today

As has been described, the disability rights movement emerged and gained momentum in Australia from the 1970s. This momentum was driven by the increased visibility of people with a disability in popular culture and the work of disability advocates. Most recently, activists living with a disability, such as the late Stella Young, a writer, comedian and social commentator who had a diagnosis of Osteogenesis Imperfecta, have had significant influence. Stella was wheel-chair dependent, short in stature and was most well known for her TED talk on disability, titled *I Am Not your Inspiration, Thank You Very Much*,⁽¹¹⁴⁾ which challenged common perceptions of disability. Stella's wit and insight further contributed to the shift in perception of disability:

That quote, 'the only disability in life is a bad attitude', the reason that's bullshit is... no amount of smiling at a flight of stairs has ever made it turn into a ramp. No amount of standing in the middle of a bookshelf and radiating a positive attitude is going to turn all those books into braille.⁽¹¹⁴⁾

The voice of Stella Young gained the attention of social media and her trailblazing work lead the way for other visibly disabled activists, such as Dylan Alcott, Carly Findlay and Jax Jacki Brown, who are now commonly featured in Australian media. The increased popularity of events, such as the Paralympic games,⁽¹¹⁵⁾ and the inclusion of children with visible disabilities such as Down syndrome in department store catalogues,⁽¹¹⁶⁾ all represent a significant change in attitude and the social construct of disability within Australian culture.

4.4 Two Dominant Models of Disability

The history of disability described above, and the work by disability advocates and activists, has given rise to two main models of disability: the medical model and the social model. It should be noted that there is a large body of work that discusses and critiques the social construct of disability and numerous models of disability. It is not relevant, nor possible, within this thesis to present all known models of disability; only the two most dominant models will be discussed. The table below from Haegele and Hodge⁽¹¹⁷⁾ describes the key differences between these two models.

Topic	Medical Model	Social Model

<i>What is disability?</i>	An individual or medical phenomenon that results from impairments in body functions or structures; a deficiency or abnormality	A social construct that is imposed on top of impairments by society; a difference
<i>Access to treatment or services</i>	Referral by diagnosis	Social referral, experience driven
<i>Outcome of interventions</i>	‘Fixing’ the disability to the greatest extent possible, ‘normalising’	Social or political change in an effort to decrease environmental barriers and increase levels of understanding
<i>The agent of remedy</i>	Normalized function; functioning member of existing society	Self-advocacy, changes in environment and understanding social inclusion
<i>Effects on individuals who are typically functioning</i>	Society remains the same	Society evolves to be more inclusive
<i>Perceptions toward individuals with disabilities</i>	The individual is faulty	The individual is unique
<i>Cognitive authority</i>	Scientists and doctors	Academics and advocates with disabilities
<i>Perceptions of disability</i>	Being disabled is negative	Being disabled, in itself, is neither positive nor negative

Table 4-1 Comparisons between the Medical and Social Models of Disability from Haegele and Hodge

The social and medical models of disability often exist concurrently. Within healthcare, it might be said there is a dominance of the medical model.⁽¹¹⁸⁾ However, given the evolving societal attitudes, there is evidence that healthcare is adopting elements of the social model of disability. The social model of disability is not without critique. Shakespeare explains that the social model of disability fails to recognise the impact of impairment.⁽¹¹⁹⁾ That is, social barriers create disability – for example, a building not being wheelchair accessible – however an impairment, such as pain associated with hypertonicity, has an impact. Shakespeare and others^(120, 121) argue that work needs to be done to accommodate both disability and impairment within these models.

As has been stated, those with a disability are more likely to experience poor health. Some of these health problems can be addressed through primary healthcare, but many people with a disability also need to be treated by

specialists at tertiary hospitals.⁽¹²²⁾ The main principles of care for the biomedical model are diagnosis focussed, and treatments are considered complete if the condition resolves. The chronic and incurable nature of disability, such as CP, contrasts with the biomedical model; treatments often aim to maximise function or comfort but cure is not possible. The access to community-based therapy and services is in a state of flux, with access and affordability of these therapies increasing, thanks to the National Disability Insurance Scheme (NDIS). The NDIS shall be explained in Section 4.5 below.

4.5 Current Supports available for Victorian Children with a Disability

It is expected that a child born in Victoria today who is diagnosed with a disability, no matter the severity of that disability, will be raised by their parents at home. Within the Australian system, the healthcare of people with a disability is fragmented.⁽¹²³⁾ Hospitals and equipment are provided by state government funding.⁽¹²⁴⁾ Welfare, funding for early childhood intervention, medications and concession schemes are provided by the Federal government. The gaps between state and federal funding may be covered by charities and philanthropic organisations.⁽¹²⁵⁾ The many and varied forms of support offered to families that have a child with a disability has often meant that the financial and systems provisions from government have been piecemeal and complex. This often results in parents having to advocate and invest significant time in applying for funding from alternate sources.

As mentioned earlier in this chapter, the voluntarism that emerged in the 1940s⁽¹⁰⁰⁾ has resulted in an expectation that charities and philanthropists will provide supplementary finances and other supports that government funding does not provide. It can be argued that this concept of disability care falling to the community has established a culture wherein it is expected that government systems will not meet the minimal requirements of parents of children with a disability. This attitude may represent a devaluation of people

living with a disability and a lack of recognition of their deservedness for a comprehensive and fully functioning healthcare and social welfare system.

Children with significant disability experience poorer health and a reduced life expectancy.⁽¹²⁶⁾ They often require intense, frequent and high-quality medical care from both their parents/caregivers and an array of medical and allied health services. A tension exists between the intense care needs of the child, the burden of care to the parent/caregiver, and the available resources within community and healthcare systems. The move from permanent care in institutions to community care by carers created a situation where overnight care was perceived as respite and became expensive and hard to access.⁽¹⁰⁷⁾ Consequently, overnight care became the sole responsibility of parents, as there was little option of care from other sources. This remains true today. A productivity report on disability services from 2011^{(127)p6} comments that the significant policy changes that occurred in Australia to normalise disability *“have raised expectations without providing solutions”*.

The current funding system, including what is provided, how much is provided and who provides it, is in a state of flux. The Australian Government is currently rolling out the National Disability Insurance Scheme (NDIS). This scheme commenced in July 2016 and is still in the process of being established across Australia. The focus of this scheme is to: *“...enhance the independence, social and economic participation of people with disability and their carers.”*⁽¹²⁸⁾ The NDIS is a federal government initiative that, when established, aimed to increase therapy and services available to all people with a disability. Through a .5% increase in the Medicare levy (a form of tax deducted during tax assessment), an extra 3.2 billion dollars in revenue was raised to be used for respite, equipment and therapy for people with a disability.⁽¹²⁹⁾ The introduction of the NDIS was remarkable, in that its implementation received bi-partisan support from the government, and also received wide-spread support from the Australian public.⁽¹³⁰⁾ It might be argued that this level of support demonstrated that the need for disability reform was widely recognised

and desperately needed. The main aim of the NDIS was to maximise participation for people with a disability and those that care for them, as opposed to curing a disease or symptom. At the time of writing, the NDIS roll out is still unfolding and the scope and function of the system remains ill defined. Because the NDIS roll out was still underway when this PhD project was conducted, research on the impact of the NDIS had not yet been published and so cannot be addressed in this thesis. However, a report from the Commonwealth Ombudsman in early 2018⁽¹³¹⁾ revealed the considerable systemic issues that have arisen relating to the management of reviews of planning and funding, causing many and lengthy delays in individuals receiving funding. There are an increasing number of media reports of frustration and dissatisfaction with the system and the mismatch between what was expected compared to what has been offered.⁽¹³²⁾ Thus, whilst expectations of the NDIS's potential to improve disability care and resources remain, the benefits of the system are yet to be quantified.

However, it is expected that this scheme will not only increase the amount of funding for people with disabilities but also unify disability services, as the funding and management will be administered from a single source. Another key change will be that the disability model will transition from a welfare-based system to a consumer-based system. Individuals or their parents apply for a funding package based on their needs for therapy, equipment and respite care. If approved, the individual or their carer then determines the service or equipment provider that they will employ with their funds. In theory, this process ultimately gives those living with a disability more control over the systems and services they need to optimise their participation in life. At the time of writing, the NDIS provides individuals with a potentially significant increase in funding for many aspects of disability care. However, the roll out has been met with many logistical issues, and parents have reported significant problems relating to finding care workers and adequate equipment for their children,⁽¹³³⁾ as well as delays in fulfilment of equipment requests and service provision.⁽¹³¹⁾

4.5.1 Disability in Australia in 2019

Whilst stigma has been reduced and inclusion is increasingly prioritised, it is important to highlight there is still significant disadvantage in having a disability in Australia. Those with a disability are more likely to be unemployed, with only 53% of Australians with a disability employed.⁽¹³⁴⁾ People with a disability are also at increased risk of experiencing discrimination based on their disability; 37% of discrimination complaints to the Human Rights Commission are based on a disability, and 39% of these complaints are cases concerning mobility.⁽¹³⁵⁾

CONCLUSION

This chapter has provided a brief synopsis of the social history and policy concerning disability in Australia. A critical perspective of the discourse surrounding disability has been presented. The background discussed aims to provide broad level social context to the meaning of disability, wherein this research is conducted. Since the time of white colonisation/invasion, the perception of disability has changed significantly from exclusion and stigma to a society that aims for inclusion and equality. However significant gaps in care and funding still exist, and these gaps may contribute to the impact of sleep problems for children with CP and their parents. This chapter has provided context and background for disability in Australian society. The next chapter will explain the social context and construct of sleep.

5 THE SOCIAL CONSTRUCT OF SLEEP IN WESTERN SOCIETIES

INTRODUCTION

The design and analysis of this thesis is built upon a core concept: a child's sleep problems occur within the context of their disability, their family, their culture, the ideology of their parents and available resources. Expectations surrounding child sleep, sleep habits and sleep norms are all heavily influenced by parenting, behaviour and socio-cultural factors. Many of these factors are the result of historical events. The following chapter describes the historical context of the contemporary social construct of sleep, sleep problems and sleep as a health issue within contemporary Western societies^{‡‡}. Parenting roles and expectations about sleep are explored. Evidence of the prevalence of sleep problems as a social discussion, the emerging sleep industry and sleep experts

^{‡‡} It is important to recognise the impact of cultural diversity on the social construct of sleep, including how non-western and indigenous cultural perspectives. It was not within the scope of this thesis to include in such a discussion.

as a new profession is presented. This chapter will explain the historical and social constructs that influence the perceptions of child and parent sleep, in which this study is situated.

5.1 Family Sleeping Arrangements in Western Society

Historically, childhood sleep was under-recorded and rarely discussed.⁽¹³⁶⁾ Indeed, there is little evidence of child sleep as a health issue before the late nineteenth century. That is, sleep was largely ignored, invisible or private. Evidence suggests that prior to the 1890s, guidelines around sleep requirements were rarely seen. The earliest evidence of sleep advice emerged in the late nineteenth century.⁽¹³⁶⁾ Newspaper and magazine articles suggest that advice given was limited; new-borns were expected to sleep 12 hours per night, and after that, some historical resources suggested there was little concern about sleep duration for children. These sources⁽¹³⁶⁾ suggest that the expectation for sleep duration was as low as six to seven hours per night. Academics^(136, 137) have suggested that from a cultural perspective, sleep was viewed with some optimism and, culturally, sleep need was minimised. Consequently, sleep was largely ignored.

Up until the early 1900s, families would often sleep in one room and one bed.⁽¹³⁶⁾ This was more common amongst the poor and working class.⁽¹³⁸⁾ Work and social lives were limited by available natural light as electric lights were not common until the 1900s.⁽¹³⁹⁾ A lack of artificial light meant that daylight dictated a routine of good sleep hygiene and adequate sleep duration. Family sleeping arrangements were also conducive to minimising sleep disturbance: small houses and an expectation of the ‘family bed’ meant that children were not separated from their parents at night.⁽¹³⁹⁾ If children did wake, it is likely they were quickly settled by a nearby parent or older sibling who had a parent-like role.

When sleep problems did occur, prevalence and ready access to opiates may have mitigated any need for sleep solutions to be sought. Opiates are a very

effective sleep agent and were readily available in child sleep tonics, such as ‘Mrs Winslow’s Soothing Syrup’.⁽¹⁴⁰⁾ The introduction of pharmacies and the medicalisation of opiates in the late nineteenth century saw access to such tonics significantly reduced.

The early twentieth century saw a rapid change in family structure and living conditions in Western societies.⁽¹³⁶⁾ There was a trend toward smaller families with a simultaneous trend towards larger houses, and a preference to provide each child, or children of the same sex, with their own bedroom.⁽¹³⁶⁾ The ‘family bed’ became less common (with the notable exclusion of poorly resourced families) and the expectation that children slept alone in a bed in a room of their own, separate to their parents, grew to be the norm.⁽¹³⁹⁾ Consequently, if a child did not sleep well and required attention overnight, a parent would be woken and would need to leave their bed to attend to the child. Conversely, co-sleeping became less socially acceptable and considered more of a disruption to parents’ sleep.⁽¹³⁶⁾ This trend has continued and today the majority of children in Western countries are expected to sleep in their own beds and rooms at night.

5.2 Gender Differences and Sleep

Within contemporary Western society, it is usual for the mother to be the primary caregiver of children.^{§§(141)} Baxter and Western⁽¹⁴²⁾ report that women do a disproportionate amount of housework within two parented families. Their study⁽¹⁴²⁾ found that the more work women did, the less satisfied they are with their work. Women who had work outside of the home or were enrolled in higher education were less likely to be satisfied doing housework.⁽¹⁴²⁾ More recently, the *Household Income and Labour Dynamics in Australia* (HILDA)

§§It is recognised that not all parents are in heterosexual, cis gendered relationships. No participants in this study were in same sex headed families, and little is known about the roles of parents in same sex families in regard to overnight care responsibilities of children. As such, only the gender roles within heterosexual cis gendered relationships are discussed in this thesis.

survey reported that the attitudes of men and women in Australian households are moving away from traditional gender roles (man as worker, woman as housekeeper and child bearer),⁽¹⁴³⁾ and younger Australians are increasingly open to non-traditional gender roles in regard to parenting and paid work. However, women still provide the majority of care. For example, married women with dependent children spend a mean of 23.3 hours per week in a care role compared to married men with children, with a mean of 2.4 hours. Men work more; married men with dependent children work a mean of 46.7 hours per week. This is compared with married women with children who work a mean of 22.2 hours per week.⁽¹⁴³⁾ Thus, while attitudes towards gender roles and the care of children are moving towards more non-traditional views, the actual distribution of work remains mostly traditional. Within the context of this care role, it is important to understand how caregiving is managed at night-time.

5.3 The Social Construct of Sleep Problems

The social construct of sleep within Western societies is a relatively new topic of exploration,⁽¹³⁷⁾ with the majority of most research and discussion conducted in the last twenty years.⁽¹³⁹⁾ Sleep is an essential biological need. Daily business, personal, religious, institutional routines and learning are all tacitly influenced by sleep.⁽¹⁴⁴⁾ Despite increasing economic pressures within capitalist Western societies to maximise earning capacity and productiveness, sleep is a biological need that has not and cannot be eliminated.⁽¹³⁷⁾ This demonstrates the influence of sleep within the socio-cultural context.

Medical knowledge and expertise in the early twentieth century advanced rapidly. The emergence of a condition then known as Neurasthenia, now known as chronic fatigue syndrome, was thought to be a catalyst for medical experts to consider the impact of sleep deprivation on health.⁽¹³⁶⁾ Williams et al.⁽¹⁴⁵⁾ conducted qualitative analysis of the newspaper coverage of insomnia and found that sleep has been both medicalised and 'healthised'. They argue that sleep is viewed as a medical matter, that of disease and disorder, and also as a

health priority: good sleep is important for good health. The medicalisation of sleep moved it from an invisible daily function to a function defined, described and advised upon by doctors.⁽¹⁴⁶⁾ As is typical when medicalisation occurs, doctors became the gatekeepers to treatments and services, which further enhanced the process of medicalization.⁽¹⁴⁶⁾ This medicalisation, and the platform that medical experts were given, equated to knowledge being sought from outside experts rather than elders in the family. Namely, doctors emerged as the authority on what is good for health.⁽¹⁴⁶⁾

5.3.1 Sleep and parenting today

Contemporary parents, within the vast landscape of sleep advice and resources, are expected to determine what is right for their child and to trial and then repeat strategies until good sleep is achieved. Amrute⁽¹³⁷⁾ argues that there is an expectation that good sleep is achieved in order to prepare the child for a better future; a child who sleeps well is prepared for a good life. Amrute⁽¹³⁷⁾ suggests that good sleep is seen as an inoculation for the future. Williams⁽¹³⁹⁾ suggests that the sleep of children is now constantly watched over and worried about by their parents. In addition to the expectation in today's Western societies that children sleep on their own, in their own bed, through the night, there is often great discussion, especially amongst middle class parents, as to how best to manage sleep and sleep problems. Indeed, Amrute⁽¹³⁷⁾ argues that for the middle class, the act of discussing the best approach to sleep is regarded as an act of good parenting itself, regardless of the outcome of that discussion.

It is important to note that the sleep management of children's sleep is heavily influenced by the resources available to the parents. Amrute's⁽¹³⁷⁾ qualitative study reveals that parents in lower socioeconomic groups often refer to elder members of the family as sleep and parenting experts, rather than outsider expert advice. Amrute's findings also reveal that the sleeping arrangements for mothers in lower socioeconomic groups are more likely to include co-sleeping, not as a choice but because house size dictates bed sharing. It is to be noted that Amrute's study was conducted in the United States of America (USA),

which has a largely private or fee-for-service healthcare system. El-Sheikh et al.⁽¹⁴⁷⁾ report that those families of lower socioeconomic status (SES) have less access to medical services and advice, and that lower SES has been linked to sleep problems. They hypothesize that this may be due to sleep environment, lower education levels, higher life stress or more worries that might impact sleep.⁽¹⁴⁷⁾

Simultaneous to changes in family structure, home environment and cultural expectations in the early twentieth century, the specialty of paediatrics was established. Paediatric experts began to publish parenting books, in which sleep problems were discussed and advice provided. Stearns⁽¹³⁶⁾ suggests that the problems of sleep were often exaggerated in order to promote the sale of their books. This acknowledgement of child experts and the need to learn and adopt the best parenting expertise has extended to the modern day. Faircloth and Murray⁽¹⁴⁸⁾ state that parents have become anxious about enacting this expertise and, indeed, the process of parenting. This anxiety includes worries about how parents can ensure that their child gets the ‘right’ amount of sleep. Simultaneously, opportunistic experts and businesses have provided books, products and services that promise parents improved sleep for their children. Thus, the industry of sleep has emerged.

5.4 Industry of Sleep

The framing of good sleep as a wellness factor, combined with the increasingly busy nature of Western life, has driven the development of sleep as an industry.⁽¹³⁹⁾ McKinsey Private Equity and Principals Investors Practice,⁽¹⁴⁹⁾ who publish quarterly reports on potential areas for investment, produced *Investing in the Growing Sleep-Health Economy* in August 2017. The eight-page report includes the schematic below, which illustrates all the potential products and services that may be generated by sleep problems or good sleep as part of a wellness plan.

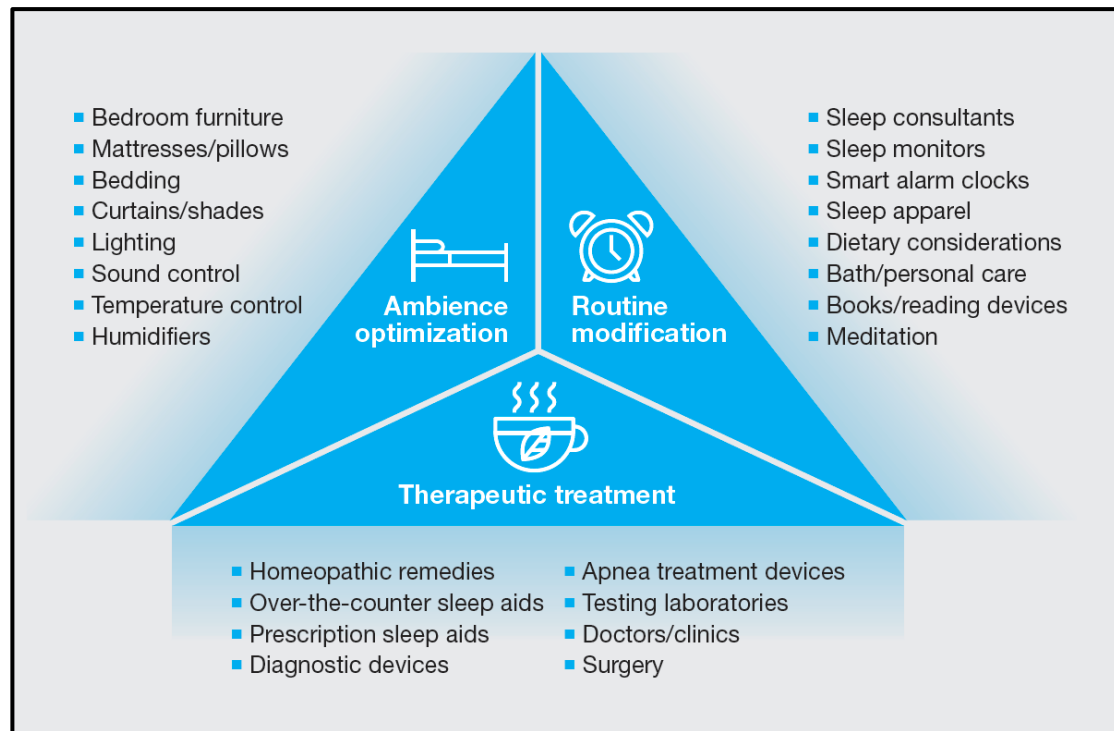


Figure 5-1 Sleep-Health Vectors and Associated Products/Services

To demonstrate the pervasiveness of sleep as an industry, the remainder of this section presents a snapshot of sleep products and sleep authorities/consultants today.

5.4.1 Sleep products

As the McKinsey report⁽¹⁴⁹⁾ highlights, there are many products available that are sold with the purpose of improving sleep. The sleep industry is reportedly worth more than 30 billion US dollars and is growing at a rate of more than 8% per year.⁽¹⁴⁹⁾ A search of Priceline Pharmacy online store for 'sleep' (performed on 21.7.2019, priceline.com.au), resulted in 77 items, including over the counter herbal or vitamin supplements, sprays, drops or pastilles. The product descriptions for these remedies claim that the supplements will address sleeplessness. Prices range from \$3AUD to \$30AUD. Advice and product suggestions for maximising child sleep are also commonplace in web-based media. For example, a subsection of the online New Yorker Magazine, *The Strategist*, which boasts 11.8 million monthly views, has an annual 'sleep week'.

In November 2018, it published a ‘Best List of Things that get Babies to Sleep’.⁽¹⁵⁰⁾ This list included: black out curtains (\$30USD), white noise machines (\$45USD), sleep suits that automatically swaddle baby (\$19USD), a weighted blanket (\$60USD), an alarm clock and night light (\$27USD). The list also included an alarm clock that slowly wakes the user by shining light into the room (\$138USD), and a humidifier that claims to prevent drying up of the baby’s mucous, enabling the infant to sleep better (\$65USD).

Self-tracking devices, such as the most commonly recognised *Fitbit* (which has the market share (35%) and has sold over 15 million devices between 2010 and 2017 – see www.fitbit.com), are promoted as not only tracking vital signs and activity but also sleep monitors. It is difficult to know how many people monitor their own sleep, or what happens as a result of this,⁽¹²³⁾ but the prevalence of these devices and the ability to self-monitor demonstrates how sleep has become problematised and prioritised in contemporary society.⁽¹²³⁾ Lupton⁽¹⁵¹⁾ argues that this self-monitoring is a profoundly social practice discussed with others. Sleep as the focus of such self-monitoring and social behaviour demonstrates the popularity of sleep socially, and the fascination that contemporary society has with sleep.

5.4.2 Popular sleep ‘authorities’ who supplement their advice with products

Dr Karp is an American paediatrician who created the *Happiest Baby* brand. Dr Karp promotes his ‘5 s’ approach to settling babies: swaddle, side or stomach position (for settling an upset baby), shush, swing, suck. Within this list of recommendations is also the ‘Snoo’ bassinet (\$1160US). This bassinet is technology enabled, ‘hearing’ when the baby cries and boosting the sound of white noise and the frequency of rocking in order to settle the baby. Dr Karp emphasises the risks of poor sleep to parent and child to promote his suite of products. A review of his website reveals this statement about using the ‘5 S’s’:

The 5 S's technique only works when done exactly right. The calming reflex is just like the knee reflex: Hit one inch too high or low and you'll get no response, but hit the knee exactly right and, presto! If your little one doesn't soothe with the S's, watch the Happiest Baby DVD / Streaming Video again to get it down pat. Or, check with your doctor to make sure illness isn't preventing calming.⁽¹⁵²⁾

The statement provides a caveat for why the 'happiest baby' technique may not work for all babies. It also suggests a level of responsibility on the parent to get the technique 'exactly right', with reinforcement that the purchase of the book and DVD is essential. This approach to sharing sleep information and its effectiveness is common throughout the webpages of the most popular public voices on sleep.

Dr Karp is amongst many admired sleep authorities who have all published books on their sleep solutions. There are two particularly well-known Australian sleep authorities. Tizzie Hall, who refers to herself as the 'international baby whisperer', has no formal qualifications but has gained notoriety within Australia for her sleep techniques. Hall's FaceBook page *Tizzie Hall Save Our Sleep - The International Baby Whisperer* (named after her book) has over 38,000 followers. Her webpage⁽¹⁵³⁾ ⁽¹⁵³⁾ sells her books and the products that she recommends in her sleep program, including the bedding that the parent must be prepared to buy in order for her sleep regime to work. Hall also provides various levels of support, at a cost, ranging from \$20AUD for access to a read only advice page through to approximately \$3000AUD for a two-to-three night stay at her home to receive in-person sleep support. Hall promotes a rigid routine of feeding and sleeping to promote good sleep, which includes following the controlled crying technique. There is also a Facebook page named *Tizzie Hall Didn't Save Our Sleep*, with the tag line "A page for mums who found 'the International Baby Whisperer' didn't save their sleep, or those that disagree with the techniques".

An equally popular voice in Australia in regard to infant sleep is that of Pinky McKay, a certified lactation consultant, with no description of other qualifications. McKay has written four books, including her sleep book *Sleeping like a Baby*. McKay has a website dedicated to her books, a blog, and a separate website just for shopping called *Shopwithpinkymckay.com*. McKay's Facebook page, *Pinky McKay*, has over 140,000 followers. Her advice follows what she describes as a "gentle parenting" approach, which includes responding to the baby if they wake overnight (i.e. not controlled crying).

These popular sleep voices have attracted significant public following and it is evident that they sell both advice and products that aim to improve sleep, and that their services are in demand (Tizzie Hall is currently not taking any new clients as she is fully booked for both email and in-person consultations, as of February 2019).

5.4.3 Sleep coaches/consultants

Whilst there is a plethora of published sleep authorities with their own books, web-stores and product lines, there is also a 'burgeoning paediatric provider group'⁽¹⁵⁴⁾ of sleep coaches or consultants. Ingram et al.⁽¹⁵⁴⁾ conducted an audit of these coaches, their experience and expertise, and pricing in the US. They found over 100 sleep coaches within the US. Of those coaches, 44% of the sleep consultants did not have any post-secondary qualifications, 24.5% had a Bachelor's qualification and 53.9% did not have any health qualifications.⁽¹⁵⁴⁾ The average price of in-person consultations was \$368USD. Typically, a consultation included a one-to-three hour interview with time limited follow up contact. Similar information is not available in Australia. However, a popular website, *SleepSchool.com.au*,⁽¹⁵⁵⁾ contains a directory of sleep consultants located in Victoria. Over twenty sleep consultants are listed in the directory. These sleep consultants vary in their qualifications; some are paediatric or maternal and child health nurses, some early childhood educators, and some claim accreditation with courses such as 'Sleep Sense'. These private services cost between \$100AUD for a phone consultation up to \$780AUD for an

overnight visit and advice. All services listed are only available for children up to the age of four years. This demonstrates that there are many sleep coaches available, should the financial resources be available to employ them. It is difficult to determine the individual effectiveness of these sleep coaches; the only evaluation of their work is provided by reviews on their webpage or social media.

It might be argued that the prevalence and popularity of these books, consultants, products and services all focussed on improving sleep for children, is evidence of the value of good sleep in this culture. Concurrently, the high price of these services and products may represent what parents are willing to pay to access effective sleep solutions. That is, there is an element of desperation associated with poor sleep; the demand for these solutions has enabled these services to charge high prices. Notably, for children with a disability/chronic disease or children older than four years, there seems to be no commercially available sleep expertise.

5.5 Good Sleep is a Priority for Most Modern Parents

It is clear from the above discussion that at the time of writing, the typical parent in Western society is likely to be aware of the impact of sleep problems and has potential access to a myriad of solutions. Indeed, obtaining good sleep may be considered a ‘holy grail’ of parenting. A powerful illustration of how common and impactful child sleep problems can be for parents is a book written by Adam Mansbach titled *Go the Fu#k to Sleep*.⁽¹⁵⁶⁾ This book was written for parents, in the style of a rhyming children’s lullaby, and is about a frustrated parent trying to convince their child to go to sleep. When it was published, this book was a sensation across social media. Videos of celebrities reading the book have been watched millions of times: Samuel L. Johnson (3.4 million views), Jennifer Garner (4.6 million views) and Noni Hazlehurst (150,000 views). The book itself made many bestseller lists (amazon.com, New York times) before it was released, has sold over 2 million copies, and has reportedly been licensed to be turned into a movie.⁽¹⁵⁷⁾ It might be argued that the success of the book

indicates the widespread relatability of sleep deprivation amongst parents across the Western world. This illustrates the context of sleep and sleep problems within which this thesis is situated.

CONCLUSION

Historical events combined with the business of problematic sleep highlights the intense focus of parents on poor sleep in their children in this culture. It is clear that sleep problems in children are widely discussed and infinite resources are available, especially for those who have the means to pay for them. However, what is not as clear is what happens to those who are not equipped to access these private enterprises and expensive equipment? What happens when sleep problems extend beyond the infant years, into school years? What is available for children with disability? This thesis was conducted within a culture where sleep problems are common, and sleep is prioritised and problematised. Sleep has been commercialised. There are many resources, experts and products for typically developing young infants and their parents. However, there appears to be a distinct gap in available resources for older children or children who have a disability.

6 PHASE ONE METHODS

INTRODUCTION

This chapter will present the methods used to conduct Phase One of the study, which was a scoping phase consisting of qualitative one-on-one interviews. Phase One provided the platform for subsequent phases, informing the design of Phases Two and Three and guiding the focus of the research enquiry. This chapter explains the multiple recruitment strategies implemented, how the one-on-one interviews were conducted, how data were collected and analysed and ethical considerations.

6.1 Phase One Aims and Research Question

6.1.1 Phase One aims

The aims of Phase One were to:

- i. examine if the clinical experience of the Researcher was consistent with the lived experience of parents of children with cerebral palsy (CP) who have sleep problems
- ii. inform the design of Phases Two and Three.

6.1.2 Phase One research questions

The research questions for Phase One are:

- i. What is the experience and impact of sleep problems and solution seeking for parents of children with CP?
- ii. What survey design factors will maximise participation in sleep survey research for parents of children with CP?

6.2 Phase One Study Setting

The research was conducted at the Royal Children's Hospital (RCH) in Melbourne, Victoria. Between August 2016 and August 2017, 315 children with CP were seen in the Department of Neurodevelopment and Disability outpatient clinics. Phase One was conducted over the period of August 2016 to July 2017.

6.3 Phase One Recruitment and Participants

Parents or primary carers of children aged between 6 and 12 years who have CP and self-report poor sleep were invited to participate. Participants were recruited to the study in one of three ways:

- i. Advertisements in newsletters of the following organisations, using their electronic mailing lists:
 - Victorian Cerebral Palsy Register (VCPR), which distributes a newsletter to registrants on the Victorian Cerebral Palsy Register
 - Neurodevelopment and Disability Department (RCH), available on the internet to both consumers and health professionals
 - Cerebral Palsy Support Network (CPSN), which is the peak-body representing individuals with CP and their families in Victoria, and provides information, resources and support to children and adults with CP and their families

- ii. Parents of eligible inpatients of RCH were approached on the ward by the Researcher.
- iii. Clinicians from the RCH, including doctors, nurses and allied health professionals from clinical teams that care for children with CP, identified children and families who met the study criteria and referred them to the Researcher.

Newsletter recruitment required the participant to contact the Researcher via phone or email, and they were then offered the choice of an interview over the phone or in a quiet room at RCH. All participants were provided with information sheets about the study via email or hard copy, and consent was obtained via a verbal statement at the commencement of the interview (see Appendix E). This statement was read aloud and included in the interview recordings and transcripts. A recruitment target of ten interviews was set in order to capture a variety of experiences across the spectrum of severity of CP and the range of possible sleep problems.

6.4 Phase One Data Collection

The interview tool was informed by the research questions, current literature regarding sleep problems in CP, and the Researcher's clinical experience. A copy of the interview tool can be found in Appendix F. The questions focused on exploring the participant's experience of sleep problems for their child. Questions about type and severity of CP and family structure were also asked. The interview tool also included a series of questions on the suitability of possible sleep assessment tools, and potential design of the quantitative phase. Participants were provided with copies of potential sleep assessment tools and quality of life surveys to assist them in this part of the interview

The paediatric sleep assessment tools selected for consideration were chosen if they were used in published research with children who have CP, or were designed specifically for use in research on children with CP. Table 6-1 presents

the key details of the sleep screening tools considered for inclusion and shared with the parents for their opinion:

Tool Name and Authors	Target Population	Number of Pages	Brief Description
The Chailey Sleep Questionnaire ⁽¹⁵⁸⁾	Children with Cerebral Palsy GMFCS Levels III-V, aged 2-10	24 pages, 140 items	Demographics, health history, comprehensive summary of co-morbidities, sleep profile. Tick box and short answer questions
The Sleep Disturbance Scale for Children ⁽¹⁵⁹⁾	Typically developed school aged children (validated in 6.5-15.3 years)	1 single page, 26 items	Questions about sleep according to key domains of sleep problems: disorders of initiating and maintaining sleep, sleep breathing disorders, disorders of arousal, sleep wake transition disorders, disorders of excessive somnolence, sleep hyperhidrosis. All tick box questions
The SNAKE ⁽⁶⁶⁾	Children with severe psychomotor impairment (GMFCS IV-V or equivalent) (validated in children aged 1-25)	4 pages, 49 items	Patient demographics, brief medical history, tick box and short free text questions
Children's Sleep Habit Questionnaire ⁽⁸⁵⁾	School aged children (6-12 years) validated only in typically developing population but has been used in multiple research studies for children with CP	2 pages, 33 items	Tick box questions and three questions that require two-word answers Assesses key sleep domains of: bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night waking, parasomnias, sleep disordered breathing, daytime sleepiness

Table 6-1 Sleep Assessment Tools Provided to Parents

6.5 Phase One: Data Management and Analysis

Data from the interviews were collected via a digital recorder. The recordings were transcribed verbatim into a Word for Windows document by the Researcher. Completed transcripts were then re-checked for accuracy against the audio recording. Inductive thematic analysis, which is thematic analysis generated by the data and not shaped by existing concepts, was undertaken.⁽⁹⁹⁾ Thematic analysis followed the six phases outlined by Braun and Clarke⁽¹⁶⁰⁾(p

87) in the table below. NVivo⁽¹⁶¹⁾ software was utilised to assist with data management and coding. Coding was performed by the Researcher and crosschecked by her qualitative supervisor. Steps three through to five of the thematic analysis occurred as an iterative process between the Researcher and her qualitative supervisor.

Phase	Description of the Process
<i>1. Familiarising yourself with your data:</i>	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas
<i>2. Generating initial codes:</i>	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
<i>3. Searching for themes:</i>	Collating codes into potential themes, gathering all data relevant to each potential theme
<i>4. Reviewing themes:</i>	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis
<i>5. Defining and naming themes:</i>	On going analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme
<i>6. Producing the report:</i>	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating the analysis back to the research questions and literature, producing a scholarly report of the analysis

Table 6-2 Phases of Qualitative Thematic Analysis

6.6 Study Rigour

Qualitative research, due to the nature of its outcomes, cannot be assessed with the same criteria as quantitative research. Lincoln and Guba,⁽⁸⁸⁾ who are cited widely by qualitative academics,^(63, 99, 162) describe trustworthiness as being the central standard to which qualitative research should be assessed for rigour and quality. Trustworthiness consists of credibility, transferability, dependability and confirmability.⁽⁸⁸⁾ How the Researcher adhered to these principles throughout the study will now be described.

Credibility in qualitative research is achieved through prolonged engagement, peer debriefing, negative case analysis, member checking and triangulation.⁽⁸⁸⁾ The Researcher has worked within the clinical sphere of CP and associated sleep problems for more than 12 years, and continued to do so throughout the course of this study. The Researcher works within the context of the healthcare system for children with CP and their parents. This bias is recognised and the risk was minimised through regular meetings with supervisors to discuss findings, provide reflexivity and challenge possible unrecognised bias. Regular meetings with academic peers (other qualitative PhD researchers) to discuss analysis and findings also provided opportunities for reflexivity. Triangulation of the data in Phase One occurred through data being analysed by the Researcher and one of the supervisors. Interesting or poignant concepts that were identified within an interview were used as interview prompts in subsequent interviews in order to seek further triangulation. All findings discrepant to the themes were reported. Member checking was deemed inappropriate for this study as the data analysis was conducted through the lens of critical social theory; there was some risk that the analysis might not resonate with the individual mothers, which would then invalidate the process of member checking. Some researchers suggest sharing the raw transcripts with the participants, giving them the opportunity to confirm or correct the information they shared.⁽¹⁶³⁾ As Goldblatt et al.⁽¹⁶⁴⁾ report, this can also be problematic; member checking can cause distress to the participant who has to revisit their account and the passage of time can influence their reflections. Additionally, the process of member checking can reinforce power dynamics between the participant and researcher; the participant may wish to edit their transcript to meet the needs of the researcher. Specific to this study, the additional request of time to review their interview may have acted as a deterrent for participation, given the difficulties in recruiting participants and the research fatigue reported by them.

Transferability, as per Guba,⁽⁸⁸⁾ refers to the applicability of the study findings to other settings. Guba⁽⁸⁸⁾ states that true transferability is impossible in

qualitative studies but may be enabled by providing a thick description of the study and its findings. This description may enable the reader to determine if the research was similar enough to enable the outcomes to be applied to another context. The research findings have been described in great detail and depth within this study.

Dependability refers to study findings being consistent and stable over time and across methods.⁽¹⁶²⁾ This is achieved through detailed explanation of the study methods. This current chapter, and subsequent Chapters Seven and Nine, explain the research methods used in this study. Finally, confirmability refers to the objectivity or relative neutrality of the study.⁽¹⁶²⁾ Confirmability in this study was achieved through the maintenance of an audit trail.

6.7 Ethical Considerations

Ethics approval was obtained from the Royal Children's Hospital Human Research and Ethics Committee (HREC 35166A). The ethics approval documents can be found in Appendix D. All guidelines by the RCH Human Research and Ethics Committee were followed during the undertaking of this research.

6.7.1 Collection, use, storage and disposal of data

The interviews occurred at a mutually agreed time, either over the phone or in person at the RCH. If participants chose a phone interview, verbal consent was obtained and recorded at the initiation of the interview. If a face-to-face interview was chosen, consent was either recorded within the interview or a hard copy consent form was signed before the interview commenced.

6.7.1.1 *Obtaining consent*

Prior to starting the interview, the interviewer covered the following consent procedure:

- i. the possible effects of participating in the interview were explained

- ii. participants were informed that they were free to withdraw from the project at any time without explanation or prejudice and with the assurance that any unprocessed data would also be withdrawn
- iii. participants were informed that the project was for the purpose of research
- iv. participants were assured that all information provided was safeguarded subject to any legal requirements
- v. participants were informed that the interview would be audio-recorded and audio-files were to be stored at the RCH and will be destroyed after seven years
- vi. participants would be referred to by a pseudonym in any presentations and/or publications arising from the research
- vii. a copy of the research findings would be forwarded to the participant if they requested this
- viii. the potential for direct quotes to be used in presentations or publications was explained and participants were assured that if quotations were used, any identifying data would be removed.

6.7.1.2 Privacy and confidentiality

Data was managed in accordance with RCH procedure *Investigators Responsibilities in Research*⁽¹⁶⁵⁾ and underwritten by the *Australian Code for the Responsible Conduct of Research*.⁽¹⁶⁶⁾ Any personal information collected was treated as confidential and no identifying information was stored with the interview data. The face-to-face interviews were conducted in a private room at RCH, or via speakerphone between the participant and the Researcher who was in a private room. All hard copy data collected were stored in a locked filing cabinet, only accessible by the Researcher and associate investigators. Any identifiable digital information was stored on a password-protected drive. These data were kept for the duration of the study and will be destroyed seven years after the research has been published.

CONCLUSION

This chapter has provided a detailed description of the methods and procedures used to complete data collection and analysis for Phase One of this study. Ethical considerations and evidence as to how study rigour has been ensured have been presented. The findings of this phase of the study will be presented in the following chapters. The methods for Phase Two and Three are described in Chapter Nine.

7 PHASE ONE FINDINGS

INTRODUCTION

This chapter presents the results of Phase One: a scoping phase of qualitative interviews with parents who reported sleep problems in their children with CP, aged between 6 and 12 years. The three main aims of this phase were to:

- i. gain an understanding of the impact and experience of sleep problems in CP
- ii. explore whether the clinical experience and assumptions of the researcher were aligned with the experience of the participants
- iii. consult parents about the design of the future phases of the research.

In this chapter, the difficulties experienced in recruiting the nine participants will be described. The outcomes of the thematic analysis will be presented: namely, the two major themes – *Seeking Solutions* and *Having to Survive* – and their subthemes. Key quotes will be used to illustrate each of the themes and subthemes. The chapter concludes with the findings that explain parental preferences and opinions regarding the design of the Phase Two survey. This chapter presents the findings of this scoping phase, which inform the design of the two subsequent phases of this study.

7.1 Recruitment and Participants

In Chapter Six, the three recruitment strategies for this study were described. Recruitment for Phase One was initially designed to be through referral from paediatricians employed in the Department of Neurodevelopment and Disability at the Royal Children's Hospital, Melbourne (NDD) over a three to six month period. Paediatricians were sent recruitment reminders monthly. The Researcher also read the medical records of the outpatient clinic lists to find eligible patients. Thirteen potential participants were referred over 12 months, with only two of those referrals resulting in interviews. The remainder did not meet eligibility criteria ($n=3$), did not respond to attempts to contact ($n=7$), or initially agreed and then cancelled ($n=1$). It was expected that this method would recruit all required participants to the study. This did not eventuate and amendments were made to the study protocol (see Appendix D) to add the alternative methods of:

- i. advertisements in newsletters
- ii. parents of children with sleep problems who were currently admitted inpatients at the RCH
- iii. extending clinician referrals to include all RCH departments that regularly cared for children with CP.

7.2 Challenges of Recruitment

The recruitment for Phase One was more challenging than expected. While this phase was expected to take six months, 17 months were required to recruit nine participants. The following factors influenced recruitment:

- i. Clinicians did not/were not able to identify possible participants: Thirteen potential participants were referred to the Researcher from clinicians, who identified potential participants from their clinics. Monthly reminders for recruitment were sent to paediatricians who work for the NDD. Later, after an ethics amendment, recruitment was expanded to include any clinician in any RCH department that routinely

care for children with CP: Neurodevelopment and Disability, Victorian Paediatric Rehabilitation Service, Orthopaedics and Complex Care. In addition to email reminders, the Researcher prompted clinicians about the study and recruitment criteria during personal conversations and staff meetings. The low number of potential participants identified by clinicians may reflect the lack of time and significant staff changes that occurred in the department at the time.

- ii. Call screening: More than half (n=7) of the clinician-referred parents did not respond in any way to the recruitment phone call. Phone calls were made from a de-identified hospital phone number. Many phone users may screen calls from unknown numbers. Curtin et al.⁽¹⁶⁷⁾ examined the response rates for telephone surveys and found a significant drop off over 25 years, attributing that loss to an increase in telemarketing calls and the additional technology of caller identification. ‘Cold calls’ from unexpected numbers are often left unanswered, as people do not want to engage with unfamiliar callers.
- iii. Advertising in a community newsletter: Five rounds of an advertisement were sent over 12 months. The majority of the mothers (n=7) interviewed were recruited this way.
- iv. Data collection method: Within the interview, two mothers specified that they were pleased to be able to take part in research. Their experience of participating in research was limited because they could not participate in written surveys due to literacy, language or visual challenges.

To address these recruitment difficulties, the research protocol was amended multiple times to increase recruitment success (see Appendix D). The first amendment included advertising in the newsletters of the Cerebral Palsy Support Network (CPSN) and the Victorian Cerebral Palsy Register (VCPR). The CPSN is a not-for-profit community group with a membership base, and consequent mailing list (email and postal) of 1568 members (personal

communication, CPSN Chief Executive Officer, Vicki Cavalieros, 24 April 2018). Each member receives a digital copy of the organisation's fortnightly newsletter. A copy of the advertisement can be found in Appendix I. The advertisement was published five times in 13 months. This resulted in 11 parents contacting the Researcher, of whom seven were interviewed. The remaining four potential participants declined to participate. Amendments to the ethics protocol were also made to include screening inpatients admitted under the NDD team at the RCH. Eligible participants were to be approached by the Researcher during their inpatient stay. No suitable participants were found this way.

Details of the participants recruited are provided in Table 7-1. These details were collected within the interviews. All participants have been allocated pseudonyms for the purpose of maintaining confidentiality. The GMFCS levels are as reported by the participants.

Table 7-1 Phase One Participants

Pseudonym	Relationship to Child	Age of Child	GMFCS Level	Family Type	Interview Format P = Phone I = In Person	Interview Length (mins)	Type of Sleep Problems Described
Stella ^{***}	Mother	11	I	Partnered, 2 children	P	21	Minimal sleep problems. Stays awake later than mother would like (11pm). Settles self and catches up on the weekend
Luna	Mother	7	III	Single, 2 children	P	41	Behavioural sleep problems, bedtime resistance sleep association
Nisha	Mother	9	V	Partnered, 2 children	P	33	Multiple co-morbidities disturbing sleep. Sleep worsens when unwell
Chandra	Mother	10	III	Single, 1 child	P	38	Behavioural sleep problems
Astra ^{†††}	Mother	8	II	Partnered, 1 child	P	41	Behavioural sleep problems. Unwanted co-sleeping. Sleep association
Vega	Mother	6	III	Partnered, 2 children	P	48	Frequent wakings due to discomfort, tone and seizures
Nova	Mother	6	IV	Partnered, 2 children	P	71	Frequent wakings (up to 30 per night) due to increased tone and other comorbidities

^{***} Stella described a sleep problem significantly different to the other children in this phase. Her child had issues with sleep latency for which she had not sought help, as *“It isn’t really that much of a problem.”* She wanted to participate in this research as it applied to her child. Due to a vision disorder, she is not able to participate in written surveys. She did provide important data in regard to informing the design of Phase Two.

^{†††} Astra was of a non-English speaking background.

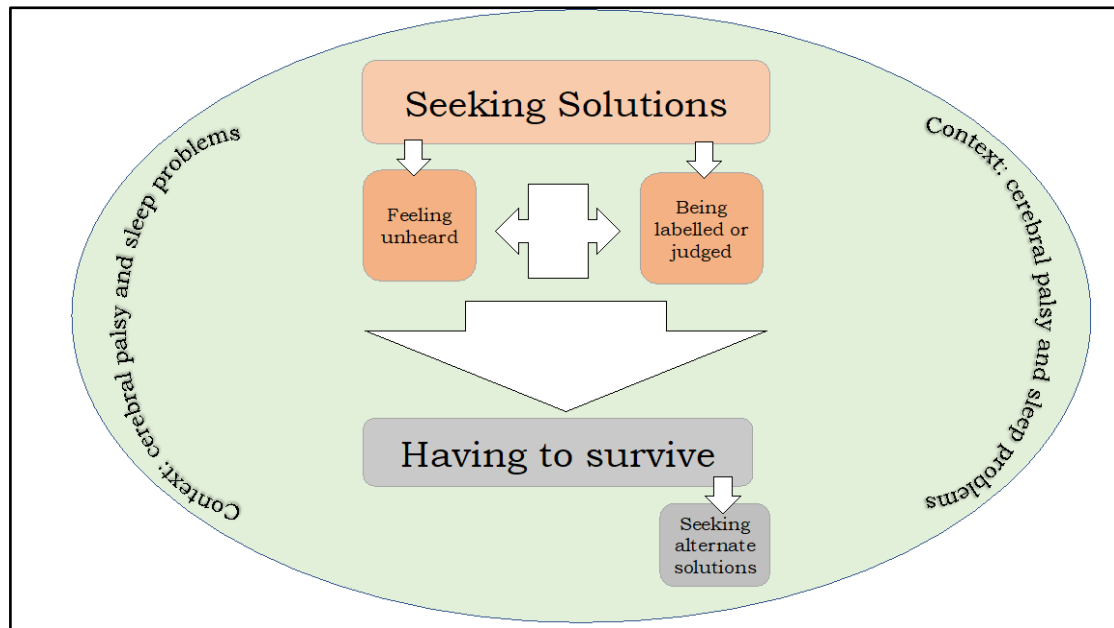
Pseudonym	Relationship to Child	Age of Child	GMFCS Level	Family Type	Interview Format P = Phone I = In Person	Interview Length (mins)	Type of Sleep Problems Described
Vesper	Mother	9	II	Partnered, 2 children	P	57	Frequent wakings and severe sleep disturbance likely due to discomfort
Esther	Mother	9	III	Partnered, 2 children	I	37	Behavioural sleep problems, sleep association

The GMFCS levels of the children were reflective of the typical distribution of GMFCS levels across the Victorian population of children with CP.⁽⁷⁾ It is noteworthy that parents in general were invited to participate, but only mothers contacted the Researcher. From this point on, the interviewees will be referred to as ‘mothers’. Interviews were offered in person or over the phone. All but one mother requested the interview to be over the phone. The one face-to-face interview was conducted at RCH as her child was an inpatient at the time. Recruitment for this phase was ceased after nine interviews were recorded as the cohort represented a broad spectrum of experiences across the CP and sleep problem spectrum, and the data set was considered to be satisfactory for a scoping phase.

7.3 Phase One: Findings of Thematic Analysis, Experience and Impact of Sleep Problems

The interviews for this phase gathered rich and detailed data from the mothers about their experience of sleep problems, seeking solutions for sleep, and their preferences and opinions on the survey design for Phase Two of this study. Thematic analysis of the nine interviews was performed using the technique of Braun and Clarke,⁽¹⁶⁰⁾ as described in Chapter Six. The thematic analysis resulted in the identification of two major themes and three subthemes. A concept map of these themes and how they relate to each other can be seen below in Figure 7-1. Importantly, all identified themes and subthemes were underpinned by the context of CP and sleep problems, which is represented by the green circle in the concept map. There was a sequential relationship to the themes, indicated by the directional arrows in the concept map.

Figure 7-1 Conceptual Map: Major Themes and Subthemes



7.3.1 Context: Accessing health solutions as a parent of a child with CP

All mothers, with the exception of Stella, disclosed stories of how their child was diagnosed with CP. These experiences were volunteered without hesitation within the context of answering the rapport-building question: *How did you find out your child had CP?* The mothers described experience of challenging or invalidating interactions with doctors early in their child's life. For example, Vega, was in the early stages of life-threatening HELLP (Hemolysis, Elevated Liver Enzymes, Low Platelet Count) syndrome, but was misdiagnosed as having reflux. The syndrome caused the pre-term birth of her son. When Vega's son was born, she was initially told he was still-born, only to find out later that he had survived but was seriously ill and receiving care in the neonatal intensive care unit. Other mothers described how they thought their child had a significant problem, but experienced difficulty finding clinicians to respond to their concerns. For example, both Esther and Chandra describe having to “push” to get a diagnosis of CP for their child. Chandra said:

It wasn't until she was just after two because [child name] was prem. She was born at 33 weeks. I had placental abruption and so she was – being my first and only child – she wasn't, sort of, rolling or crawling and I thought,

‘Oh! That’s a bit slow,’ and they kept telling me that they usually catch up. And they usually catch up by two, but she wasn’t walking or anything. But then, when she finally did, she kept falling over and her leg was twisted and so I kind of pushed it. And the paediatrician made me feel like a neurotic. And I pushed it, and he sent me to see a podiatrist and they made me see a physio and they sent me to [doctor name] at [tertiary hospital] and as soon as I saw the specialist they said she had CP.

Later in the interview, Chandra used the word “*fight*” to describe what she had to do to get her child diagnosed. It was overwhelmingly clear that these mothers all experienced challenges accessing medical help, gaining a diagnosis or receiving treatment for their children when they were infants, and that it was a battle to get the care they wanted for their child. The mothers also provided additional context to their history of sleep problems. Some mothers described their medically vulnerable newborns, who required observation overnight; others described how they felt they needed to watch their sleeping toddlers, one of whom had a history of febrile convulsions. It was clear that many of these women spent their baby’s first months (sometimes longer) being vigilant overnight, in anticipation of their baby becoming unwell. Several of the mothers described initiation of co-sleeping because of medical vulnerability. Nova started co-sleeping because she was worried about her son:

When [child name] was a baby and he used to sleep with us too, especially when he was really little, I was so paranoid about his breathing. I don’t have a problem with co-sleeping, I’m happy to have the kids in there with us. I kind of got used to not moving because if I moved he would wake up and stuff. So, I would stay perfectly still if he pushed up against me, I would let him.

Luna was worried about her daughter having seizures:

Because when she started having seizures, she would sleep with me because I was so scared to leave her on her own. So I thought, ‘She is a baby, she is a baby, it’s ok.’ So, it was my behaviour as well. I fed the problem, so I would bring her into my bed.

Because these mothers were confronting sleep problems within the context of parenting a child with CP, they often approached seeking sleep solutions against the background of their own, often negative, experience of accessing healthcare for themselves or their child.

7.3.2 Major theme: Seeking solutions

Overwhelmingly, the mothers of children who slept poorly were aware that sleep could be better and had sought sleep solutions from their healthcare providers. All but two of the mothers described accessing more than one form of sleep solution. Nova, Vesper, Esther and Vega had all sought help from the family general practitioner (GP). Chandra, Astra, Luna and Vega had attended or tried to attend sleep schools with their children. In fact, Luna had taken her daughter to three sleep schools. Vega, Luna and Vesper had asked physiotherapists for help with sleep. Luna and Astra were about to start working with psychologists (this seemed to be associated with new funding from the National Disability Insurance Scheme (NDIS)). Nova, Vega, Nisha and Esther had all asked their paediatrician for help with sleep. The timing of when the mothers sought sleep solutions varied greatly. Some mothers attempted to seek help early in their child's life from various sources, including sleep schools, and maternal and child health nurses. None of the mothers found helpful services in early life, meaning that all the children discussed in Phase One experienced sleep problems into the early school years. Several mothers discussed the catalyst for seeking help. Nova said: *"So, um we got to the point where we weren't coping very well so we made an appointment to see the GP."* Vesper explained:

So, there was a period of time when he didn't sleep at all of a night. And then, obviously, things got better, where he could sleep at night, but it would only ever be for an hour at a time. And, you know, I guess he was obviously then probably tired all the time. I suppose, if you are going through that every night. But, then sort of towards the end of last year and the beginning of this year, I couldn't take it any longer.

Both Vesper and Nova described enduring long periods of poor sleep before seeking help, in the form of an appointment with their GP, to specifically discuss sleep problems. However, Luna tried early and often to find sleep solutions for her daughter:

Luna: *Well I have gone to three sleep schools with her... And I've done sleep rescue – somebody came through the night...*

Researcher: *What is sleep rescue?*

Luna: *A specialist will come in and stay the night. So, for example when she was a newborn, they would wrap her and tell her it is sleep time and get rid of the dummy, really drastic measures. And you shut the door and walk out and do three minutes, five minutes and then eight minutes and then 12-minute check and you keep... It's kind of controlled crying. Which is what I will have to do when I have the time. It worked with my son and it did work a little bit with [child name], then she got sick, so I had to go back again. So then, by that stage, I just got her and brought her to me.*

Luna had accessed multiple sleep specialists to help her with sleep training and possessed good knowledge of the methods of sleep training. However, she commented that she hadn't found the time to start sleep training yet, despite wanting to do so. She explained how she had postponed previous attempts because her daughter had become unwell. Chandra also took her child to a sleep school and described why this was an unsuccessful solution for her:

I went to that sleep school, I left there, and I was really upset because I was like, well, that doesn't work for me and I don't agree with it. But I was like, what other options are there? Was there a gentler option? Like, why isn't there another approach that I could try that works? And I thought, really, sleep deprivation with a little baby is like a nightmare. So, I really was disappointed that there wasn't something else that I could do or try. Which

is why I guess I just resorted to letting her be with me, and then, I suppose, now especially, because I thought she would grow out of it, but she hasn't.

Chandra's daughter was 10 years old at the time of the interview and her sleep problems persisted. Chandra was asked whether she had requested her current paediatrician for help with sleep:

Chandra: *I haven't really discussed sleep with him, it has always been other stuff (laughs).*

Researcher: *So, do you think that other stuff gets in the way?*

Chandra: *Yeah, I think I have placed more importance on the other stuff.*

Researcher: *That's interesting, even though you've just said how bad it is...*

Chandra: *Yeah, because I think part of me is just, that is just how it is, and this is how she is, and this is what we need to do to get through, and we have to just get through.*

Vesper described talking to many clinicians on her child's healthcare team, her maternal and child health nurse, allied health professionals and paediatricians. She explained why she stopped asking about sleep:

I guess by the time we got to Melbourne and we started to see [doctor name] and the paediatrician, I had honestly given up on really talking about sleeping, with him. It was just, I had come to the, I honestly had given up, and I was just, I was getting, I just thought I had to get through each night.

Astra, who had recently started seeing a neuropsychologist for help with her eight-year-old daughter's sleep, explained why she didn't seek help for her child when she was younger and sleep first became a problem:

No, I just, thinking about, she still young, she still not mature, she still behind for the mental development. She still behind. So, I just keep going but until six years old, seven years old, something wrong. So, I tried to get out of her bed but just starting battle. Every single day.

One participant described an experience that was divergent from the other mothers. Stella was the only mother interviewed who had not sought help for sleep. She explained that her son (11 years old) found it hard to get to sleep at night, falling asleep at 11 o'clock at night, instead of at an earlier, more desirable time, which made him tired the next day. She reported she had not sought sleep help as it wasn't that much of a problem – her son seemed to “*catch up on sleep*” on weekends.

The mothers, other than Stella, described a myriad of attempts at seeking sleep solutions from different sources. The interviews revealed that the outcomes of requests for help varied, but the majority of mothers reported negative or unhelpful results. This fruitless search for answers for sleep was identified as a subtheme of *seeking solutions* and lead to the next major theme of this phase: *being labelled or judged*.

7.3.2.1 Subtheme: Being labelled or judged

The feeling of being labelled or judged was a concept that was repeated throughout the interviews. Over half of the mothers interviewed either felt like they had been treated like a “*neurotic*” (Vesper), “*psycho*” (Esther) or “*crazy*” (Vesper) mother. The mothers also described taking action to try and convince a clinician that they weren't neurotic, psycho or crazy. This labelling was applied to both their search for sleep solutions and other aspects of care for their child. Vesper described how she was fatigued, exhausted and in need of sleep because her son was sleeping less than two hours per night. She said she was emotional and crying when she attended the appointment with her GP and told him about how she needed help with her child's sleep. She was told that sleep was not a problem and that her child would grow out of it. Then she was given a screening tool for depression. She was asked what the tool contained:

Do you ever... have you thought about hurting yourself? All those type of questions. I guess they have to do it. But as stressed as I might have been, I wasn't suicidal at the same time. Both the chemist and the doctor did that suicide check on me..., which is kind of OK but a little bit embarrassing as

well. Maybe embarrassing isn't the right word to use. You are asking for help, but then they put it on you like you're... it's like its making out that the sleeping problem, is not that significant and maybe it's you being crazy, you know?

The mothers discussed how they had prepared for their appointments, to help facilitate accessing the sleep solutions they needed. This was in response to worrying about being judged by their doctors. In anticipation of her appointment with her GP, Nova self-initiated a sleep diary:

No, I did it myself, because it got to the point where we knew we had to do something. And we couldn't get in to see his paediatrician at the hospital. So, we got in to see the GP, in the meantime. And just in my experience, I find when you go to the GP and talk about sleeplessness, as a mother of young children, they don't take you very seriously.

Nova felt she needed documented evidence in the form of a sleep diary in order to convince her GP that sleep was a problem. In their discussion of seeking sleep solutions, the majority of the mothers reported this experience of presenting to healthcare providers and yet feeling they were not being heard. These experiences were identified as the second subtheme to *seeking solutions: feeling unheard*.

7.3.2.2 Subtheme: Feeling unheard

The mothers described their experiences of accessing help with sleep problems. They reported that attempts to get help were often thwarted by a clinician who either normalised their sleep problem or dismissed sleep as a problem. Nova described her husband's experience when he took their son to the GP for sleep help:

The GP was shocking. My husband said, 'We are getting about three hours' sleep and this has been going on for months now.' He [doctor name] said to my husband, 'You know, you can survive on that amount of sleep.'

Luna said that she asked about her child's problematic sleep at every appointment with her paediatrician. Despite this, she hadn't received any sleep solutions:

Yes, I have asked her directly and she said, 'Well, let's tackle one thing at a time,' and I should be tackling toilet training at this point. I just don't know how to do it, I don't know where to start.

Vesper described how she had asked many healthcare professionals for help. Each attempt was met with a normalisation of her child's bad sleep and her requests for help were unheard, and so she stopped asking:

I talked to them about it and they said, 'Don't worry about, he'll get past it,' that sort of thing. Talk about the cramping, the tightness, and it was always like, you know, it was almost like no one believed what I said, like I was a dramatic new mother. I was being dramatic, but it was a very real situation.

Vesper went on to reflect: "I really did feel like in those early years I was really dismissed about my concerns." Vesper describes the effect of poor sleep and feeling unheard on her relationship:

It probably did put our relationship under pressure as well, I think, over that time. Like, you know, just the non-sleep and then the tired and the helplessness. You know, my husband would be like, 'Take him, take him to the doctor.' I would take him to the doctor – 'What did the doctor say?' 'Nothing, just get on with it, kind of thing.' If you can just imagine all of that stuff going on.

As is evident, the parents often felt dismissed and unheard when seeking sleep solutions. This feeling of being unheard was significant for the mothers, perhaps as significant as not finding solutions for their child's sleep. Vesper was asked if she remembered feeling listened to; she could not remember anyone hearing her questions about sleep.

Some mothers did report successful attempts in their search for sleep solutions. A less common yet important finding was the few instances when parents were

heard and successful in obtaining sleep solutions. Of the nine mothers who were interviewed, Nisha, Vesper and Nova had successfully improved their child's sleep with assistance from a clinician. The impact of this improvement was significant and was demonstrated in two ways: how the child was affected by improved sleep, or how the mothers felt when their concerns were recognised and they felt they were being heard. Vesper and Nova discussed how much of a relief it was to be heard, and how much of a difference improved sleep made to their lives. They both reflected that they did not feel like they could function properly without sleep. Furthermore, both commented that had they been asked to participate in research when sleep was bad, they would not have been able to respond to the invitation or even be able to discuss what it meant to have sleep problems. Nova found a paediatrician who addressed her concerns about sleep, and she discussed how this felt:

I sort of came to that first appointment with a whole lot of information and whole lot of questions of what my feelings were that was happening. It was good just to talk about them with her, and pretty much have it all confirmed. And then to get a plan for what we were going to do to tackle things. I actually had a whole heap of questions to ask her, but I felt she was so in tune with [child name] and worked out what was going on with him, that when I looked at my list of questions, she'd answered them all before I asked them. That was great. Certainly when I saw her the first time, sleep was the biggest issue.

Nova explained that when her son was not sleeping, he would have 'outbursts' daily at school. Nova described how her son's daily functioning changed when his sleep was improved:

He is certainly not having the same outbursts at school. He was having really regular hysterical screaming matches at school, at the point where he would have to be removed from the classroom, and that hasn't happened this term, which is good. It's only two and a bit weeks into the term (laughs) but even so, that's a huge improvement.

Nisha described that her daughter was often awake from 11 pm until 5 am most nights until she started school. At that time, her daughter was started on several medications that improved her tone and epilepsy and this, combined with a better sleep routine and less daytime naps, meant that her daughter would sleep through the night, if she was well.

All of the mothers interviewed described pervasive sleep problems and experienced challenges finding successful solutions. Those mothers who had success, had spent years with a child with significant sleep problems before solutions were found. This was the second major theme from this phase: the mothers learnt to survive sleep problems.

7.4 Major theme: Having to survive

When attempts to find successful sleep solutions failed, the mothers learnt to adjust to poor sleep. This was identified as the second major theme in this phase: *having to survive*. It was evident that the mothers actively accommodated sleep disturbance, even if this meant having a terrible night's sleep as a consequence. Luna described how she tolerated co-sleeping even though she would rather not, because it was better to co-sleep than to have to wake up at night:

So, I choose: do I want to be disturbed in the middle of the night, or do I want to just cave and get some sleep? That's what I have chosen, to have her in my bed so she doesn't wake up at night.

Other mothers described purchasing double beds and co-sleeping with their child, learning the triggers of bad sleep and changing their routine to avoid those triggers.

The mothers described their nightly experiences with sleep problems as well-known and habitual routines. Enveloped in this discussion was the concept of how the child's CP influences sleep. Mothers described the many aspects of CP, including care, comfort and the comorbidities of CP that may have contributed

to the establishment of behavioural sleep problems. Accommodating this routine was part of having to survive, as was the mother's adjustment to the effects of poor sleep. The mothers discussed the mental, physical and emotional impact of sleep problems, and how this impact would be reduced to 'survival' or 'just getting through'. Nova explained that she has issues with back pain, because of co-sleeping. The Researcher commented on the additional impact of the lifting required when a child has severe CP, and Nova replied: *"Yeah, I know. I brought it on myself, but when you are sleeping poorly you kind of think crap sleep is better than no sleep."*

Mothers discussed at length their child's behavioural problems associated with sleep, including bedtime resistance and separation anxiety. Luna described her experience of bedtime:

She arcs up every night, she is like a newborn: (baby voice) 'Come to bed.' And I just have to distract her and say, 'I'm coming... I'm just doing the dishes, I'm coming.' So half an hour of 'I'm coooming [whining]... I'm coming,' you know like that?

Luna had tried to get help with these sleep problems, but her paediatrician had said the first priority should be toilet training. Luna, knowing that she could not get advice from her paediatrician, then accepted that she had to endure this nightly routine. Vesper described how she became used to the habitual nature of her child's disturbed sleep routine, and the dread she felt when her child exhibited the signs that he was going to have a bad night:

Well, his whole body seemed tight, it's like he was clenching, his whole body was clenching. I would get him settled but every hour, on the hour, he would wake up like this. It wasn't even a cry, it was like a wail. I don't know, it was a very strange sound he would make, and we would hear it and we would tense up because we knew what we were in for.

Esther found that after trying to get help with sleep, or with the things she thought were causing sleep problems, she just resigned herself to learning to

cope and she and her partner would work together to make up for the sleep she didn't get:

Now, when I look at it, I think, you learn to cope and think, 'Nah, be better to just leave us alone to get on with it' and... luckily, [husband name] had a job that was flexible and that meant he didn't have to be in an office at 9 am. He could work a little bit from home. He used to be able to come home early and take the kids away for a bit and play up at the oval or something.

Nisha's daughter has severe CP and many comorbidities. She described being awake for long periods at night:

And the first it started with her sleep, but not continuously. And then I noticed that we had a lot of sleepless nights, for me. Sometimes she would sleep like 7-8 o'clock and then she wakes up about 11 o'clock and then from eleven to five or six in the morning she would stay awake

Nisha went on to explain the routine she adopted with her daughter:

She was very noisy, no one can sleep. Because my husband had to go to work and my other daughter, she had to go to kindergarten at that time. Yep, so I had to be with [child name] and calm her down, and she was laughing and playing all the time.

The word 'survive' was used many times throughout the interviews. It was often used in reference to how desperate the mothers were feeling. This was revealed in the interviews in many ways, one of which was the physical impact on the mothers. Nova described how she felt when her son was waking up to 30 times every night:

Researcher: *How did you cope during the day?*

Nova: *Not good not good at all. A lot of headaches, I would cry.*

Researcher: *You were getting actual headaches?*

Nova: *Yeah, yeah, yeah, I was getting headaches and I was crying.*

Researcher: *You were crying - not him?*

Nova: *Yeah me (laughs). I was more emotional than usual, just because um it sort of got to the point where it was so much, I was so tired that I felt physically sick.*

Nova went on to say she made an appointment with a GP, specifically because she was concerned about what would happen if the situation didn't change: "*We were at the point where we needed something right away, you know, before anyone was going to come to harm.*" It is clear that the impact of sleep deprivation was significant for Nova. She was worried that the effects of sleep deprivation may be a risk for herself and her child. Astra talked about how sleep deprivation impacted her life: "*Yeah, yeah, yeah, I [was] also grumpy and your body has no energy, for clear mind, to do things.*" Esther described the extent of her tiredness: "*I can remember times where I almost had car accidents because I was falling asleep.*" Later in the interview she said: "*I don't know how I survived looking back now (laughs). I don't know how I survived.*" Vesper articulated:

People have babies and say they are up all night, but I am telling you, I was awake all night with him, and I also had another little toddler and so I was awake all day. And so, really, for a good 18 months, I genuinely don't know what I was doing. I don't know how I survived, cause I genuinely didn't sleep. Like, maybe I got an hour here or there.

Vesper went on:

When I look back, to the younger sleep deprived years. You do go a bit insane, the mother sitting in front of someone, most of the time she is going to be crying her eyes out, in front of you (laughs)..., you might even have to have counsellors because they will be a little bit crazy (big loud laugh).

Vesper described how she felt when she was told by a GP that three hours was enough sleep to survive:

Well, [I felt] terrible because I don't believe that. That is, I just can't believe that that is normal... for a parent having to be awake for such extended periods of time. Like, maybe another family could have just lost the plot? Maybe, you know what I mean? I don't know.

A question asked in all the interviews was: *If I had a magic wand, what would good sleep look like?* Surprisingly, the mothers' answers indicated that their expectations for better sleep were not to have a child who sleeps through the night, but simply a child that would sleep for a block of time. Vesper explained:

Vesper: *I can remember a point in time, I remember thinking, 'Oh, if only I could put him to bed and he would sleep until midnight.'*

Researcher: *What time would he go to bed, 7-ish?*

Vesper: *Yeah 7-ish. By 8:30, the time I'd be having my dinner, he would be up. It would start. So I would never sit down to dinner, or you know, cooking dinner. It would start, pretty much an hour after he went to bed. I can remember saying, 'I wish he would just sleep until midnight and I can deal with that.' Yeah, no! Ideally, other times I would wish he would just wake up twice. I guess I didn't have an expectation that he would sleep through.*

Nova said:

Probably not waking before 3 am – so you get the solid block. I mean, that varies though, it comes and goes. You know what I mean? He will have good stages where it lasts three to four weeks, then it goes crap for a few months and then it might go good again. It is probably more bad, than it is ever good. It's very quick, we just turn him over, we are so used to it we don't wake up properly ourselves, we turn him over, go back to bed and then you go back to sleep sort of thing.

The theme of *having to survive* is clearly articulated in the mothers' descriptions of how they learnt to adjust to sleep deprivation and disturbance.

Mothers adjusted their night-time to accommodate the need to be awake for or with their child. They also made changes to their day, if they were able to do so, to increase their amount of sleep. The mothers described the impact of tolerating chronic lack of sleep, and the physical, emotional and mental consequences. The mothers articulated this impact exquisitely and talked at length about how poor sleep would become routine, a situation to which they adjusted. They anticipated what their child might need in the night ahead and prepared themselves, and sometimes their partners, to optimise sleep for all. Mothers who sought solutions and felt unheard or labelled, settled for learning to survive, despite poor quality and quantity of sleep, and frequently pursued sleep solutions from alternative sources. Hence *seeking alternate solutions* was identified as a subtheme to *having to survive*.

7.4.1.1 Subtheme: Seeking alternate solutions

Four of the mothers described how, when their care team and clinicians could not or did not provide effective sleep solutions, they sought help from other sources, including non-Western medicine and alternative therapies/treatments. The mothers who had accessed an alternate therapy all expressed some reservations about using these therapies. They wanted to improve matters for their child and to do so, they were willing to try anything. Vega had discussed sleep problems with her paediatrician and her son was trialled on medications, which caused adverse reactions. In an attempt to find treatments beyond mainstream Western medicine, Vega saw a naturopath:

Yeah... the magnesium didn't come from the normal doctor, it came from the naturopath. Like, I try different things, I have been to a naturopath. I don't know, to get something, maybe something to calm him or whatever. He had taken magnesium powder and things like that and I don't know, and things to try and keep him calm at night-time.

Vega talked about the naturopath with a tone of scepticism, as if she was not sure the treatment would be effective. Vesper, after a G.P. told her that her son's sleep was normal, asked her local pharmacist for advice on sleep:

When I went to the chemist, they were really good and they did offer to help me get into a sleep school at that same time, and they gave me a natural spray to spray under his tongue, and I used it as well and to be honest it is probably just water, I don't know.

The alternate solutions that parents sought included naturopathy, medication advice from pharmacists, massage and over the counter natural remedies. All the mothers who sought alternative treatments had no previous history of using non-Western treatments. The failure of occidental medicine was a catalyst for seeking alternative treatments. The two major themes and three subthemes identified in this thematic analysis demonstrate the challenges parents experience in seeking sleep solutions. This analysis also demonstrates the impact and consequences when solutions were not found.

The mothers interviewed in this phase disclosed the many challenges and struggles that were the result of sleep problems with their child. Astra was a mother who unwillingly co-slept with her daughter because she would refuse to sleep alone. Astra explained that when she co-slept with her child, she would sleep an average of four hours a night. Her child was difficult to wake in the mornings and often refused to participate in the morning routine. At the conclusion of the interview, Astra said:

I just want you to be successful, to help us. Because we are struggling and lots of people don't understand. They know we have kids with disabilities. It's not just physical torture. It's mental. Mental torture. I put my head to the wall four or five times this morning. I cry. I scream. Maybe we are very brave in the class... But at home we are drowning.

7.5 Survey Design: Parent Preferences

As previously mentioned, a pilot study preceded this thesis.⁽²⁾ Within this pilot study, paperwork fatigue or frustration with household administration tasks were a key limitation of the recruitment process. Parents reported that they were happy to talk over the phone about their experience, but frequently

refused to complete a written survey: paper forms for a research project were simply another administrative task for which they did not have time. Given this key outcome of the pilot study, it was crucial that the survey design in this thesis considered the preferences of the potential participants. The semi-structured interviews of Phase One included consultation with parents about the design of the quantitative survey to be used in Phase Two. This consultation is in keeping with the principles of critical social theory (as explained in previous chapters) and aims to ensure that:

- the survey attracts the maximum number of participants: its feasibility is maximised; and
- the research outcomes are relevant to the experience of those it targets to benefit, that the problem is well understood in order for effective change to be implemented.

Parents were sent copies of potential sleep surveys to be used (see Chapter Nine) and asked to read them before the interview took place. All the interviews followed a similar format, guided by the interview tool (see Appendix F). It was expected that the participants would review the tools and offer their opinions about which survey they preferred, and why. However, as has been demonstrated by the thematic analysis in this chapter, the conversations about sleep were rich and descriptive. In all but one interview, the conversations about preferred surveys and survey design were less descriptive; the answers were shorter and less detailed. The majority of the mothers made a comment that there was a lot of information to read in the surveys that had been sent to them. Only one of the mothers, Nova, had read the screening tools before the interview. Nova provided detailed and reflective opinions about the surveys she had been given. The general lack of engagement by the mothers to review the validated survey tools and provide feedback meant that inclusion or exclusion of particular tools, based on feedback about each tool, was not possible. If the mothers had not read the surveys, the interview questions were modified to address survey design more broadly, asking questions about the preferred length of surveys, question format and question content.

7.5.1 Survey duration and question format

Parents were asked: *If you received an email that said, 'This survey will take xx minutes to complete,' what is the ideal length of time a survey would be (in minutes)?* The mothers preferred the survey to be brief, preferences ranging from five to 20 minutes. The mothers also articulated a preference for tick boxes or short answers; they didn't want to have to write explanatory answers.

7.5.2 Inclusiveness of surveys

The majority of the validated sleep screening tools selected in this study were designed for typically developing children; they often contained questions that were not inclusive of a range of abilities. For example, questions about getting out of bed would not apply to a child who is unable to walk. The parents were asked how they felt about completing a survey that was not inclusive of their child's abilities. Both Nova and Esther mentioned that they preferred questionnaires that have an option to select 'not applicable'.

Esther said:

I think I have a very low care factor with stuff like that (laughs). Sometimes with some of the parents... of kids with disabilities, they are very quick to call discrimination. I think that most of the world isn't set up for these kids, you are likely to come across questions that don't match. I think it is handy with those questions to make sure there is a 'not applicable', so you can tick that, so you don't feel like you are having to answer – that doesn't apply. I think there was one question somewhere, where I thought I kind of had to answer 'never', but it wasn't so much. It was the 'Have you observed your child sleep walking?' I had to circle never. I really wanted to say N/A.

What could be deduced from the minimal discussion that occurred was that parents wanted short surveys with few free text answers, inclusive of their child, or at least with the option to select 'Not applicable' if the question did not apply to their child. This information was used to inform the Phase Two survey design.

7.6 Summary of Parent Preferences

Overall, the parents expressed the following preferences for survey design:

- i. Survey to be as brief as possible.
- ii. Minimise amount of free text answers required.
- iii. Preference to not answer questions that do not relate to their child's health or abilities. For example, parents of children classified within GMFCS level II CP did not want questions related to immobility.
- iv. Parents were not offended by non-inclusive questions in surveys but those who have less physically able children prefer to have the option to select 'not applicable' (n/a).

These parent preferences were used to choose the paediatric sleep survey tool. How these preferences were applied is described in Chapter Eight, Section 8.2.

7.6.1 Inclusive research design

Both Astra and Stella explained that part of their reason for participating in this study was because they knew they would be able to participate. Astra was from a non-English speaking background. She said that she has trouble reading English and so to participate in a survey, she would have to wait for her husband to interpret the questions for her. Similarly, Stella explained that she could not participate in written surveys due to a visual impairment. Both mothers expressed that they were glad to have the opportunity to participate, as many research invitations are sent to them that they have to decline. The recruitment criteria for Phase One was very broad, in order to maximise participation, this allowed for diverse participants and insights.

7.6.2 The clinical experience of the researcher compared to the lived experience of the parents

As described in section 6.1.2 one aim of Phase One was to examine if the clinical experience of the Researcher was consistent with the lived experience of parents

of children with cerebral palsy (CP) who have sleep problems. The findings of Phase One revealed a significant contrast between the assumptions made based on clinical experience and the parent's lived experience. Clinical experience suggested that parents of children with CP who sleep poorly may have normalised sleep problems within the context of disability. The data collected in Phase One suggested that parents were aware that their child's sleep problems were not normal. However they may have endured chronic sleep problems with their child due to significant health care system challenges when trying to obtaining sleep solutions for their child.

CONCLUSION

Presented in this chapter are the findings from the scoping phase of this thesis. The two main themes *seeking solutions* and *having to survive*, and their subsequent subthemes, provide evidence that seeking solutions for sleep problems can be challenging for parents. Sleep disturbance and deprivation has a significant impact on children with CP and their parents. The mothers' perceptions of survey-based research and quantitative sleep measures have been presented. These data provided critical guidance for the design of Phase Two and Three of this study.

8 THE APPLICATION OF PHASE ONE FINDINGS TO PHASE TWO AND THREE: DESIGN MIXING

INTRODUCTION

As previously described, the first phase of this study was a scoping project. A cohort of parents of children with sleep problems was interviewed to examine their experience of sleep problems, approaches to seeking sleep solutions, and opinions and preferences regarding the second phase of the study design. Phase One resulted in thematic analysis of the impact and experience of sleep problems, attempts to find solutions, and descriptive data regarding parent opinion and preferences regarding the design of the Phase Two survey. This chapter presents an explicit explanation of how Phase One findings informed the design of Phase Two and Three of this study. In-depth discussion and triangulation of the findings of all three phases occur in a final discussion presented in Chapter Twelve.

8.1 Phase One Findings: Brief Synopsis

As reflected in Chapter Seven, the key findings of Phase One were the themes of *seeking solutions* and *having to survive*. These themes and their subthemes reflect the experiences of the mothers interviewed, who frequently sought sleep help and often felt unheard or dismissed, and then resorted to learning to accommodate their child's poor quality and/or quantity of sleep. In addition to the thematic analysis, the interviews also captured descriptive data about what parents preferred in a survey design.

8.2 Parent Preferences and Opinions regarding Phase Two Quantitative Survey Design

A summary of parent preferences are described in Chapter Seven, Section 7.5. The table below explains how the parent preferences align with the sleep assessment tools that were under consideration.

Parent Preference	SNAKE	CHAILEY	CSHQ	SDSC
<i>Survey two pages or less</i>	×	×	✓	✓
<i>Survey relevant to all GMFCS</i>	×	×	✓	✓
	(GMFCS IV and V only)	(GMFCS IV and V only)		
<i>Minimal free text answers</i>	×	×	✓	✓
<i>Option to choose N/A as an answer</i>	×	×	✓	×

Table 8-1 Parent Preferences for Survey Characteristics

As Table 8-1 indicates, the CSHQ is the only tool to meet all parent preferences, and it was therefore chosen as the paediatric sleep screening tool for Phase Two of this study. Parent preferences were also considered when the Researcher designed questions that were written for the survey. Questions were structured as multiple choice 'tick box' style questions wherever possible. Free text answers were kept to a minimum. The entire survey was designed to be

completed in less than 15 minutes. The thematic analysis of Phase One also informed the research design and focus.

8.3 Experience and Impact of Sleep Problems and Finding Solutions: Redirecting the Inquiry

The clinical experience of the Researcher led to a suspicion that parents of children with CP normalise poor sleep, and therefore do not ask for sleep solutions from their healthcare team. This led to a presumption that the main focus of this study would be to provide parents with sleep education and motivate them to seek sleep solutions from their healthcare providers. However, the thematic analysis of this scoping phase revealed that the issue was not a normalisation of poor sleep on behalf of the parents. Instead, parents were asking for help with sleep and finding that clinicians did not validate their concerns or offer solutions. It is evident from the themes of *seeking solutions*, *having to survive*, *feeling unheard* and the subtheme of *seeking alternative solutions*, that parents were aware that their child's sleep was a problem, that it was not normal, and that sleep could be better. All but one of the mothers had asked for help with sleep. It was these data that shifted the focus of this study from why parents did not seek help, to why their attempts to seek help were both fraught and fruitless.

Table 8-1 below summarises how the main findings from the thematic analysis in Phase One informed the design of subsequent phases.

Phase One Finding	How Finding Informed Phase Two or Three
When asking for help with sleep, clinicians often normalised poor sleep for these families. Others dismissed the mother's concerns about sleep.	Phase Two: Survey questions included details about sleep solutions that were sought, what they were and if they had been effective Phase Three: Interview tool included questions about the experience of accessing sleep solutions, feelings and experience of the journey to find sleep solutions
When clinicians did not offer solutions or offered solutions that did not work, the mothers often sought alternative solutions to sleep problems. Alternative solutions include asking pharmacists, alternative or natural therapists	Phase Two: Questions about any alternative therapists/therapies included Phase Three: Interview tool included questions about the experience of accessing alternative therapies and attitudes towards alternative treatments
The parents appeared to build an armour of persistence, wherein they navigated the system, acknowledging the dynamics of the doctor-parent relationship and what they have needed to do to be taken seriously	Phase Three: What is their experience of seeking solutions in regard to their child's health? How has this impacted their efforts to get sleep solutions? Do the children who have good sleep have a different experience of navigating the system?

Table 8-2 How Phase One Findings Informed Phase Two and Three Design

In summary, the findings of Phase One shifted the focus of the study away from increasing education and knowledge about sleep for parents, to a new focus on exploring the parents' experience of accessing sleep solutions, how they navigate the healthcare system and what might be changed to improve access to effective solutions. In addition to the thematic analysis and descriptive data from Phase One, the recruitment process and challenges were also informative for Phase Two and Three.

8.3.1 How Phase One recruitment strategy and response informed future recruitment strategy

The factors listed above were informative for recruitment. Strategies for future phases needed to be refined and targeted to engage this group of parents. The target participants for this phase were primary caregivers who are likely sleep deprived and time poor. It is important to note that some of these primary caregivers will be unreachable, regardless of the recruitment strategies used. As Nova said in her interview:

Nova: *Yeah, I probably couldn't have had this conversation a few months ago (laughing), when things were really bad, I would have been the world worst person to talk to.*

Researcher: *I will remember that.*

Nova: *It's really important point to remember. In this journey, there are certain points in time when you know you are not good to anyone. You would say, 'No I can't do a research project, because I am just going to be...' You don't even want to reflect on whatever is happening enough to share it with someone else, because you are just surviving.*

Indeed, the mothers who had experienced sleep problems wherein their child was awake for significant portions of the night also reported that their child's sleep had since improved. That is, they were talking in retrospect about when sleep was worse. Mothers with children who were currently experiencing frequent wakings were not amongst this study cohort. The mothers whose children had a current sleep problem were those children with behavioural sleep problems: children who resisted bedtime and needed their parents present to fall asleep but generally, once asleep, would stay asleep. The difficulty of recruiting primary caregivers who are in the midst of severe sleep deprivation needs to be acknowledged. It may mean that any research in this area may not reflect the worst sleepers, as they are too fatigued to be participants.

One method to increase the likelihood of success for recruitment was to ensure that the participants were contacted via the method most appealing to them. During the interviews, parents were asked about their attitudes towards different contact methods: emails, phone calls and text messages. It was clear that an email or text message was preferred. Future phases of this study ensured that participants were able to choose their preferred contact method.

One strategy identified to address the recruitment difficulty was to offer financial compensation for parents who participated in Phase Three of the

study. Philanthropic scholarship funding awarded in the third year of this study enabled this project to offer gift vouchers of \$50AUD to participants, or if they preferred, for the \$50 to be donated to a charity that benefits childhood disability. This offer of an appreciation gift was explained to the participants in the Phase Two survey tool as an incentive to consent to being contacted to participate in the interviews of Phase Three. Another aspect of Phase One also informed the design of Phase Three as a qualitative phase: the benefit of telephone interviews in this cohort.

8.4 Context of Interviews

Participants were offered face-to-face interviews at the RCH or interviews over the phone. All but one mother chose a phone interview. The discussion was faceless, with the Researcher and mother having very little knowledge of each other, other than the minimal information exchanged in recruitment emails or phone calls. This relative anonymity may have contributed to the candour with which mothers disclosed their experiences. Sleep is an intimate and private experience,⁽¹⁶⁸⁾ yet these mothers freely disclosed detailed information about various aspects, including what happened at night, family dynamics, their experience of accessing help, the complex emotional and physical consequences of sleep disturbance, their child's disability, and their experience of parenting in general. Novick⁽¹⁶⁹⁾ has noted that phone interviews may provide an interview scenario wherein the interviewee feels relaxed and able to disclose sensitive information.

To provide an example of the candour with which the mothers disclosed information, one mother discussed how her child's sleep impacted on her sex life and her relationship with her husband. This level of trust in the interviewer is significant. Nurses are amongst the most trusted health professionals.⁽¹⁷⁰⁾ In the hierarchy of the biomedical model, nurses are also often viewed as equals or partners to the healthcare user, or at least lower in the hierarchy than doctors. Nurses are known to provide emotional care to patients and families⁽¹⁷¹⁾ and are reportedly⁽¹⁷⁰⁾ the most trusted profession in the world and

have been for decades. The level of trust placed in nurses reflects their position in society as approachable and helpful clinicians, while not having the power or intimidation associated with medical practitioners or even academic researchers. It is plausible that the interviewer, as an experienced nurse who works within the clinical area of CP, was perceived by the interviewees, by qualifications alone, as a trusted and safe person with whom to disclose personal details.

Historically, using a telephone for interviews has been viewed sceptically⁽¹⁷²⁾ as it is often considered the means to organise the interview, not the primary medium to conduct the interview.⁽¹⁷²⁾ The content of these interviews included a critique of medical systems. Interviewing in a hospital, with hospital staff, about a person's experience of healthcare could be the cause of some intimidation for the participant. A faceless interviewer, without a fixed location or uniform, may remove the bias or judgment associated with these visual cues and may reduce judgment of status or power. This lack of bias may facilitate trust and decrease intimidation associated with a parent talking to a healthcare professional. The convenience of an interview format that allows the participant to call in from their preferred location, at their preferred time, with no need to travel, no associated costs, and the participant also being faceless, likely contributed to the relaxed nature of the interviews and the richness of the information shared.

The above findings confirmed that telephone interviews are an effective data collection method for this area of research, and this method was offered again in Phase Three, the final qualitative phase of this study.

8.5 Objective Sleep Monitoring

At the outset of this study, it was planned that the quantitative arm of the study would include real-time objective monitoring of sleep in addition to the survey tool. This monitoring would be actigraphy (utilising a watch-like device that monitors movement, light, heart rate), video monitoring (utilising a small video

set up in a child's room) or the maintenance of a sleep diary as a paper diary or smart phone application. When asked about these methods of observation, the mothers were open to the use of actigraphy: many expressed curiosity about their own and their child's sleep and what the monitors might show. The mothers expressed self-consciousness in regard to using video monitoring, worried about what clothes they might wear, what the video may show, and one mother (Astra) was worried her husband would not agree due to concerns about privacy. At the conclusion of Phase One, the opinions of the mothers about the observations, and the difficulty in recruiting poor sleepers, were considered in combination with the value of potential data collected. Mothers were also open to a smart phone application or phone call from the Researcher to ask about the previous night's sleep, but the mothers expressed how difficult it would be to remember how many times per night they had got up to their child. The Researcher decided to not pursue objective sleep observations for the following reasons:

- i. The mothers reported that when they complained about sleep problems, they were not listened to or labelled, and several mothers talked about needing to provide 'proof' or prepare for appointments where they asked about sleep problems. Using an objective measure of sleep to compare to the parent report would align the Researcher with the sceptical clinicians who asked the mothers for evidence.
- ii. Through the lens of CST, the use of an objective sleep measurement to corroborate a parent's report could be perceived as giving power to the objective measure and disempowering the parent's report.
- iii. The difficulty of recruitment in Phase One was likely to apply to subsequent phases of the study; the typical response rate for VCPR projects is 30% (personal conversation, VCPR Manager, Sue Reid, 27 May 2015). Asking for an additional research task to be completed could have been too onerous and may have resulted in an even lower recruitment rate.

CONCLUSION

The thematic analysis of the Phase One interviews informed the design of the subsequent phases of this multiphase study. The assumptions held by the Researcher prior to Phase One were somewhat contradicted, and the research design was adjusted accordingly. This phase highlighted that recruitment of this participant group is difficult. It is evident that the experience of seeking solutions for sleep problems is often challenging and disappointing for parents/carers. Analysis of Phase One supported the need to design future phases of this study with a focus on exploring those challenges. This chapter has described the outcomes that informed the design of Phase Two and Phase Three of this study, namely the challenges of recruitment, survey design and redirecting the inquiry focus. Conversely, the successes of Phase One have also informed the design of future phases, including the interview context, which will be mimicked in the future qualitative phase. The following chapter will describe the research methods applied in Phases Two and Three of the study.

9 PHASE TWO AND PHASE THREE METHODS

INTRODUCTION

The previous chapter discussed the findings of Phase One and explained how these findings informed the design of the second and third phases of this study. This chapter describes the research methods used for the quantitative (Phase Two) and subsequent qualitative (Phase Three) phases of this study, including recruitment and data collection procedures. Considerations regarding the handling and storage of data, as well as ethical, privacy and confidentiality factors, are presented. The chapter also includes a short explanation of how Phase Two results informed Phase Three.

9.1 Phase Two

Phase Two methods are described in Chapter Ten, which is presented as a manuscript that was submitted to the *Journal of Paediatrics and Child Health* on August 26, 2019 and is currently under editorial review. The methods will not be repeated in this chapter, which only presents information on Phase Two that has not been already presented as part of the journal article that is Chapter Ten.

9.2 Aims and Research Questions

In addition to the aims described in Chapter Ten, Section 10.2, the aims for Phase Two were to:

- i. inform the design of the Phase Three interview tool
- ii. act as a conduit for recruitment for Phase Three.

The research questions were as outlined in Chapter Ten, Section 10.2.

9.2.1 Use of Phase Two results

The quantitative phase of this study was used in three ways:

- i. The results were used in corroboration with the Phase One results to inform the design of the interview tool for Phase Three. The parents' responses to survey questions were used as prompts within the interviews. Specifically, the type of sleep problems described, what happened when they asked for help, if they didn't ask for help and relevant aspects of the sleep screening tools.
- ii. Phase Two was a conduit to recruit all participants for Phase Three. The final question of the survey asked participants if they would agree to be contacted for a follow-up interview. They were asked to include their preferred contact details and preferred contact method: phone number, email or text message.
- iii. The core concepts of critical social theory were also applied to the Phase Two results, which involved consideration of the socioeconomic resources of the study cohort and research questions/focus for the Phase Three interview tool.

9.3 Phase Three Interviews

9.3.1 Aims and research questions

The aims of Phase Three were to:

- i. explore the experience of sleep for parents of children with and without current sleep problems, and to explore if those with sleep problems report a different experience of finding sleep solutions than those without sleep problems
- ii. explore the experience of accessing sleep solutions for those with sleep problems
- iii. consult with parents on potential sleep interventions

The research questions were:

- i. What is the experience and impact of sleep disturbance and seeking of sleep solutions for parents of children with CP?
- ii. What do parents seek in an intervention for sleep problems?

9.3.2 Phase Three recruitment and participants

9.3.2.1 Inclusion criteria

Participants of Phase Two who answered *yes* to the question *Do you agree to be contacted by the researchers to discuss your participation in an interview?* and provided their contact details, were eligible to participate in Phase Three.

9.3.2.2 Purposive sampling

Purposive sampling is intentionally recruiting participants who have experienced the key concept being explored in the study.⁽⁶³⁾ In order to answer the research questions for this phase, eligible participants from Phase Two were invited to participate, based on their child's total CSHQ score and their GMFCS level (as reported by their parents). In order to align with the analysis of Phase Two, and provide greater ability for comparison between results in both phases, participants were grouped into one of three GMFCS subsets: GMFCS I & II, GMFCS III, GMFCS IV & V. Parents for each GMFCS group who had either the highest (worst sleep) scores or the lowest (best sleep) score on the child's CSHQ were contacted. The participants were contacted in successive rounds of

up to 15 invitations per round, with two or more weeks' wait time between invitation rounds.

9.3.3 Phase Three recruitment and data collection

9.3.3.1 Invitation to participate

Participants were contacted via their preferred contact route (email, text message or phone call). Within this invitation, the study was briefly explained and they were asked to contact the Researcher if they were interested in participating. One reminder was sent two weeks after the initial invitation if no response was received. The email invitation included a copy of the Participant Information and Consent Form (PICF) (see Appendix E). Those potential participants who were invited via text message or phone call and who expressed an interest in participating were sent copies of the PICF before the interview was conducted (via their preferred contact method).

9.3.3.2 Semi-structured interviews

The procedure utilised in Phase One was also followed in Phase Three of this study (see Chapter Six, Section 6.5). The interview tool was designed based on the analysis of Phases One and Two. A copy of the interview tool can be found in Appendix H. In addition to this tool, the information taken from the participant's survey responses was also used as a prompt for questioning. Throughout the recruitment period of Phase Three, interview transcripts were revised and considered, and topics that warranted further exploration were added to the interview tool. These are described Chapter Eleven.

9.3.3.3 Voucher of appreciation

A Visa eftpos card voucher worth \$50AUD was offered to those who completed an interview. If the participant declined the voucher, it was donated to a charity on their behalf.

This voucher was offered for two reasons:

- i. To encourage participants to engage with the research. The slow recruitment in Phase One highlighted the difficulties in engaging these parents. The financial reward was offered as an incentive.
- ii. In alignment with CST – recognising that the time of the participant is valuable, and the payment represented a recouping of any time that may be lost in talking to the Researcher.

9.3.4 Phase Three data management and analysis

This qualitative phase used the thematic analysis of Braun and Clarke⁽¹⁶⁰⁾ described in Chapter Six, Section 6.5. However, within this phase, the interview recordings were transcribed by an external transcriber.

9.3.5 Ethical considerations

Ethical considerations for all three phases are described in Chapter Six, Section 6.7. There were no additional ethical considerations for this phase. Ethics approval was obtained from The Royal Children's Hospital, Melbourne Human Research and Ethics Committee (HREC 37300). Documents associated with ethics approval for Phase Two and Three can be found in Appendix D.

CONCLUSION

This chapter describes the design of the second and third phases of data collection in this study. The research procedures, ethical considerations and data collection and analysis are described. How the Phase Two results informed the design of the Phase Three interview tool has been explained. The results of these phases are discussed in subsequent Chapters Ten and Eleven.

10 PHASE TWO RESULTS

INTRODUCTION

This chapter presents the findings of Phase Two, the quantitative survey. The chapter is presented as a manuscript that was submitted to the *Journal of Paediatrics and Child Health* on August 26, 2019. This paper is currently under editorial review.

The manuscript includes the background, methods, data analysis and results of the survey, from which 126 complete data sets were received. These quantitative findings provide a broader understanding of the frequency and type of sleep problems for children with CP. Appendix J contains the required documentation for thesis by publication (primary supervisor and co-author forms). Following the manuscript are additional tables that were not relevant to the focus of the publication but are discussed in this thesis. The results of Phase Two are triangulated and discussed in Chapter Twelve, the final chapter of the thesis.

Title: *Sleep problems and solution seeking for children with cerebral palsy and their parents*

Type of manuscript: Original article

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10.1 Abstract

Aims: Sleep problems are common in school age children with cerebral palsy (CP). Despite the significant impact of sleep disturbance and deprivation, there is a paucity of research in the area. The aims of this study were to 1) investigate the frequency of sleep problems in children with CP and their parents and 2) understand what happens when parents ask for help with sleep problems from their healthcare professionals.

Method: This was a prospective cohort study using an online survey sent to parents/primary caregivers of children with CP aged 6-12 years recruited through the Victorian Cerebral Palsy Register (VCPR). The sleep assessment tools: The Children's Sleep Habits Questionnaire (CSHQ), the Pittsburgh Sleep Quality Index (PSQI) and the Gross Motor Function Classification System Parent Rating Tool were administered along with custom designed questions that were informed by a preceding qualitative scoping study.

Results: Complete data sets were received from 126 parents/caregivers. Almost half (46%) the parents reported their child had sleep problems. Of the 64 parents who reported seeking help for a child's sleep problem only 21 indicated that their attempt was successful. If a child had poor sleep, the parent was more likely to have a sleep problem than parents who did not report poor child sleeping.

Conclusion and Implications: Sleep problems are common in children with CP and their parents. Parents do not always seek help and those that do may not find an effective solution. Future research should explore how sleep problems can be effectively prioritised for children with CP and their parents/caregivers.

Brief Points:

What is already known on this topic:

- International studies indicate that sleep problems are common in children with CP, yet accurate Australian data are lacking on both sleep problems and help seeking for sleep problems.
- The comorbidities associated with CP such as pain, discomfort, gastrointestinal issues and the need for repositioning can all impact on sleep.
- There is a paucity of descriptive data that could inform the implementation of effective management practices.

What this paper adds:

- Frequency and type of sleep problems in children with CP in Australia concur with similar international studies.
- Results provide additional evidence that sleep problems in a child with CP are concurrent with poor parental sleep quality.
- Parents seeking help for sleep issues often fail to find effective solutions from their healthcare team, demonstrating a real need for evidence-

based approaches to make sleep a health priority and to improve access to sleep solutions for this cohort.

Keywords: Sleep, cerebral palsy, parent sleep, child

10.2 Introduction

Cerebral palsy (CP) is a static neurological disorder caused by damage or malformation to the foetal or developing brain affecting movement and posture.⁽⁶⁾ Cerebral palsy is associated with many comorbidities, including but not limited to: vision impairment, intellectual disability, respiratory conditions, gastroenterological conditions, epilepsy, and sleep disturbance.⁽⁹⁾ Current research suggests that between 30%⁽⁶⁵⁾ and 60%⁽⁸²⁾ of children with CP have sleep problems. International research suggests that sleep issues impact on children with CP; a negative association has been found between sleep problems and physical and emotional health⁽⁸²⁾ and behaviour.⁽⁷⁶⁾ Similar data are not available about sleep in Australian children with CP. However, a report from the Victorian Equal Opportunity and Human Rights Commission states that sleep deprivation and night-time vigilance are associated with parents surrendering care of their children with disabilities.⁽⁶²⁾ It is clear that the impact of sleep problems in children with CP is significant, consequently there is a need for good quality evidence to inform the development of effective sleep solutions.

The majority of published research in CP and sleep for school-aged children consists of studies with small sample sizes that use prospective parent report sleep assessment tools such as the Child Sleep Habits Questionnaire (CSHQ) and the Sleep Disturbance Scale for Children.^(64, 65, 72, 76, 79) These studies demonstrate that sleep problems are prevalent in children with CP. Few studies^(64, 65, 68, 71, 78, 79, 83) have explored the impact of the child's sleep problems on the parent. Again, there is a paucity of Australian based studies that specifically focus on CP, with only two published studies, a pilot⁽²⁾ that led to

the current study and a larger study,⁽⁶⁹⁾ which was a retrospective audit of children who attended a sleep service.

There is little published evidence about whether parents seek help for sleep problems in children with CP, and if the interventions suggested are effective. Prior to determining how to address sleep problems, it is essential to understand if and when parents ask for help, and the subsequent outcome of their request. This study aimed to describe the sleep problems of children with CP and their parents and how families seek solutions in Victoria, Australia.

Specifically, this study aimed to explore:

- i. the frequency and type of sleep problems in Victorian children with CP aged 6-12 years and whether parents concurrently had sleep difficulties
- ii. whether, and from whom, parents/primary caregivers seek help for their children's sleep problems.

A secondary aim was to understand if the parents who sought help found the advice or treatment offered effective.

10.3 Materials and Methods

10.3.1 Study design

This was a population-based cohort study using an online survey that included validated sleep questionnaires and custom designed questions. The survey was managed and administered through the data management program REDCap⁽¹⁷³⁾ hosted by the Murdoch Children's Research Institute.

10.3.2 Study population

Parents/caregivers (hereafter referred to as parents) of children aged 6 to 12 years with CP, whose names were recorded on the Victorian Cerebral Palsy Register (VCPR), were invited to participate. The age group was chosen to exclude developmentally appropriate sleep problems that may occur during the pre-school years and to align with the age limits of the validated CHSQ.⁽⁸⁵⁾

10.3.3 Recruitment process

Potential participants who met the study inclusion criteria were identified via the VCPR. The VCPR, established in 1987, collects data on people with CP born or living in the Australian state of Victoria since 1970. It is used to recruit people with CP and their families or carers who have provided consent to be contacted about research projects. Potential participants were sent the REDCap⁽¹⁷³⁾ survey link and a brief information letter via email or post over an eight-week period from December 2017 to February 2018. Email invitations were sent four times including three reminders after the initial invitation. The hard copy letter was sent once with one reminder.

10.3.4 Measures

The survey consisted of three validated questionnaires and the custom designed questions. The choice of validated sleep assessment tool and the content and structure of the custom designed questions were informed by a preceding scoping study of qualitative semi-structured interviews of nine parents of children aged 6-12 years with CP with sleep problems, as reported by their parents.⁽¹⁷⁴⁾ Parents reported that they preferred ‘tick box’ surveys (i.e. not free text answers) that could be completed quickly, and questionnaires that allowed for an answer of ‘not applicable’ for surveys not inclusive of children of all abilities. All validated tools were transcribed, unaltered into the REDCap⁽¹⁷³⁾ program, and the custom designed questions were then added.

10.3.4.1 Children’s Sleep Habits Questionnaire

The CSHQ abbreviated version was used to measure the children’s sleep. Individual scores can range from 31 to 97⁽⁸⁵⁾ with a score higher than 41 indicating problematic sleep. Use of this tool requires parents to report on their child’s sleep in the preceding four weeks. It is a concise and accessible survey, designed and validated for typically developing children and has been used in the CP population.⁽⁷⁹⁾

10.3.4.2 Pittsburgh Sleep Quality Index

The Pittsburgh Sleep Quality Index (PSQI), a validated sleep screening tool,⁽¹⁷⁵⁾ was used to assess parent reported sleep quality over the month prior to completing the survey. The tool consists of 18 questions that are summed into seven components that give a global score where scores of five or more indicate a sleep problem.

10.3.4.3 Gross Motor Function Classification System Parent Rating Tool

The Gross Motor Function Classification System (GMFCS) is an internationally recognised classification system that describes the gross motor function of children with CP.⁽¹⁶⁾ The GMFCS classifies gross motor function into five levels: people at levels I-II are ambulant; those in level III use mobility aids such as walking frames; people in levels IV and V primarily use wheelchairs. The GMFCS Family Report Questionnaire is a reliable and validated questionnaire⁽¹⁷⁶⁾ developed as a self-report tool for parents of children with CP. It contains five descriptors of the GMFCS levels, and parents are asked to select which descriptor best matches their children. This ensures an accurate report of the child's GMFCS level for data collection.

The custom designed questions included demographics of the parent and child, socioeconomic status, a single item asking parents about whether their child has sleep problems, methods used to seek sleep solutions and data about the child's healthcare team.

10.3.5 Ethics

Ethics approval was obtained from the Royal Children's Hospital, Melbourne Human Research and Ethics Committee (HREC 35166 and HREC 37300).

10.4 Data Analysis

Descriptive statistics were produced for the outcome measures, proportions for the categorical data (PQSI and parent report of child's sleep) and mean (sd) for

the continuous outcome (CHSQ). Comparisons of the categorical variables were tested with chi-square tests while the continuous variables were compared using a t-test. Free text survey answers were grouped and labelled according to similarity which was decided by consensus between all authors.

10.5 Results

Figure 10-1 describes the participant recruitment process.

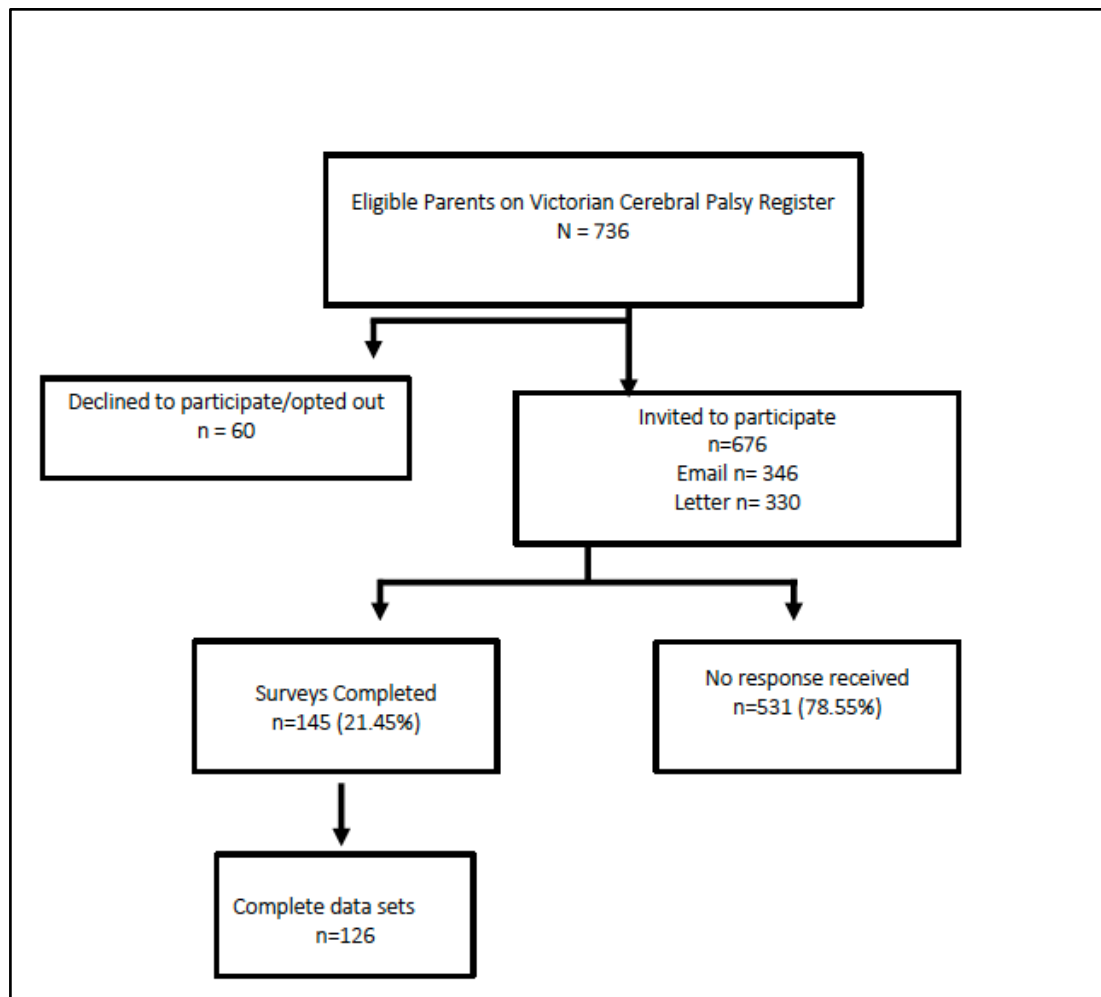


Figure 10-1 Flow Chart of Participants

The demographics of the parents and children are detailed in Tables 1 and 2 respectively.

Demographic	N=	%
GENDER		

Female	115	91.27
Male	11	8.73
AGE		
26-50 years	114	90.48
51-65 years	12	9.52
HIGHEST LEVEL OF EDUCATION		
High School (up to year 10)	5	3.97
Victorian Certificate of Education (VCE) or equivalent (year 11 or 12)	25	19.84
Bachelor Degree or Diploma	58	46.03
Post Graduate Degree	21	16.67
TAFE or job training	17	13.49
RELATIONSHIP TO CHILD		
Biological mother/father	118	93.65
Non-biological mother/father	2	1.59
Adoptive mother/father	3	2.38
Foster mother/father	0	
Grandparent	2	1.59
Aunt/Uncle	1	.79
Unrelated Guardian	1	.79
SIBLINGS		
Only child	28	22.22
1 sibling	51	40.48
2 siblings	34	26.98
3 or more siblings	12	9.52
HOUSEHOLD INCOME		
I'd rather not say	21	16.67
Less than \$20,000	3	2.38
\$20,000 to \$34,999	9	7.14
\$35,000 to \$49,999	8	6.35
\$50,000 to \$74,999	23	18.25
\$75,000 to \$99,999	16	12.7
\$100,000 - \$150,000	32	25.40
\$150,000-\$200,000	9	7.14
\$250,000-\$300,000	5	3.97
COUNTRY OF BIRTH		
Australia	96	76.19
Asia	4	3.17
UK	9	7.14
Europe	5	3.97
INDIGENEITY		
Indigenous or Torres Strait Islander	0	0

Table 10-1 Parent Demographics

Demographic	N=	%
AGE		
6	14	11.11
7	19	15.08
8	15	11.90
9	9	7.14
10	26	20.63
11	18	14.29
12	23	18.25
13	2	1.59
GMFCS LEVEL		
I	40	31.75
II	45	35.71
III	17	13.49
IV	6	4.76
V	18	14.29

Table 10-2 Child Demographics

The study sample was mostly Australian born biological mothers aged between 26 and 50 years, tertiary educated with reported above-average education and household incomes for the Australian population as compared to Australian Census data.⁽¹³⁴⁾

10.5.1 GMFCS and sleep

Given the children in the sample had varying severities of CP as measured by the GMFCS, the data were initially examined to investigate the proportion of sleep problems in children and their parents in each of the GMFCS classification groups.

	GMFCS level 1&2	GMFCS level 3	GMFCS level 4&5
	N=85	N=17	N=24
PSQI			
PSQI less than 5 (no issue)	28 (32.9%)	7 (41.2%)	9 (37.5%)
PSQI 5 or greater (poor sleep)	57 (67.1%)	10 (58.8%)	15 (63%)
Total score on CSHQ (score range: 31-97)	46.2 (11.3)	43.2 (8.9)	45.2 (6.5)
Would you say your child currently has problems with sleep?			
Yes	39 (45.9%)	7 (41.2%)	13 (54.2%)
No	46 (54.1%)	10 (58.8%)	11 (45.8%)

Table 10-3 Results of PQSI and CSHQ Measures, and Whether the Parent Believes the Child has a Sleep Problem, by CP Status (as Measured by Grouped GMFCS)

As shown in Table 10-3 the proportion of parents with poor sleep (PQSI) was similar across the three GMFCS classifications of their children (59% to 67%, chi square =0.510 p=0.775). There was also no evidence that the CSHQ scores varied between the GMFCS classifications (F=0.6, p=0.551), or parent reported presence of sleep problems differed by GMFCS classifications (46% to 59%, chi square =0.768 p=0.681).

10.5.2 Parent and child sleep

From the custom designed item *Do you think your child has a sleep problem?*, 59 (46.8%) parents reported that they thought their child had a sleep problem at the time of the survey, with an additional 30 (23.8%) indicating that their child had previously had sleep problems. Children whose parents reported that they had a sleep problem had a higher mean CSHQ score (mean=52), compared to children whose parents did not indicate their child had a sleep problem (mean=39; mean difference:12.1 (95%CI:9.2-15.0) (p<0.005)).

Overall 82 (65%) of parents were classified as having poor sleep by the PQSI, with 48 (81.4%) of the 59 parents who stated that their child had a sleep problem reporting poor sleep quality themselves, compared with 34 (50.8%) of

67 parents who reported their child did not have a sleep problem (chi-square=12.93, $p<0.005$). See Figure 10-2.

Of those parents who reported sleep problems in their child 59 provided brief free text answers for the type of sleep problems, most commonly experienced. These included night-time waking ($n=31$), sleep latency (issues getting to sleep) ($n=20$) and a sleep association ($n=12$). Notably 26 of the 59 responses reported more than one sleep problem.

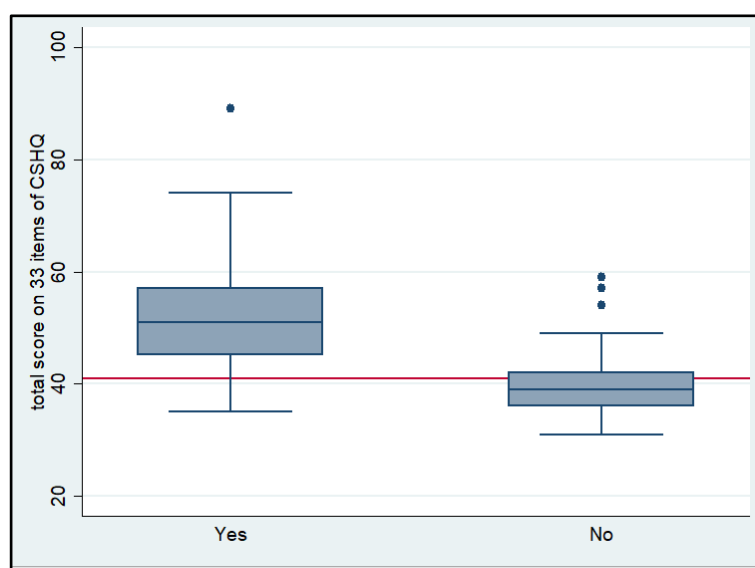


Figure 10-2 Box Plot of Total CSHQ Score by Parental Report of Sleeping Problem
(Red Line is Score of 41)

10.5.3 Seeking sleep solutions

Parents were asked which healthcare professionals their child had seen in the previous twelve months. Physiotherapists (84%), general practitioners (GP) (78.5%), paediatricians (72%), occupational therapists (69%), speech therapists (44%), rehabilitation specialists (32%) and psychologists (15%) were the most commonly seen. For the parents who had ever asked for help with sleep problems at some point in their child's lifetime ($n=64$) help was sought from a paediatrician (72%) and/or a GP (19%), psychologist (15%), maternal and child health nurse (12%), physiotherapist (12%), and/or an occupational therapist

(12%). Figure 10-3 shows the outcomes of those parents who asked for professional help with their child's sleep. Only 21 of 64 parents reported that their request for help led to advice/treatment that was effective.

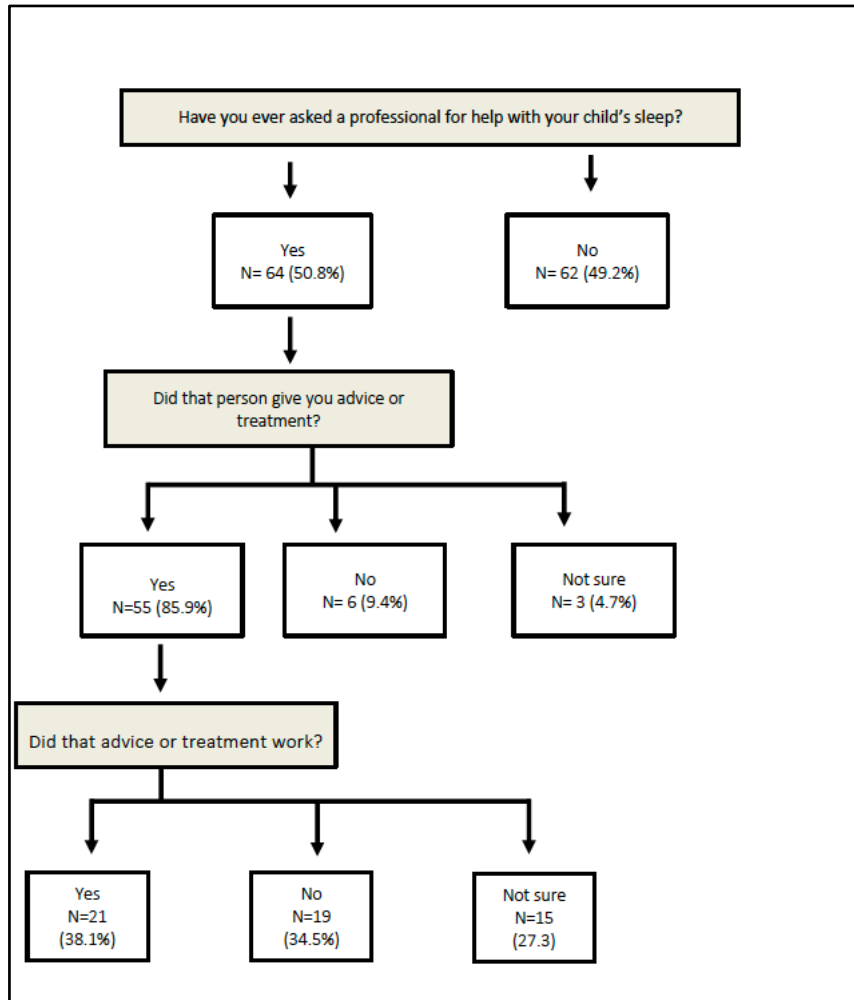


Figure 10-3 Parent Experience of Asking for Sleep Solutions

10.5.4 Reasons for not seeking help with sleep

Eighteen parents who reported that their child had a sleep problem completed the free text question *Why haven't you asked for help with sleep?* Answers were grouped for similarity with the most common reasons being that they planned to manage it themselves (32%), did not see it as a problem (21%) (this is despite reporting in the survey that it was or is a current problem), or did not see the sleep problem as having a solution (21%).

10.6 Discussion

This study examined sleep problems and solution seeking in a cohort of children with CP and found that sleep is problematic for almost half of the cohort. Furthermore, a child with CP who sleeps poorly is likely to have a parent who sleeps poorly, as reflected in the parents' PSQI scores. Sleep problems were present for children across all GMFCS levels, aligning with international studies^(65, 71) which report similar rates of frequency of sleep problems and associated sleep problems for parents of those children. Parent reports of their child having a sleep problem correlated with the child having a high score on the CHSQ.

These results provide important new information about how not all parents ask for sleep solutions and of those that do ask for help, not all have a positive outcome of child sleep improvement. It might be hypothesised that parents tolerate chronic sleep problems because of their inability to find effective solutions from their healthcare professionals. It is essential to consider the long-term impact of living with sleep disturbance and deprivation. An argument could be made that a sleep screening tool specific for children with CP may be a useful clinical tool to determine if a child has a sleep problem. However, the results of this study indicate that parents are aware when sleep is a problem, therefore simply asking the parents about sleep may be the most efficient screening method. The issue may not be with identification of the sleep problem by the parent but that solutions for sleep problems are not easily accessible, for reasons that are not well understood. A recent Canadian study⁽¹⁷⁷⁾ described a significant knowledge gap for healthcare professionals concerning sleep and highlighted their lack of sleep education; some clinicians reported that they have less than three hours of training about sleep. Similar data are not available for Australia, however a recent Australian Government inquiry recommended that sleep knowledge of both doctors and nurses needed to be assessed and addressed.⁽¹⁷⁸⁾ Data from this study demonstrate these children have multidisciplinary care teams, with a paediatrician being the

healthcare professional from whom help with sleep is most commonly sought. However, as the majority of these children have other healthcare professionals in their team, sleep education may also be sourced from them. It was not within the scope of this study to fully explore the use of the healthcare team and the process of seeking sleep help. The initial findings of this study indicate more research is needed in this area.

There are a number of limitations that may impact on the generalisability of this study. The participants were more educated and were of higher socioeconomic status than the general population of Victoria and this may have resulted in some sample bias. However, there is no data on sleep in Victorian children with CP and their parents. It might be argued that the results in this study underestimate the extent of sleep problems as those with more significant resources and education are more likely to have success in advocating for themselves accessing private services.

The recruitment rate of this study was 20% of the potential cohort. Considerable effort was made to maximise the recruitment but despite these efforts, participation was still low. This may demonstrate the difficulty in engaging this population due to time pressures, the additional care needs of a child with a disability and the fatigue associated with problematic sleep.

10.7 Conclusion and Recommendations

Sleep is a problem for many children with CP and this study highlights how sleep problems need more attention in the Australian setting. Many parents are aware of a sleep problem for their child but are not seeking help. For those parents seeking sleep solutions, they do not always find effective treatment. Future research needs to address three key areas: 1) exploration of barriers and facilitators for parents seeking sleep solutions for their child, 2) sleep as a health priority for healthcare professionals who care for children with CP, and 3) how best to assist both parents and healthcare professionals to make sleep a health priority.

It is further proposed that a mixed methods research approach might be best suited to investigate these issues that are both clinically and sociologically complex. Sleep is an important determinant of health that is frequently overlooked within the clinical setting. Improved sleep is likely to improve overall health and quality of life and there is considerable work to be done to address the evidence gaps for children with CP and their parents.

PHASE TWO SUPPLEMENTAL DATA

Below are three tables presenting additional data from Phase Two that were not included in the journal manuscript above but are discussed in Chapter Twelve of this thesis.

Characteristic	N=	%
FAMILY TYPE		
Nuclear Family	95	75.3%
Extended Family	6	4.7%
Reconstituted Family	6	4.7%
Single Parent Family	17	13.5%
Same Sex Family	0	0
Not Answered	2	1.5%
WHO PROVIDED OVERNIGHT CARE BY RELATIONSHIP		
Parent	124	98.4%
Other family member	2	1.59%
Non-Family Carer	0	0
WHO PROVIDED OVERNIGHT CARE BY GENDER		
Female	97	76.6%
Male	5	3.8%
Care Shared Between Both Genders	19	15%
Not Answered	5	3.8%

Table 10-4 Family Type and Provision of Overnight Care

The REDCap tool used in Phase Two can be found in Appendix G.

11 PHASE THREE FINDINGS

INTRODUCTION

Drawing on analysis from the previous two phases, the third and final phase of this study focussed on the experience of parents of children with CP in relation to sleep, the impact of sleep, and the experience of accessing sleep solutions. For those parents who had children who slept well, this phase explored how their experience differed from that of those with children who did not sleep well. The interviews in this phase were focussed on the experience of finding effective sleep solutions and what the parents reported was helpful. The purpose of this phase was to ask parents to reflect upon their experience of the healthcare system, with the goal of identifying what systems issues could be changed or strategies applied to mitigate the impact of sleep problems for the research cohort. This chapter presents the results of the recruitment campaign, the context of the parents' experiences and the findings for Phase Three. The findings of this chapter and how it synthesises with the findings of Phases One and Two is discussed in Chapter Twelve, the final chapter of this thesis.

11.1 Recruitment

A detailed description of the methods of recruiting participants and collecting data for this phase has been described in Chapter Nine, Section 9.3.2.

Participants were purposively sampled from the Phase Two respondents; the best and worst sleepers for each of the GMFCS levels were identified and invited, in successive rounds (10-15 invitations per round), to participate in a one-on-one interview with the Researcher. Rounds were used to ensure that there was time to conduct and transcribe each interview before moving on to the next group of participants. This allowed for iterative analysis; data from each round informed subsequent interviews. Of the participants from Phase Two who completed the survey, 111 agreed to be contacted about an interview in Phase Three. The following table demonstrates the number of participants contacted per GMFCS level and CSHQ score, and the number of participants who were interviewed for these groups.

	GMFCS Level	Invited	Interviewed
<i>Scores below 41 on CSHQ (likely no sleep problems)</i>	I	5	3
	II	5	1
	III	5	2
	IV	2	1
	V	5	0
Total		22	7
<i>Scores above 41 on CSHQ (likely sleep problems)</i>	I	14	4
	II	19	3
	III	6	0
	IV	4	1
	V	11	4
Total		54	12

Table 11-1 Recruitment Outcome by GMFCS Level

Recruitment spanned over the period August 2018 to March 2019. During August 2018 to December 2018, 10 participants were recruited. Four rounds of invitations were sent over the recruitment period. An average of one to two acceptances per round of invitations were received. Between each round of invitations, the transcripts were read, and data reflected upon. Key issues or concepts were identified and used in subsequent interviews. For example, after interview two, parents were asked to rate where sleep problems sit as a health priority for their child. This iterative process ensured that concepts that arose

in interviews were then corroborated in subsequent interviews. After the tenth interview, steps one to three of analysis as described by Braun and Clarke⁽¹⁶⁰⁾ were applied to the transcripts. That is, the transcripts were read, possible codes were identified and possible themes were considered. These codes were assessed for frequency and possible patterns or trends. In this preliminary analysis, the entire dataset was assessed for diversity and breadth of experience. It was evident from the dataset that the greatest imbalance/possible bias was that only three of the 10 interviews were from parents of children who had a problematic sleep score. It was therefore decided to attempt to recruit more participants with CSHQ scores above 41 (worst sleepers). Based on the recruitment rate from past rounds of invitations, it was expected that this might result in a further two to four participants. In this last round, 22 invitations were sent. Of those 22, nine consented and were interviewed. There was a total of 19 participants in Phase Three. A response rate of 40% in this last round was not expected but was welcomed. The invitations coincided with the end of summer school holidays, which may have influenced availability.

11.2 Participants

The following table describes the interview participants, interview format and basic demographics of the child, as per their survey responses from Phase Two. All identifying information has been removed and pseudonyms have replaced the participants' names.

Table 11-2 Participant Characteristics

Pseudonym	Relationship to Child	Age of Child	GMFCS Level	CSHQ Score	Family Type	Interview Format P=Phone I=In Person	Interview Length (minutes)	Type of Sleep Problems
Vela	Mother	12	IV	44	Partnered, 3 children	P	84	Currently sleeps well. Long history of sleep problem. Sleep latency and frequent wakings
Ursa	Mother	11	V	58	Blended family, 4 children	P	60	Multiple sleep problems related to comorbidities of CP
Halley	Mother	10	II-III	34	Partnered, 4 children	P	30	Good sleep now, did have poor sleep prior to starting school
Juliet	Mother	10	V	36	Partnered, 2 children	P	32	Currently sleeps ok, occasionally wakes. Long history of night-time wakings and screaming at night
Atlas	Father	7	II	38	Partnered, 2 children	P	32	Sleeps well. History of mild sleep latency
Bianca	Mother	7	II	44	Partnered, 3 children	I	56	Sleeps well mostly, always has
Alya	Mother	12	II	36	Partnered, 2 children	P	38	Sleeps well now, some issues with anxiety and sleep latency. Has found strategies that work
Lyra	Mother	12	III	41	Partnered, 3 children	P	33	No sleep problems
Cressida	Mother	12	I	37	Partnered, 3 children	P	42	No sleep problems

Pseudonym	Relationship to Child	Age of Child	GMFCS Level	CSHQ Score	Family Type	Interview Format P=Phone I=In Person	Interview Length (minutes)	Type of Sleep Problems
Cordelia	Mother	12	I	53	Single, 4 children	P	60	Restless nights and often sleep latency
Orion	Father	13	I	45	Partnered, 2 children	P	22	Good sleeper, no history of sleep problems
Elara	Mother	8	V	48	Partnered, 1 child	P	63	Sleep problems related to comorbidities of severe CP – tone and discomfort
Ariel	Mother	10	II	46	Partnered, 3 children	P	49	Night-time waking and anxiety
Phoebe	Mother	8	III	53	Partnered, 2 children	P	50	Night-time waking and bed time separation anxiety
Ophelia	Mother	11	III-IV	60	Partnered, 3 children	P	70	Co-sleeping. Significant attachment frequent night waking
Pandora	Mother (adopted)	13	II	46	Partnered, 2 children	P	26	No current sleep problems. History of significant sleep problems as an infant
Portia	Mother	13	V	51	Partnered, 2 children	I	32	Sleeps well, requires repositioning and care overnight
Titania	Mother	10	II	52	Partnered, 2 children	P	40	Long periods awake overnight
Norma & Leo	Mother & Father	7	V	47	Partnered, 3 children	I	27	Light sleeper, but generally sleeps well

The participants were a diverse group of parents and children, representative of the heterogeneity that occurs within the CP population. The group consisted of mostly mothers, with three participants being fathers. As such, from this point on participants will be referred to by their pseudonym or the word ‘parent’, as all participants were parents. Interviews took between 22 and 84 minutes. Those parents who had children with better sleep generally had shorter interviews. Notably, of the seven who had a ‘good’ sleep score, five had some experience with poor sleep even if they currently reported no sleep problems. This meant that interviews with those who had no current sleep problems contained rich and informative data about the experience of sleep problems and what had been done to improve them.

The parents interviewed in this phase disclosed a plethora of experiences in regards to their child’s CP diagnosis, from Vela, who went into premature labour because she had appendicitis, to Ariel, who was attending a maternal and child health nurse appointment for her newborn son when the Maternal and Child Health Nurse (MCHN) noticed Ariel’s almost two year old daughter’s unusual walking style and suggested that she take her to a specialist. Of the 19 interviews, 12 were parents of children who scored over 41 on the CSHQ (indicating likely poor sleep) and seven scored 41 or less on the CSHQ (indicating no sleep problems). Only three parents reported that their child had no current problems and had never had any sleep problems. That is, 16 of the 19 participants had experience of sleep problems in their child. In the instances where parents had no experience with sleep problems, they were asked about their experience of accessing healthcare for other health problems. Where relevant, the experiences of good versus bad sleepers are highlighted with specific examples from the data set.

11.3 Thematic Analysis

The 19 interviews were transcribed and then entered into NVivo software.⁽¹⁶¹⁾ The thematic analysis techniques described in Chapter Six, Section 6.5 were used to code the data. Coding was undertaken by the Researcher. The data

were analysed and the codes were identified through the lens of critical social theory: particularly, looking for data that represented imbalances in systems, power and the concept of false truths. Codes were then grouped into themes according to similarity and themes were labelled using relevant quotes, or slightly edited quotes, from the participants. Thematic analysis was an iterative process between the Researcher and her qualitative research supervisor. Those themes are represented in the concept map below.

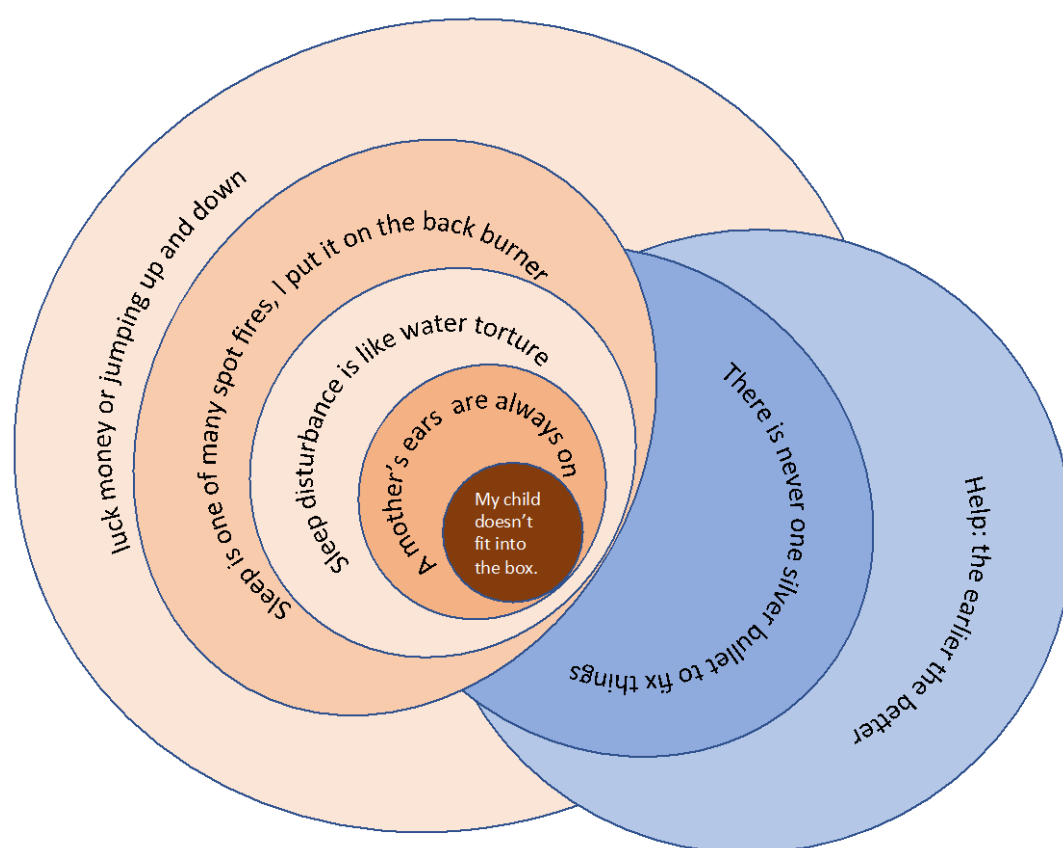


Figure 11-1 Phase Three Thematic Concept Map

11.3.1 Thematic concept map

The themes identified in this study are represented in the above concept map (Figure 11-1), which uses a series of circles to illustrate the themes. The circles overlap, representing links between the themes. At the centre of the concept map is the dark orange circle, which represents the parent and the child with CP and the theme *My Child Doesn't Fit into the Box*. This theme encapsulates

data that described how CP or disability makes a child different to the typical child that accesses healthcare and education systems. This difference consequently impacts upon the experience of finding adequate sleep solutions. Furthermore, this difference often created additional challenges due to systems not being designed to serve atypical children. The subsequent orange circles represent the ripple effects of the experience of sleep problems from the parent's perspective, which are linked to this perception of difference. The child's mismatch to the system and care leads to the requirement for parents to always watch out for their child (*A Mother's Ears are Always On*), including the work done overnight to care for their child, or to be awake with their child because of their child's sleep problems (*Sleep Disturbance is like Water Torture*). This then extends to sleep being a health issue that competes with many other, more urgent, health issues (*Sleep is one of Many Spot Fires, I Put it on the Backburner*). The final theme in the map (*Luck, Money or Jumping Up and Down*) illustrates the work that parents do to find sleep and other health-based solutions. That is, the central difference, the context of the sleep problem comorbidities, the inability to find clinicians familiar and skilled in CP care, and the increased care needs of CP, all impacted on sleep and seeking sleep solutions. The blue circles that fall on the opposite side of the map illustrate themes that are linked to effective solutions for sleep, or what the parents think may be effective solutions. These are placed in opposition to the themes that represent the experiences and challenges of systems, care or sleep problems.

Overall, the data from this phase plainly demonstrate that the experience of sleep in CP is not clear; it is a messy, convoluted and complex experience that is dependent on the resources of families, the individuals navigating the systems and their child's other health needs. The scattered nature of the circles illustrates the complexity and the non-linear nature of sleep problems and sleep solution seeking that was demonstrated in this cohort of parents. Sleep and CP cannot be separated, and CP and sleep problems are enmeshed. This enmeshment is at a body systems level and from a healthcare system, family

and parenting perspective. The six themes and one subtheme that have been identified will now be presented.

11.3.2 My Child Doesn't Fit into the Box

Overwhelmingly, the majority of parents shared that they thought their child with CP was atypical. This was the first and core theme identified in Phase Three, *My Child Doesn't Fit into the Box*. This theme encapsulates the frequently expressed perception that parents of a child with CP feel as if their child is different to other children. There were many ways in which this difference was described. It may have been a reflection on the parent's own knowledge; not knowing what to expect or what is typical in a child with CP. Several of the parents discussed how their own unfamiliarity with CP and what to expect influenced their experience of their child and how they planned what to expect. Halley said:

I didn't know kids come out that early. Like I had no idea, totally no idea. So, for me, I was like, 'Now what happens?' And because I had nothing to relate it back to, 'Oh so now this happens with him. Oh, ok'. I don't know other kids with CP.

Cordelia is a mother of four children and her youngest child has CP. She talked about how despite being an experienced mother, when her fourth baby was born, she wasn't sure where she could find the right help. Cordelia said that if she needed CP specific information, she would often go to disability support groups, but that it had taken almost five years for her to feel like she could do that. When asked why it had taken so long, she explained:

I think I had to grow into it. I don't know if that sounds right, but it was learning. Before, as I said, I would rely on the health nurse, I would rely on the GP, because it was just general every day. Like, your child, they've got a cold or they're looking a bit funny or they're not eating as much and you go, 'Ok, is this normal?' Whereas, because [child name] has special needs, you're like, 'Oh the GP doesn't really know, ok, who else can I talk to?' And it's like, 'Ok, I'll just wait to talk to the paediatrician, or I'll just wait to talk to the

neurologist.’ Whereas now, if I can’t find that information, I’ll go and look somewhere else.

Many parents gave examples of how they would often wonder about the best person to talk to about issues with their child. Participants Norma and Leo (both parents were in the interview) clearly articulated this challenge:

Norma (mum): *Sometimes I feel like all my questions aren’t answered and I feel like I’m not seeing the right person.*

Leo (dad): *So sometimes it’ll be quite good and we’ll get good results, but then other times, we’ll be kind of going around in a circle kind of thing.*

Norma (mum): *Yeah. And it’s hard to find the right person for him and his needs because you don’t know if it’s just a normal kid thing, or a CP thing, or just any one sort of thing, and sometimes I feel like we’re going back and forth a lot, or people might forget about it, sort of thing.*

Beyond knowing who to talk to, another issue that was identified was getting access to those experts. The concept of needing specialised care was common throughout the interviews, best described by Halley:

Seeing paediatricians and his neurologist and all that stuff, just trying to get answers. It’s really a waiting game, a balancing game. His neurologist... we get to see him just once every six or seven months. It’s pretty much all the key people you need to see, you don’t get to see them anywhere near as much as you need to see them. And they say, ‘Oh, go back and talk to your GP.’ But our GP, he’s just a GP. I shouldn’t say just a GP, but he is. He’s not quite as knowledgeable on cerebral palsy, epilepsy, that stuff, that I need him to be.

In addition to describing how their children did not fit into the healthcare system, parents discussed how their child did not seem to fit in anywhere. Vela explained how her son was excluded:

He loves dancing... And he could crawl around on his knees. He's really good at crawling. At that time, he didn't use a walker as much. But he was never included in that. So, there'd be times that you went to the school and the school were dancing in the hall, he would go sit in the classroom.

Several parents talked with sadness about how their child is treated differently, and the suffering this creates for their child. This was most powerfully articulated by Phoebe, who described how her child has an aversion to school because she feels different:

Society is cruel when they see people are a little bit different. And that's why, where she gets that, 'I don't wanna go to school because I don't wanna have to face that. It's a lot easier to stay at home in front of my computer, and just be in that fantasy world where no one can hurt me or upset me.' So, a lot of things are going in her head.

Phoebe went on to explain that worrying about attending school was one of the triggers for her child not sleeping at night. Indeed, several parents mentioned their child's anxiety, and then explained situations they thought had been anxiety triggers. Ariel conveyed her child's experience of school; her child was in year four at the time of the interview:

She had a traumatic prep year. My mother passed away, she started school and was bullied quite badly by a group of boys calling her twisty and all that type of thing. Till this day she still mentions that, so to me, she's still got that knot inside her, and she is seeing a psychologist at school, that's helping her work through it, because she's got a little bit of anger inside of her and I think that's connected with her lack of sleep as well, and she overthinks things, and she gets worried and she starts having [a] negative mindset.

Thus, the theme *My Child Doesn't Fit into the Box* encapsulates not only how CP and disability may create difference for a child in regard to accessing healthcare, but also how disability may create difference that impacts on the child and how they are treated by peers or school systems.

This notion of difference, in regards to the complexity and diversity of sleep problems within the context of disability, is highlighted by the experience of Ophelia. Ophelia is the mother of a child who has CP and ASD. Ophelia experienced a traumatic pregnancy and birth due to placenta accreta, with subsequent limited mobility due to lymphodema, a complication of the pregnancy. Ophelia explained about her child's obsession with the moon, how he would wake at night, needing the presence of his mother. She herself had limited mobility and he had separation anxiety. Ophelia, at the start of the interview talked about sleeping 'near' her child. As the interview unfolded, she confided that she co-slept with her child every night. As she disclosed her co-sleeping, she said: *"I have to be honest with you [Researcher name], or this will not be useful to you."* She went on to explain that she often did not disclose that she co-slept because of fear of judgement. Previously, she had encountered NDIS staff and an allied health worker who had shamed and judged her for co-sleeping:

I mean, she could not hide her – disgust is the only way I can put it. I felt really judged and so did [husband name]. She's sitting at our kitchen table and it was horrible actually, to be completely honest with you, and the OT that's working with him at the moment was disgusted as well.

She explained that she had been judged by many allied health professionals in addition to the NDIS caseworker. She continued:

And unfortunately, you feel so judged that I don't honestly think I'm gonna be honest with her about what we're doing, 'cause now she's already said what she's said. It's very hard to undo that.

The theme *My Child Doesn't Fit in the Box* demonstrates that most parents articulated in various ways how their child is unusual, unique or different. This theme illustrates that there is some homogeneity of this experience for a very heterogeneous group. It is this difference that is central to all of the themes identified in this phase. This concept of difference meant that parents, usually mothers, were required to navigate these differences, or the gaps they create, in order to optimise care for their child. This concept of the work or domain of mothers of children with CP is encapsulated by the theme *A Mother's Ears are Always On*.

11.3.3 A Mother's Ears are Always On

The second theme in this phase represents the vigilance of parents, usually mothers, in the overnight care of their children. This theme incorporates the data that describe both the overnight work as being the domain of the mother and also the impact of that work on the mothers. The name of this theme is taken from a direct quote from Portia. However, it is recognised that it does apply to some fathers. The majority of the participants in this phase were mothers. While three fathers (Atlas, Orion, and Leo) were interviewed, participants Atlas and Orion articulated that their female partners (mothers) were the providers of overnight care, with Leo being the only father undertaking this role. However, his children did not have sleep problems. Of the interviews with mothers, only Pandora, Vela and Phoebe reported that their husbands shared the night-time care equally.

According to the mothers, providing overnight care was a natural expectation and an extension of their caring role. The majority of the mothers did not work, and this was the most common reason why their family accepted that the night-time work would be done by the mother. Many of the mothers described the need for their husbands to sleep so they could fulfil the requirements of their paid work. For example, Ophelia said:

He is making life and death decisions at work... for a while, [child name] was sleeping in between us, and [husband name] wasn't getting any sleep. So, I can't put him through that. It's just not fair.

Atlas, a father, explained that his wife did not work when his son with CP was young:

My wife didn't work for quite a long time. She just went back to work the last couple of years... we didn't want to be a stressful household... My wife would get up during the night and do that, and then the next day she doesn't have to worry about work.

Interestingly, participant Bianca, who was a mother of three children, shared that her child with CP slept well but she had significant sleep problems with her youngest, typically developing child. For this child, the mother's "ears were on":

Bianca: *When I have to get up six times, and the sixth time, I'm tumbling through the hallway thinking I'm going to like drop.*

Researcher: *What came into your head then? Like what sort of help...?*

Bianca: *Like to throw him out in the rubbish bin, but that was one of the thoughts. And this is the thing, this is what happened with us. So, then I would say to my husband, 'Honey, like I got up six times. I'm literally going to faint next time I get up, you have to take over.' The next crying, he gets up, he gets him and brings him to our bed. Well I could've done that on the first waking up, but I'm trying to... all that hard work, because sometimes it's just...*

Others described their partners as just "not knowing how" to do the overnight work. For example, Halley explained:

I don't know that he knows how to. I know that sounds bizarre, but I don't actually know that he knows how to. He's more old-school, so he's like, 'Yep,

you go to bed. That's it. You sleep.' Like he doesn't see that there could be a problem. Like he's like, 'Just go to bed! That's it. If you wake up, bad luck, you deal with it.' Whereas I'm more of an, ok then, there's reasons why he's not sleeping.

These accounts from Halley and Bianca, and accounts by multiple other mothers in Phase Three, demonstrate the gendered nature of overnight care in this group and a great imbalance in the caring roles in these couples.

Divergent to the examples shared by other parents was Pandora, who related how she and her husband both stayed up with their newly adopted son, who required constant rocking in order to be settled:

I wasn't working. My husband was. He just looked like a zombie most of the time, really. My husband is very – he's a rock. He literally is the most stoic, responsible, duty-conscious person I know, and so that was what he had to do and he did it. And I got... that his work did suffer in regard to him [being] able to make good managerial decisions, but I don't think, it didn't certainly manifest in him losing his job or whatever, but certainly it may not have improved his opportunities for career progression either.

Another aspect of this theme was the work that mothers do in anticipating their child's sleep and needs. A key example of this was Portia, who described getting up to her child every night from the age of three years to turn her, change her if necessary, even though her child did not wake at night:

I don't really sleep very well. It's just a habit now – it's just a routine for me... I'll start at about 11:30 to 12 o'clock, I'll get up the first time, and I'll turn her over, I'll just stretch her legs or she will stretch herself. Sometimes, I just check on her.

There were also two mothers who did not get up to their child if they woke at night. This was because they had found a solution that meant they did not have to stay alongside their child. These mothers directly contrasted with the experience of the other parents in the cohort. Juliet explained:

- Juliet: *We're not people who wake up and attend to our children. [Child name] often will wake up of a night and start screaming, but it's just because he's awake and he's wondering where everyone is. So, we deliberately sleep him a long way away from us so that he doesn't necessarily wake everybody up. We've always done that and he's in a secure, safe cot. He's not a climber, he can't climb, so he can't get out and he's warm and safe so he can scream all he likes, but he's not going to get out until 7 o'clock.*
- Researcher: *And does he self-settle?*
- Juliet: *Yeah. Well, we don't get up to him, so eventually he does go back to sleep after an hour or so, but he does eventually go back to sleep.*

A similar experience was reported by Titania, who has a child with multiple disabilities, including CP and ASD. This child used to wake for long periods in the middle of the night; he would wake to play with toys and jump on a mini trampoline. The parents installed a baby gate so their child could not get up and wander. These two divergent cases demonstrate that there are mothers who choose sleep strategies to avoid getting up to their children overnight.

It has been clearly demonstrated that mothers mostly do the night-time care and the care work extends beyond paying attention to their child in real time. This care also involves worrying about and for their child, anticipating their needs, and the needs of the family. Mothers also explained that their lack of sleep was often due to staying awake longer in order to do work or activities unrelated to their children or their role as a mother. Therefore, a child's sleep problem is not the only reason parents have reduced sleep; there is much work to be done beyond caring responsibilities for a child with CP, and this work may be done once a child is asleep.

Four mothers in Phase Three had some form of respite or care assistance from family members or paid carers, either overnight when their child was sleepless, or during the day to reduce the mother's workload. This care appeared to mitigate some of the effect of sleep deprivation. While all mothers talked about their ears always being on, participants Ursa, Elara, Phoebe and Juliet also reflected on the impact of people other than themselves providing care. All mothers who reported having carers described the positive impact of these carers in helping with overnight care or care during the day so the parents could gain respite or get more sleep. Three of the mothers had regular help from carers. Ursa's mother stayed overnight with her son. Phoebe explained that her parents moved from the UK on carers' visas to help with her son:

It got to that point of either they come over or we go back, because we just needed a bit of support.... So, they're great and we are so grateful for the mental health they give us.

Two mothers had non-family carers who came to the house. Elara had a carer who came to their home after school until their daughter was settled in bed. She told how her daughter (now eight years) had such high care needs that her husband, herself and a carer were required to complete the evening routine and ensure that her daughter was in bed within a short time of taking her night-time medications. She explained that if the window was missed, the child's movements would escalate, and it would take one and a half hours to get her asleep. The presence of the carer made a distinct difference to their experience of night-time. In contrast, Portia had past experience with respite carers during the day, but since transitioning to the NDIS, had not found new carers that were as helpful. Within the interview, she was asked if she would consider overnight care, if it was available:

I would just do it myself 'cause then I wouldn't be sleeping anyway. I'll just be awake and I'll just be thinking, 'Oh my God, someone is here just doing...' I would just do it.

Thus, the work of the mothers at night-time in attending to their children and worrying about their children, and the impact of additional care, is evident within this theme. It is striking how few of these parents had carers, and how many mothers did the care without any help, some of them even doing all the care and having work outside of the home. It is also important to understand the impact of this work, which is highlighted by the next theme *Sleep Disturbance is like Water Torture*.

11.3.4 Sleep Disturbance is like Water Torture

The third theme to be identified was *Sleep Disturbance is like Water Torture*, which encapsulates the impact of poor sleep for the parents themselves, their child and their family life. All but three of the study participants discussed this theme. The naming of the theme came from Elara who, when asked about the impact of poor sleep, described disrupted sleep as, “*It’s like Chinese torture, water torture.*” This theme directly addresses one of the research questions: ‘What is the impact of poor sleep on the parents and child?’ It covers how the parent described the impact of their child’s sleep on themselves and also what they perceived to be the impact of poor sleep on their child. Parents gave examples of how poor sleep impacted on their ability to participate in daytime activities with their family. This varied from changes in mood and patience through to opting out of joining in family activities. Ursa shared:

Sometimes I’ll want to go and do something, or the kids would want to go, and I think, ‘Oh my God! I don’t want to participate. I haven’t had enough sleep, I’ve got a headache, I feel tired,’ and I just think, I really can’t be bothered. Or I’ll get him into bed, and I think, ‘Oh great, I’ll put dinner on,’ and then someone else will want something from me, and I think, ‘Nah, I’m out. I’ve got nothing left in me. I’m sorry.’ I think as he’s gotten older, it’s more known that it’s all related, rather than I’m just being a moody cow.

Others talked about the nature of repeated bad sleep and how that can impact on their own health. Portia sent a text message to the Researcher after the

interview, which read: *“One thing I forgot to tell you was that my memory has been affected by the sleep, I forget more things than I used to.”*

Additionally, sleeplessness impacted on parents’ daytime activity. Phoebe explained how when her son has a bad night it impacts on what she is able to do the next day:

I’m just miserable, miserable, lack of energy. He also wakes his sibling up quite a lot, which means that she is feral. Generally, just feeling like crap and then not having that energy that maybe I would have to put the effort into trying... When you’re running on empty, you just can’t do it.

The concept of not having time to focus on the impact of sleep was mentioned by Alya. Alya provided insight into how the impact of poor sleep isn’t always apparent during prolonged periods of sleeplessness. At the time of the interview, her child was sleeping well and she was asked if her child’s past sleep problems had an impact:

I think the thing I’ve noticed is once he started sleeping through, and then he’s unwell or something and wakes up, then I notice. It’s not obvious now, the impact it has on me, but you become a bit in routine of waking up and getting sleep. It obviously has effects that you don’t notice when you’re in it, other than feeling tired.

As previously discussed, none of the parents described their current sleep as being the worst they had experienced. Indeed, some of them said that their child’s sleep was no longer problematic. However, several of those parents flagged that while their child’s sleep had improved, their own sleep was still disturbed.

In addition to describing the impact of lack of sleep on themselves, the parents also explained about the impact that poor sleep had on their child. This was best summarised by Ursa:

It has a great impact on him, I think... It relates to everything... it impacts socially, either by not being able to take him out to do social things, or it impacts him school-wise, and concentration, and things like being able to participate in the community. It impacts I think nearly almost every part of his life, directly or indirectly.

The benefits of a good night's sleep for the child were best described by Cordelia:

When he gets a good night's sleep, he's a different child. He's a lot calmer, we don't have as many meltdowns, it's not nought to a hundred. You can actually almost, not reason with him, but he is far more open to discussions. Everyone knows it. When he's had a good night, or slept in, rarely, mum and dad would be like, 'Oh, he's in a good mood. Oh, he's great today,' and we're like, 'Yeah, this is what it should be like or could be like.' So it's huge. It's huge.

Several mothers discussed the impact of poor sleep on relationships, including relationships between the mother and the child, within the family and between the parents. Cordelia explained that the ramifications were more than just tiredness and had the potential to directly impact relationships:

It breaks marriages because then you don't want to be intimate with your partner because you're tired, you've got that child in the bed with you all the time. You are pleasing all the time. Men are so selfish, for them that's what it's all about. And they don't want to have another child if that child is still there and they're not getting any action. It just pulls a mother down. She's drained the whole day because she's the one getting up doing it all. It's big stuff, I reckon.

One participant voiced an experience divergent to the other parents. Titania said that having little sleep did not seem to affect her child:

He seems to cope okay with not very much sleep. So, he's going off to school today and I guess he's had five or six hours of sleep, but he seems to cope okay.

It is clear from these powerful quotes that the impact of sleep deprivation is significant for both the parent(s) and the child. Parents described long periods of sleep problems, with consequences on health and their daytime functioning. This theme has demonstrated the significant impact of sleep problems on both the parent and the child. Poor sleep being tolerated for long periods of time may be due to attitudes toward sleep problems. This is the topic of the next theme: *Sleep is One of Many Spot Fires, I Put it On the Backburner*.

11.3.5 Sleep is One of Many Spot Fires, I Put it On the Backburner

Parents frequently talked about their child's sleep problems in the context of a more complex health profile. For all parents interviewed whose child had sleep problems, sleep was not the only health issue experienced by their child. This theme encapsulates data that conveyed where sleep sits as a priority for both parents and for clinicians (as reported by the parents). It was evident that sleep was valued by the parents but not necessarily prioritised. Within the context of caring for a child with CP and the associated comorbidities and complexities, sleep was one of many problems on a list. It was clear from the interviews that sleep was not a common focus within the clinical setting. The Researcher inquired whether participants had been asked about sleep at clinic appointments. The majority of parents reported that they were rarely asked about their child's sleep.

According to Ariel, sleep hadn't been discussed at clinic appointments due to competing priorities. Ariel explained that despite her child waking frequently overnight and resisting bedtime, it wasn't a priority for her:

Sleep has never been a high priority for me. It was more how does she cope through the day. But the more thinking that I do, it's like, 'Oh my gosh, she needs more sleep.' That is so vital for the body to relax, the mind to relax, and I would see it as very important. But prior to this [study], I didn't see it as being – it wasn't a fire that I was wanting to put out because there were so many other spot fires that I needed to put out.

Vela highlighted the myriad triggers for poor sleep and why it was not prioritised

I think it's always been mentioned, 'How's his sleep?' 'What sleep?' sort of thing. So, it's always been something that's been there, but we never really like, you know. One night it's contractures, the next night it's a vomit. Then he might have had a seizure. So, there's never really been a cause or something to follow it through with. It's just like, 'Oh you know, he's not sleeping very well. We think it's contractures this week.' 'Ok, once he is at the back of it, see how you go.'

Interestingly, while most parents did not prioritise sleep, there was evidence from most parents that sleep was seen as something they had some control over as opposed to other comorbidities like epilepsy, pain or surgical procedures. Ursa said:

Even though the sleep does go back into [influencing] the epilepsy and those sorts of things, I think because it's something that I can lifestyle-manage rather than, 'We'll go in and have an operation and you'll sleep better.' Like yeah. Cool. Look, if we don't sleep for two nights, it's not that big a deal. I'll just won't leave the house for two days and you can sleep during the day. Fine, whatever works... Because it's not a medical something, I feel like it's not as high on the priority list.

However, this evaluation did not translate to making sleep a priority. The quote above demonstrates that good sleep is aspired to, and is a goal for the parent, but it is talked about almost like it is a lofty dream to have help with sleep; it is not a concrete plan. Parents gave many examples of other issues that had knocked sleep off the priority list. Cordelia indicated in the Phase Two survey that they were about to see a psychologist for sleep help. At the time of the interview, 12 months later, they had not discussed sleep with the psychologist because strategies for coping with bullying had taken priority. Others discussed looming surgery as their main priority. For some parents, sleep was not a conscious problem in their lives, despite them describing

significant sleep problems. It was clear that they did not actively think about getting sleep help or improving sleep for their child.

For three parents, Cressida, Ariel and Ophelia, the research itself prompted them to think about sleep. Ariel said:

We were linked up with the neurologist at the [hospital] and [community disability organisation]. Like I said, until I read that letter I received from you, it never came to the forefront of my thinking that, 'Oh Jesus, yes, it happened.' For me, I was in I guess autopilot just to live life and get on with things and just do things, and it was like just to react and deal with what's going on and just accept that it's normal, because that's just how I'm surviving, especially when you had three little ones. And with all the needs that [child name] has and also my other two boys' needs they have as boys, it's just get on with it and you cope with what hits you in the front.

There was a suggestion that sleep was not the domain of any particular clinician and this meant that no one clinician took responsibility for sleep care. For example, Titania said that her son was admitted as an inpatient for video monitoring in preparation for epilepsy surgery. Her child was videoed jumping up and down in the middle of the night and she was asked if that was normal for the child, but no one addressed why the child was behaving in this way. Other parents described how problematic sleep might be talked about briefly, but not addressed as a problem to be resolved. Halley recounts an interaction with her GP:

He once said to me, 'Oh, you look a bit tired. How is the kid sleeping and stuff?' And I said, '[Child name] doesn't sleep.' 'Oh yeah, that's pretty normal.' So I went, oh ok, so it's normal and I didn't really ask. And then I thought like possibly the hospital or the paediatrician or someone had said, 'Hey, how's is sleep going?' And I had answered. And then that might've been different, but yeah, I don't know. And I didn't really know who to ask. If you have a problem with anything else, their speech, you go to a speech therapist, or if it's medical, you ask the doctor or the neuro or someone, but sleep, who do you ask?

Juliet's experience was divergent to the other parents:

No. We did ask for help but not so much for the sleep. Because, as I said, we've always taken care to soundproof ourselves from him because we're not going to function without sleep, so we've always recognised that sleep deprivation is not good for any of us. So, we've just simply refused to go without sleep...

Juliet made sleep a priority; they chose to do what they could to make their own sleep better, almost irrespective of what was happening for their child. Conversely, Alya considered her son's sleep problems as important as other medical problems. One parent did not ask for help about sleep, not because it was not a priority but because they did not want to consult with medical professionals. Pandora, who ascribes to homeopathy to treat all of her child's health problems, made the following comment:

Look, you know what, we're not great with medicine. We're not great at all. We did speak with some colleagues who were nurses and that they had various opinions. I guess, for us, it was really trying to understand what was happening and the cause. We certainly didn't wanna give him anything to make him sleep, and I think we talked to a whole lot of people, but I guess we just relied on a bit more of a natural therapy.

In summary, the theme of *Sleep is One of Many Spot Fires, I Put it on the Backburner* includes data wherein parents describe their attitudes towards sleep and the competing factors that mean that sleep is shuffled down the 'to do' list, because there is always something else that needs to be done. It is clear from these powerful and articulate quotes that good sleep is valued but cannot be prioritised, and this is often because of the juggle parents experience in addressing their child's needs. This leads to the next major theme identified in this data set, a theme that illustrates the work that parents need to do to navigate systems for their children: *Luck, Money or Jumping Up and Down*.

11.3.6 Luck, Money or Jumping Up and Down

This major theme depicts the experience of parents interacting with systems. These systems include but are not limited to, education systems, healthcare in general and the NDIS. This theme includes *luck*: parents who described their experience of good care as 'lucky'; *money*: parents who described electing to pay for private care (therapy, paediatricians, etc.); and *jumping up and down*: the advocacy and assertiveness required on behalf of the parents in order to navigate the system. Each of these elements will be presented with key quotes to illustrate their meaning.

11.3.6.1 Luck

It was clear from the interviews that many parents who had experienced good and responsive service from big systems (health, education or funding) considered themselves 'lucky'. For some, this luck came in the form of one knowledgeable and approachable worker, for others it was a multidisciplinary team that proactively coordinated care. Lyra described the excellent care received from a physiotherapist, who was a central point of contact for all of her child's needs:

Me getting on to this particular physio was pure luck. Again, it was just a random recommendation from another mum who had a child with a disability – not even CP.

Ursa recalled her son's early diagnosis:

Early diagnosis to me was a godsend. Because we didn't have to wait a year until he didn't eat or sit up, which then could be really quite hard for parents to then get intervention or to get that recognised in that first few years. So we were very lucky in a way.

She continued that she was lucky to be linked up with a responsive team early in her child's life. This concept of luck extended even to situations where the parents had fought for a service to be implemented. Ophelia described feeling

lucky because her son gets picked up by a school bus, even though she herself has limited mobility and is no longer able to collect her son from school herself:

The Education Department got involved and they said it is discrimination, given my medical situation as well. So, late last year, they started picking him up from home and dropping him back at home. And so now, I'm very lucky that I can just put him on the bus at our front door – well, our front steps, and down the path, at our front gate – I can put him on the bus and then they drop him off at 25 to 4 every afternoon. So, yeah, I'm lucky. I'm lucky with that. It's made a huge difference.

It is clear from these examples that when parents did receive good care or effective support, that they considered they were fortunate to receive it. Other parents reported they found effective support through paying for private services.

11.3.6.2 Money

A notable discussion point from several of the parents was the assumed need to pay for private therapy or healthcare, in order to get a service that satisfied their needs. This choice of private care may have been for a service that is not available publicly (therapy for children in mainstream schools) or for a clinician to be more accessible (private paediatrician with urgent availability). Parents described paying for services to avoid the wait that occurs within the public health system, or because they wanted a particular expert clinician. Phoebe discussed her rationale for paying for care:

Again, it's a private GP, a private paediatrician, and I think the only way you get these things done fast is if you pay for it, sadly, rather than going through the public system and waiting for your appointments and your referral. And I think that's probably why when we've had stuff and we've needed stuff, it's happened quite quickly. But we've paid for it.

It was clear that most parents who did pay for services chose to do so, but that it was not necessarily easy to accommodate these expenses. Phoebe explains how she and her partner paid for therapy for their son:

We're very much stick-it-on-the-credit-card-and-worry-about-it-later type of people. We spent our lifesavings on therapy for him when he was younger because we knew, actually we're glad that we knew, that those formative years were the most important. And that's just the type of people we are, and I guess it's what approach you'd take.

Lyra discussed how she had received financial help from family for private treatments:

And then obviously we've accessed funding throughout, which makes a big difference as well. But if there is anything over and above then we will just get it and my in-laws are very supportive, they offer to pay for a lot of things as well.

It was clear from the parents who did pay privately for services for their child that they thought there was a strong need to pay, but that this cost was not easily accommodated. The parents interviewed also described the advocacy and persistence needed to access effective healthcare.

11.3.6.3 Jumping up and down

The third and final aspect of this theme was a perceived need among parents that they had to advocate for their child to get the services that they needed. This advocacy was not limited to their experience of sleep. In five interviews, parents discussed the pressures of navigating the NDIS funding that has recently been implemented (see Chapter Four, Section 4.5 for an explanation of NDIS). Alya described how their early intervention service had been very effective; if they had a problem, they would ask their key worker and get referrals and resources as required. This changed when her child reached school age:

That finishes at school age level, so they get you into school and then they really leave them. And then we had to go back to finding private therapy at [hospital name]. And so then you end up back at a spot where you're trying to source things yourselves, and it can be quite challenging at that point. Because we liked the certain type of care, but then trying to find a therapist that works that model, like you end up trialling multiple people. And so the same thing, like sometimes, you have to sit down and think, where do I have to go for that? Who's the best person? Who has the best knowledge? Yeah, so that's a challenge.

Elara discussed what she had to do to get respite care for her daughter:

I've been on the waiting list for about four years because they jumped up and down saying I need help. So, when I have the specialist maternal healthcare nurses, they were jumping up and down looking for different alternatives for providing the support.

Within this theme, a frequently discussed aspect of systems was the experience of accessing the NDIS. Discussion about the NDIS came unprompted within the interviews. It was clear that the NDIS was topical at the time of the interviews and that the parents wanted to talk about it, as it bubbled to the surface. Ursa had actually stopped working in order to accommodate the demands of the NDIS:

I don't work anymore. I was working up until May this year. And because I was working fulltime, but with NDIS and things, it's just become a lot more admin and advocating than I had anticipated... I've spoken to the Federal Social Services Minister in relation to that sort of stuff. And then in terms of the rollout... yes, I'm very lucky that I have all of this funding, but the services for children at his level are not available to actually use the funding. So I said, 'Look, I'm so grateful that I have \$10,000 for respite but I can't find a carer or an agency who can take him.' So they're now using it as big case study or something – no names mentioned of course and all that stuff.

It was evident that the parents interviewed had the skills and expertise to navigate the system and advocate for themselves. Elara obtained a PhD before she had her daughter. When asked what would happen if she had not had the tenacity to keep seeking solutions for her daughter with severe CP, she reflected:

I think [child name] would've fallen by the wayside and wouldn't have got the support that she needs. I'm confident enough to go, 'I know what to ask. I know what my rights are,' sort of thing.

Lyra discussed what she has needed to do to coordinate the care for her child:

Every appointment that has ever been offered or any referral I've ever received, we've always followed through on. But I think that I've been able to do that because I've had the time myself. Like, as a mum, I wasn't having to go back to work and I think that has made a huge difference... Financially, we've been fortunate where if we have to follow up a private referral or go private with something, we just do it and we don't have to think about it. And obviously all of our specialist appointments and things like that, we can financially afford it, so we do it. So I think finances and time make a huge difference, I think, to what you can follow up and what you can do in your day.

Overall, the concepts of *luck*, *money* and *jumping up and down* demonstrate the diversity within the systems that parents have to navigate. Simultaneously, it is clear from the experiences shared in the interviews, that parents need many personal and socioeconomic resources to coordinate effective care for their child with CP.

11.3.7 There is Never a Silver Bullet to Fix Things

Previously presented themes have highlighted the significant impact of sleep, the difficulty of navigating the system, and the difference created by CP, which is difficult to accommodate in a rigid system. Nine of the sixteen parents reported they had found sleep solutions for their child. Vela, Halley, Elara and

Ophelia found paediatricians who helped improve their child's tone and in turn sleep. Atlas, Alya, Cordelia, Ariel and Phoebe discovered solutions to help with behavioural management of sleep. Pandora used mostly homeopathy to treat her child. Juliet was advised to prioritise her own sleep over the sleep of her child from early in life and followed this advice consistently. However, of those nine who had reported better sleep, Elara, Ophelia, Phoebe, Cordelia and Halley still experienced some sleep problems with their child. That is, better sleep was not always good sleep. What is clear from the data encapsulated in this theme is that the path to improved sleep is not linear. No parent reported a single treatment or intervention that solved their child's sleep problem; there is no 'silver bullet' to fix sleep. Indeed, many parents described trialling many unsuccessful sleep solutions. For example, Ophelia said:

So, we just kept trying and trying and trying ourselves, and I would speak to the GP every now and again when it just got to a crisis level, and we'd just try something else and/or we'd move to a different room or we'd get a new bed, or various things like that [happened]... I read up about on the internet that really we just muddled through ourselves obviously.

Vela had some in-home help for sleep problems. She had seen a medical specialist who then sent a midwife into the home for at-home sleep help. This intervention lasted six months but was not successful. It was a paediatric rehabilitation specialist that eventually implemented interventions that helped with sleep, after seven years of sleep problems. Phoebe asked their private paediatrician for help with sleep:

Yeah. So, we went to a paediatrician, [doctor name] and discussed it with her. And basically, we've done a lot of things at home. We've got a white noise machine. We did the basic, trying to put him back into bed routine... and nothing was working. So, she was the one that prescribed the melatonin to start us off, and then that was helping him get off to sleep... And then he started getting up in the nights and it became more intense. We went back to her and she gave us a referral for the sleep clinic.

Cressida also saw a sleep specialist but found them less useful, explaining that the clinician made an assumption that did not resonate:

At the time, my husband was doing a lot of working in the evening, so he would be there for dinner but then go out and work. So the first comment was, 'Oh that's probably why he's not sleeping because he's waiting for his dad to come home.' I was like, 'Well no, because it's a new thing that my husband had to do these work things at night, it's not for the past five, ten years he hasn't done that.' And it always came back to that. So that's why I found her not very helpful.

Alya described how her first child (typically developing) had significant sleep problems and she had done sleep courses and accessed many sleep resources, which she used with her second child with CP. Alya eventually found her own solution for her son:

So, I learnt a lot from those and tried to acquire different things for [child name]. And potentially, it was comfort. Like in the way that we now talk about things and he's able to process them, potentially there are other things like that that we didn't realise with him. I mean it just slowly reduced. I think we learnt more about it when he had a full night through, and that can sometimes in itself lead to positive outcomes.

Elara, whose daughter had severe CP (GMFCS V) and many comorbidities, had spent some time looking for a paediatrician who would address her child's high tone, which was causing sleep disturbance at night:

Elara: *Yeah, and I think it's actually [doctor name] was the first one that actually got the right symptoms and the right cocktail.*

Researcher: *And it took a while?*

Elara: *Yes, two years or so.*

Researcher: *So two years of mucking around with drugs?*

Elara: *Yeah. And it's a continual thing anyway because she grows and stuff like that.*

Titania's son participated in an overnight sleep study. Titania explained that when she told her care team that her son was awake for long periods (hours) overnight, they requested a sleep study because they wanted to know if he was awake or if it was seizure activity or anything else. Titania described that the sleep study was ineffective as her child slept well on the night it was conducted. After the sleep study, they were not given any more advice on her son's long periods of awake time overnight.

By contrast, Pandora explained at the outset of the interview that her family avoided Western medicine and preferred to manage presenting problems with homeopathy. They had found homeopathic solutions for many of her child's problems, including sleep:

So we treat our children homoeopathically, and so we basically embarked pretty much from a couple of months after we had him, really, because he had very bad eczema as well, and so he's been [treated] homoeopathically pretty much since then, really.

Indeed, this mother emailed after the interview to add that: *"There is never one silver bullet to fix things, but I believe that homeopathy, cranial osteopathy and good nutrition did some help overtime."*

Many of the parents in this phase had sought alternative therapies for sleep problems. Vela had used meridian therapy (a form of Chinese medicine), Halley had taken her child to see a chiropractor, Ursa had purchased weighted blankets and Phoebe had attended a naturopath with her child and used massage therapy. It is clear that the use of alternative therapies for sleep is common in this cohort.

While the majority of parents struggled to find a solution and felt largely left to their own devices, four parents reported they had found someone to help them

with sleep. Elara found a paediatrician to help her child in addition to support received from a more general clinic:

It was difficult because we still are with the rehab clinic at [hospital name]... and they'll say, 'We'll see you in six months,' and we see them in nine months or 12 months or something like that. It's a quick go in and band-aids solution, whereas it's not really a long-term work together situation with that clinic. So I would say getting the help has really only been since we've got [doctor name] and we really feel like [doctor name] is on our side and trying to help us get to the right place.

Elara continued:

I think it was a few years before we got to a point where I go, 'Oh, thank god, someone is listening to us and someone finding something that's gonna work.'

Ursa recalled how a paediatrician had helped her:

But [doctor name] is extremely knowledgeable. She, in a lot of ways, has reassured me, like the things with the sleep, like, 'You can get sleeping tablets for him.' 'OK, no one really ever said that before.' We're using Valium as a sleep aid in a way. And I was like oh, so they can have sleeping tablets. So that's reassured me, and she has been very helpful and said, 'Look, you know if you have questions or you want to try things, we can do that.'

Phoebe's son was referred to a sleep clinic by her private paediatrician and she described her experience getting sleep help:

Yeah, a little bit because it's quite similar to what you would do with a neurotypical child. I've worked with kids for 22 years now, and as a nanny as well, and I've gone through that with a few of the kids I've looked after. But it's far more intense with a special needs child and I think you can't just do the traditional kind of put them back in a room even 50 times, stand outside the door, because [child name] will start head butting things and self-harming, so there was definitely a lot more guidance in regards to it

being a special needs kid. If you wanted standard sleep information then, yeah, you could definitely go and get yourself techniques.

The sleep specialist remained involved in the care of Phoebe's son. At the time of the interview they had plans to see them again because his sleep problems had worsened over the school holidays.

It is clear from these recounts that sleep solutions are time intensive and require multimodal strategies. Of the parents who found effective solutions, they reported that a variety of strategies were required and in some cases a clinician to assist with bespoke advice and repeat assessment. Parents also described factors that mitigated poor sleep, such as setting up a comfortable co-sleeping situation or sourcing respite through carers. In the best case (e.g. Vela), improved sleep meant a transformation from being awake all night to sleeping through the night. The worst case (e.g. Elara) transitioned from being awake all night, every night, to only being awake for some of the night on several nights a week. It was evident that for the parents whose child's sleep quality and quantity remained mediocre, a small difference still made a positive impact on the parent.

11.3.8 Help: The Earlier the Better

A predominant theme that was identified in the interviews was the need for very early intervention in the form of knowledge sharing about CP and/or sleep. This theme includes what parents reported as being helpful or had helped in either the healthcare of their child with CP or their child's sleep problem. Overwhelmingly, when parents discussed what was or would have been helpful, the importance of early intervention, from when their child was young and newly diagnosed, was apparent. Many of the parents reported that early intervention had been helpful, or, on reflection, early intervention would have been beneficial. This help may have been specific to sleep or the provision of general information about what to expect in CP or disability. Vela said:

I think the earlier the better. Because if I was able to have got a routine at a really good, back as early as possible, even when he was just two, to get something like that...

Education and information about CP were also important; several parents mentioned how they felt more able to navigate the system when they were more familiar with it. Norma and Leo (two parents) talked about how their knowledge growth had made them more comfortable with the system and what to expect:

Norma (mum): *No. I think it's grown a lot as he gets older and I'm experienced more, and I know more about it.*

Leo (dad): *You tend to learn – you tend to – as he gets older, you tend to learn more as he gets older... I think it's easier now to think about the future and things like that. When sort of at the start, I didn't really know that much or where we were going, but now I can sort of see that path.*

This sentiment was mirrored by Cressida:

Back then, we didn't know anyone with cerebral palsy. We weren't really exposed to CP. So, when these words started coming out we instantly, you know, we didn't know there was different aspects of it, to mild to very severe. We didn't know what to expect and whether he would walk, wouldn't walk, all those questions came.

Portia, who got up multiple times a night to re-position her daughter in anticipation of her being uncomfortable, was asked if it would be different if she had been asked about sleep early in her child's care:

Maybe. I mean I probably would have been interested in hearing about, is there something to maybe help her settle a lot quicker at night-time. Yeah, definitely, that would have been quite useful. But I think because of her

situation, and how she's become unwell, I just myself thought, 'Okay, well, this is part of her condition,' so it was another part that I had to manage.

Halley said:

And then I thought like possibly, the hospital or the paediatrician or someone had said, 'Hey, how's is sleep going?' And I had answered. And then that might've been different, but yeah, I don't know. And I didn't really know who to ask.

Within this theme, some parents considered that when and how information was delivered had an impact on their experience. Juliet clearly articulated that the nature and type of information she and her husband were given early on was helpful to their experience of navigating sleep problems:

I guess what I would add to that is that the really good, no-nonsense advice that we got in those early years, it really carried us through, it really did. And I see other families – and I know every family is different – but I see other families really struggling and I think it's often because their expectations of themselves are so high. Whereas we had a no-nonsense paediatrician sit us down and tell us that we just have to get on with life. And I suppose we were pretty no-nonsense people that were going to do that. But to be given permission to do that when... [child name] was our first child.

Later in the interview she said:

And if the doctor tells you what to do, you do it. It was really nice to have a doctor, an authority figure actually tell you what to do and to do it. It gave us permission to take care of yourself and live your life normally. It was very, very liberating.

Elara also reflected on needing more direct information:

Look, nobody is willing to say to you what they think is actually gonna happen... That's when you ask them and say, 'Do you think she'll ever walk? Do you think she'll ever do that?' and you get an answer like 'I had a boy I

looked after and when he was ten, he took his first independent step.’ And that’s the closest thing you get. People aren’t willing to say ‘cause they’re frightened that you’re gonna react badly... I think it was just frustrating. I’d like to know what I’m dealing with, and then try and get the resources as I can, to help to feel some way in control. And it’s a bit wishy-washy. That was a bit frustrating.

Vela reflected on her experience of the differences in MCHNs in city and country locations. They moved while her son with CP was an infant. Regarding the country, she said:

Like the ones in the country are really talkative. So they’re really good in the country. Like they’re really laid back and you know, ‘Oh, they’ve put on this much weight and now next week we should be looking at this...’ They tell you that. And, ‘Oh, you can try a bit of this food and try a bit of that food.’

Regarding the city nurses, she said:

Yeah, they didn’t do that. They just weighed them and just said, ‘Oh you know, he’s a little bit underweight.’ They didn’t make any suggestions or no help. Because you say, ‘What do you think?’ and they said, ‘Oh, well that book if you’d like to read it.’

From the reports of these parents, clear and direct information and instructions are helpful in caring for a child with CP and/or their sleep problems. Thus, this theme *Help: The Earlier the Better* includes data about the need for clear and direct education early in life, before sleep problems arise.

CONCLUSION

This chapter presents the seven themes identified through thematic analysis of the third and final phase of this study. These themes represent parents’ concerns about their children with CP not being accommodated within the systems because of their difference, which is central to the experience of sleep problems and seeking solutions. Parents clearly articulated the powerful negative impact of sleep disturbance, and the difficulties they have making

sleep a priority in the gamut of things that they have to accommodate while caring for a child with CP. These themes also demonstrate the work that parents do to navigate the healthcare and disability systems for their child, and the personal and socioeconomic resources required to be successful in this navigation. The findings of this phase are synthesised with the previous two phases to create a mixed methods interpretation in the final chapter of this thesis.

12 SYNTHESIS, RECOMMENDATIONS AND CONCLUSIONS

INTRODUCTION

This chapter provides a synthesis of all three phases of this mixed methods study. As has been discussed, the true benefit of a mixed methods enquiry, especially for a topic where little is known, is that the different paradigms of research corroborate each other and allow for a multidimensional understanding of the research problem. In this chapter, the two qualitative phases of this study are triangulated with the results of the quantitative phase. Synthesis of the rich and nuanced accounts from parents of children with CP, in combination with the more generalisable findings of the online survey and validated sleep assessment tools, provides a comprehensive understanding of the parent experience of sleep problems and their attempts to find sleep solutions. This chapter first provides a brief synopsis of the overall findings of the three phases. Then, a joint display table illustrates how the three phases are triangulated. Details are provided about how this research sits in comparison to existing research. How CST may be applied to the study

findings, and consequently the recommendations that arise from this research, will be discussed. The importance of this study, the benefits from a mixed methods approach, and the significance of the research findings will also be presented. The limitations of the study are then described. Recommendations for implementation of these findings and directions for future research are articulated.

12.1 Study Importance

The results of this research indicate that parents of children with CP experience sleep disturbance and deprivation and those problems have a significant impact. This study also demonstrates that there is a lack of impetus to address sleep problems for children with CP from parents and clinicians. Most importantly, these findings have revealed that finding a sleep solution can be challenging for parents and requires great personal strength, skill, education and resources. The findings of this research are important for several reasons:

- i. Disturbed sleep has a significant negative impact on bio-psychosocial health for both the parent and the child.
- ii. The challenges that the parents experienced exposed problems in the healthcare system that impact on parents' quality of life and family workload. There is potential for these problems to be addressed and to positively improve not only sleep, but the family experience of accessing healthcare.
- iii. Good sleep is valued, but sleep problems are not a priority for parents of children with CP and are rarely a focus of clinical care. This lack of attention often results in sleep problems being tolerated and accommodated for long periods of time, sometimes years.

The findings of this research have richly described the problem and demonstrate the potential impact of poor sleep quality and quantity, and conversely, the potential for great impact and clinical change.

12.2 Study Significance

This study is significant for two reasons. Firstly, this is the only study of its kind to obtain qualitative and quantitative data about experience of sleep problems and their solutions, specifically for children with CP and their parents in Victoria, Australia. As presented in the literature review (Chapter Two), there is very little research in general that quantifies sleep problems for children with CP in Australia. Currently, there are only two published studies that examine sleep within the specific context of CP for Australian children.^(2, 69) There is a growing body of research in the area of sleep in children with CP internationally. However, most published research seeks to quantify the type and frequency of sleep problems in isolation. The mixed methods approach utilised in this study sets the findings apart from other research in the field as it provides context and nuance to the experience of sleep problems and seeking sleep solutions.

Secondly, this study has collated data that can be used for transformative change; to inform a meaningful intervention or provide insight as to how to mitigate the impact of poor sleep quality and quantity. As has been demonstrated by the synthesis of the results of all three phases of this study, recognising that sleep is problematic is not always a catalyst for addressing sleep problems. There are many barriers to resolving problematic sleep for children with CP. The qualitative findings of this study have provided insight into the multidimensional nature of sleep problems and will enable meaningful and likely more successful sleep interventions to be designed to address the systems problems identified.

12.3 Summary of Findings

12.3.1 Triangulation of results

This thesis collected three separate sets of data sequentially. The first phase of this study informed the design of subsequent phases. How these sets of data integrate, and the way the three phases are similar, contrast and complement

each other, form the answers to the research questions of this thesis. Creswell⁽⁶³⁾ and Tashakkori and Teddlie⁽⁹⁰⁾ explain how mixed methods data can be presented in a joint display table. The purpose of this table is to synchronise the multiple phases and their individual analysis to produce a mixed methods interpretation of the results. In this study, the synthesis of the three phases demonstrates how the different research paradigms support each other. Presented below is a joint display table that summarises the qualitative data in the first two columns, the quantitative data in the third column, and the fourth column describes the mixed methods interpretation of the entire study.

Table 12-1 Joint Display Table: Mixed Methods Interpretation

Qualitative Finding		Quantitative Results	Mixed Methods Interpretation
Phase One	Phase Two		
Main theme: <i>Seeking Solutions</i> Subthemes: <i>Being Labelled or Judged</i> <i>Feeling Unheard</i>	<i>Luck, Money and Jumping up and Down</i> <i>My Child Doesn't Fit in the Box</i>	Of the 126 surveys, 64 (50.4%) reported they had asked for professional advice about their child's sleep.. Of those who asked for help, 6 parents (9.4%) didn't get help and 3 (4.7%) weren't sure if they had received advice or treatment on sleep. Of the 55 parents who got advice or treatment for sleep problems, 19 (34.5%) reported that said treatment or advice didn't work and 15 (27%) were not sure if it had worked (See Chapter Ten, Figure 10-3 and Section 10.5.3). Those that said they thought their child had a sleep problem had a higher sleep score (see Chapter Ten, Figure 10-2)	Meta-theme one: Finding successful sleep solutions can be challenging Parents were likely to recognise that their child has sleep problems and sought help from their healthcare providers. Often asking for help did not result in effective sleep solutions
<i>Having to Survive</i> <i>Seeking Alternative Solutions</i>	<i>Sleep is One of Many Spot Fires, I Put it on the Backburner</i>	Of the 126 complete data sets, 39 (45.9%) of the 126 had current sleep problems	Meta-theme two: Sleep problems are prevalent and persistent but are often untreated; sleep problems are not a priority Sleep is valued but not prioritised by parents. Parents report that other health problems take priority over sleep. Parents report sleep is rarely a focus of clinicians
<i>Having to Survive</i>	<i>Sleep Disturbance is like Water Torture</i>	A higher CSHQ score was significantly associated with high PSQI score. (see Chapter Ten section 1.5)	Meta-theme three: Sleep problems in a child with CP have a negative impact on parent sleep and daily life: Disturbed sleep of a child often results in a parent that is awake with the child

Qualitative Finding		Quantitative Results	Mixed Methods Interpretation
Phase One	Phase Two		
			and sometimes a parent that is awake while the child sleeps. This sleep disturbance impacts on the parent's physical, emotional health and ability to participate.
Context of sleep in CP	<i>There is Never One Silver Bullet So Many Spot Fires to Put Out</i>	42% had more than one type of sleep problem (see Chapter Ten section 1.5.3)	Meta-theme four: Sleep problems are complex for children with CP Often there is more than one sleep problem, or the causes of sleep problems are multifactored
Was not evident in thematic analysis	<i>Good Care Makes a Difference Help: The Earlier the Better</i>	38% that asked for help with sleep received effective sleep solutions	Meta-theme five: Sleep problems can improve in children with CP There are likely effective solutions that may improve sleep available for many children with CP. Parents reported that whilst sleep problems did not resolve completely, an improvement in sleep was still valuable
<i>Seeking Solutions</i>	<i>A Mother's Ears are Always On</i>	Of Phase Two participants, 97 (76.6%) of the cohort who provided overnight care were female. Five (3.8%) of those who provided overnight care were male and 19 (15%) of the families shared care between. Both genders (see Chapter Ten, Table 10-4)	Meta-theme six: Overnight care of children is often the responsibility of mothers The mothers do this work, and much of the work is to navigate the system. The consequence of doing that work has a significant impact on mothers

It is clear from this table that the qualitative data aligns with the quantitative data. The six mixed methods interpretations are the key findings of the study. These key findings are, in essence, meta-themes, as has been described by Farmer et al.⁽¹⁷⁹⁾ Across the three phases of the research, the data support these six meta-themes: 1) finding effective sleep solutions can be challenging, 2) sleep problems are prevalent and persistent but are often untreated, 3) sleep problems have a significant negative impact on parent sleep and daily life, 4) sleep problems are often complex, 5) sleep problems can improve and 6) overnight care is often the responsibility of mothers.

This table also highlights the benefits of applying a mixed methods approach in this thesis. The qualitative findings provide detail and context to the issues identified in the survey; these could not have been deduced from the quantitative data alone. This included the advocacy and care coordination required of parents when seeking sleep solutions, and the details and dynamics of the parent and doctor relationship that were evident in the Phase One data set. The Phase Three data set exposed the overall systems challenges that parents experience when accessing healthcare, the responsiveness of systems to requests, and the magnitude of work that parents do to ensure their child's care needs are met. It is important to note that these were findings that the qualitative data alone revealed. For example, the theme *My Child Doesn't Fit into the Box* demonstrates the tension that parents feel when navigating a system that is a mismatch for their child. How these meta-themes compare to current published literature will now be discussed.

12.4 Synthesis of Findings with Existing Literature

This thesis presents a research project that adopted an innovative approach to a clinical question, and consequently, several elements of the research findings are novel. The following section will discuss where the findings of this research are positioned amongst the empirical evidence, and where the findings fill a gap in the literature.

12.4.1 Meta-theme one: Finding successful sleep solutions can be challenging

All three phases of this study demonstrated that parents who sought help for sleep problems were often unsuccessful, either not receiving advice or treatment, or receiving advice or treatment that was not effective. This difficulty is punctuated by parents who felt that their child's needs did not match the systemic structures, or conversely, that the system did not match their child. The parents spoke of sleep not being a priority in the context of other more urgent health problems, and related that they felt clinicians rarely focussed on sleep as a health issue. There is very little published research about the facilitators and barriers for parents accessing sleep solutions. In contrast to this research, McHugh⁽¹⁸⁰⁾ found that parents did not ask for sleep help and suggested that the context of the disability may have been a factor for parents not asking for help with sleep. McHugh's qualitative research identified that the parents were tired, grieving or adjusting to their child's disability diagnosis, and this prevented them from asking for help. A study by Robinson and Richdale⁽⁷⁵⁾ reported that up to a third of parents with children with intellectual disability, including children with CP (6.5% of the study group), did not seek help for sleep problems. These two studies contrast with the current findings; in this research parents reported that they frequently asked for help with sleep from their healthcare team.

Within Phase Three, identified by the theme *Luck, Money or Jumping Up and Down*, an additional facet of seeking solutions was revealed: the work that parents, usually mothers, were required to do to navigate the system and find effective solutions. No new evidence on the experience of accessing sleep solutions has been published since the time of the literature review. However, some Australian studies exist that present parents' general experience of navigating the healthcare system. These challenges have been reflected in the work of a Victorian based study by Bourke-Taylor et al.⁽¹⁸¹⁾ They conducted a qualitative study of four mothers of children with a disability and four clinical

professionals who work within the disability sector (paediatricians, occupational therapists). Bourke-Taylor⁽¹⁸¹⁾ found that mothers reported a lack of cohesion between services and spent much time seeking resources, planning, locating and retaining services. This finding was supported by international studies.⁽¹⁸²⁾ Within Bourke-Taylor's study, both mothers and professionals reported that the mothers were expected to constantly advocate for their children.⁽¹⁸¹⁾ This mirrors the thematic analysis of the current project, which identified the advocacy and care management work parents performed for their child. A later study by Bourke-Taylor⁽¹⁸³⁾ found that service system limitations, including lack of respite and family centred care, were the main barriers to maternal participation in the paid workforce for parents of children with disabilities. Several mothers in the current study reported that they were not able to undertake paid work because of sleep deprivation and also the care needs of their child. Strikingly, an Australian parenting resource owned by the Australian Government (Raisingchildren.net.au) explained finding disability services to parents in the following way:

*At first, you might feel overwhelmed by all the information about services and not know where to start. Parents have said that it **seems like a maze**, or a complicated road map.⁽¹⁸⁴⁾*

It is clear from these existing studies and the current study that parents of children with CP are required to be tenacious care managers for their children in order to receive effective care. That is, there are significant gaps within the provision of health and disability care systems that parents are required to fill in order to avoid detrimental outcomes for their children.

The qualitative findings of this thesis provide evidence that parents felt that learning about CP and the healthcare system better equipped them to do this navigation. This finding aligns with the qualitative study by Gibson,⁽¹⁸⁵⁾ who found that an essential part of parenting a child with a disability for mothers was learning about their child's disability and the healthcare system. Gibson concluded that this process of learning was empowering for the mothers. The

thematic analysis of Phase Three, in particular the theme *Help: The Earlier the Better* and several mothers accounts in Phase One, reiterate this concept of knowledge equating to empowerment.

There has been significant investigation into the experience of parenting, in particular mothering, children with a disability. A qualitative study from Canada⁽¹⁸⁶⁾ identified that parents of children with complex care needs had little time for anything other than caring due to the demands of navigating care for their child. Woodgate⁽¹⁸⁶⁾ found that the parent assumed many roles in caring for their child, including being a ‘detective’ to determine what their child needed in regard to their care; an ‘advocate’ ensuring their child’s needs were met; and a ‘case manager’, assessing, coordinating and evaluating their child’s care needs.⁽¹⁸⁶⁾ The number and diversity of the roles identified by Woodgate et al.⁽¹⁸⁶⁾ reflects the immense care work that parents are required to do for their child with complex needs. The findings of these studies^(182, 183, 185) resonate with the outcomes of the current research project. Furthermore, they reiterate the complex context in which sleep problems are situated for these families and that this expectation of immense workload for parents is global. It might be argued that the volume of work that parents need to do every day to ensure good baseline care for their child is so high that a problem like sleep, for which there is little clinical urgency, could easily be deprioritised. If sleep problems are deprioritised, they likely go untreated, which in turn leads to chronic sleep disturbance and deprivation.

12.4.2 Meta-theme two: Sleep problems are prevalent and persistent but are often untreated; sleep problems are not a priority

As presented in Phase Three, many parents of children with a low CSHQ (no sleep problem) also reported a history of sleep problems at some time in their child’s life. Of the seven children with a low (below 41) CSHQ score, four parents reported their child had experienced significant sleep problems in the past. This reinforces the high frequency of sleep problems in children with CP.

Notably, this study explored sleep in children aged six to twelve years; parents of children who are typically developing might expect sleep quantity and quality to return to baseline by the time their children are school aged. Horwood et al.⁽¹⁸⁷⁾ found an incidence of 20.7% of children with a problematic total sleep score on the Sleep Disturbance Scale for Children (SDSC). A key finding of this study was the incidence of sleep problems were higher in the school-aged group, which supports the findings of the current research project. This highlights the propensity for sleep problems to be chronic in children with CP. A direct comparison between Horwood's⁽¹⁸⁸⁾ study and Phase Two results cannot be made due to the difference in sleep assessment tools (SDSC instead of CSHQ). Most recently, a German team⁽¹⁸⁹⁾ conducted a very large (n=2541 women, n=2118 men) longitudinal study of the impact of pregnancy and childbirth on sleep satisfaction and duration for parents of typically developing children. Richter et al.⁽¹⁸⁹⁾ found that the nadir for sleep satisfaction and duration occurred at the age of 3 months post-partum and did not return to baseline until the child reached six years. This demonstrates the chronic impact of child sleep on parent's sleep, but also illustrates that a typical parent should experience a return to baseline (pre-parenting) sleep when their child reaches school age. Thus, it is significant that sleep problems are so frequent amongst school age children with CP. Sleep problems need to be considered early and as a clinical priority in children with CP.

As has been described in the literature review in Chapter Two, there is very little published research about the type and frequency of sleep problems for children with CP and how it impacts their parents. Phase Two, the quantitative phase of this study, demonstrated that 46% of the parents reported that they thought their child had a sleep problem. This aligns with the range of frequencies in already published research, demonstrated in Table 2-1. Four new papers that quantify the frequency and type of sleep problem in children with CP have been published since the initial literature review in February 2016 (see Table 12-2 for a summary of study findings). The similarity of these papers^(187, 190-192) to each other and to the Phase Two survey of the current study,

in combination with those discussed in the literature review,^(2, 64-83), demonstrates that across the world, the incidence of sleep problems is consistently high in children with CP. This consistency throughout similar studies suggests problematic sleep and CP are inextricably linked.

Table 12-2 Papers that have been Published since the Literature Review

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT)	Cause of Sleep Disturbance (Child)	Key Results Child	Key Results Parent	Limitations
Horwood, Mok, Li, Oskoi, Shevell, Constantin, 2018, Canada ⁽¹⁸⁷⁾	Questionnaire SDSC Researcher designed questionnaire on sleep-related characteristics PedsQL	Total n=146 children with CP Age range: 3-12 Age mean: 6.9	GMFCS I =66(44%) GMFCS II =40 (26%) GMFCS III =5 (3.3%) GMFCS IV =16 (10.7%) GMFCS V =23 (15.3%)	Disorders of initiating or maintaining sleep 16 (10.7%) Disorders of excessive somnolence 14 (9.3%) Sleep hyperhidrosis 13 (8.7%)	Pain was biggest predictor of abnormal total sleep score	Abnormal total score: 31 (20.7%) Children of school age were more likely to have an abnormal sleep score N=66 (44%) had more than one sleep disorder	N/A	Response rate 41.7% (150/360) Parent sleep not considered
Kelmanson, 2017 ⁽¹⁹⁰⁾	Questionnaire Child: CSHQ Teacher: Achenbach Caregiver- Teacher Report Form	n=20 children with diplegic CP of level GMFCS I or II without significant comorbidities, who attend a special school n=80 TD children Age range: 5	GMFCS I and II (% of each not presented)	Sleep onset delay Sleep duration Daytime sleepiness	N/A	Sleep disturbances were significant predictors of anxiety, pervasive developmental and oppositional defiant problems	N/A	Limited age range Limited to children with GMFCS level I or II Total sleep score on CSHQ not presented Participants recruited from clinics. Potential total population not described

Authors, Year, Location	Data Collection Method and Tools Used	CP and Non-CP Child Demographics Age Range (years)	CP Descriptors	Most Frequent Sleep Problems Identified (Type) on Sleep Assessment Tool (SAT)	Cause of Sleep Disturbance (Child)	Key Results Child	Key Results Parent	Limitations
								Parent sleep not considered
Munyumu, Idro, Aboo, Kaddumukasa, Katabira, Mupere, Kakooza-Mwesige, 2018, Uganda ⁽¹⁹¹⁾	SDSC	N =135 children with CP Age Range: 2-12	GMFCS I =26 (19.26%) GMFCS II =25 (18.52%) GMFCS III =13 (9.63%) GMFCS IV =26 (19.26%) GMFCS V = 45 (33.33%)	Disorders of initiating and maintaining sleep (27%)	N/A	Overall 32% of cohort had sleep problems Severe disability and presence of epilepsy were associated with sleep disorders	N/A	Limited to SAT Sample population higher proportion of children with GMFCS level V CP Parent sleep not considered
Jacquier, Newman, 2018 ⁽¹⁹²⁾	Questionnaire SDSC Researcher designed questions	Total n=245 children with motor disability n= 109 CP (44.5%) n= 2353 TD children Age Range: 4-18	Spastic unilateral = 46 Spastic bilateral = 35 Dyskinetic = 10 Mixed bilateral = 18	Sleep breathing disorders Disorders of initiating and maintaining sleep	N/A	Children with motor disability CP were more likely (7% vs 1.9% OR of 3.98) than typically developing children to have a sleep problem Single parent households and drug resistant epilepsy were positively associated with pathological sleep scores	N/A	CP population not well described. GMFCS not used Parent sleep not considered

While the small collection of quantitative papers is consistent in its findings, there are no published data that explore how parents of children with CP have successfully managed sleep problems, what happens when they seek sleep help, or the context and complexity of sleep problems specific to CP. Indeed, a systematic review by Galland et al.⁽¹⁹³⁾ found that there were no published studies in which an intervention for sleep for children with CP was evaluated; only studies that included sleep as an outcome measure were found. Since that review, only one study has been published on sleep intervention specifically for children with CP. The lack of studies on sleep interventions demonstrates a significant gap in the literature and highlights the novel findings and importance of the current study. The application of the findings of this thesis needs to be considered in future planning of sleep research for children with CP.

Since the commencement of this study, a systematic review of the psychometric properties of parent and child sleep assessment tools in children with CP has been published.⁽¹⁹⁴⁾ This review concludes that the quality of the research conducted using sleep assessment tools is poor, with a distinct lack of psychometric data to validate the tools.⁽¹⁹⁴⁾ Notably, the authors urge that a condition specific sleep assessment tool is required. Similarly, Micsinszki et al.⁽¹⁹⁵⁾ conducted a systematic review of sleep outcomes for parents of children with neurodisability and examined parent sleep outcomes in isolation to the sleep of their child. Of the 31 papers reviewed, eight included parents of children with CP in their sample. The authors concluded that the overall body of published evidence was of poor quality and used tools designed for typically developing children, which have limited validity in the context of neurodisability. This review emphasises the paucity of research that has been conducted in this area and reiterates the call for high quality evidence with validated tools. These studies and others^(61, 196) demonstrate there is a pattern within published research calling for greater quality research.

It might be argued that for this cohort, the quality of research is likely poor due to the heterogeneous nature of children with neurodisability and the difficulties in recruiting sleepless children and their families. The call for high quality studies with large sample sizes aligns with a reductionist approach to research that measures sleep problems as binary: present or not present. The mixed methods interpretation of this project has demonstrated that sleep problems are multifactorial and complex and deeply entwined with many other aspects of disability: the parent child relationship, worry for a vulnerable child, the comorbidities of CP, and the non-linear nature of raising a child with a disability. Researchers need to design research projects that move beyond outcomes that simply count the number of sleep problems in study cohorts. The greater context of sleep problems needs to be considered, and a greater focus on meaningful interventions is required, in order to create clinical change for these families. Indeed, a study by Romeo et al.⁽⁷⁶⁾ concluded their paper with the declaration that a structured in-depth interview may have provided more accurate data to make better diagnoses, providing further support for the need for a multi-modal approach to data collection.

It is good science to use validated sleep assessment tools. A condition specific tool is likely to mean a more accurate representation of the scope and type of sleep problem. However, it is also important to consider the context in which this tool might be used. In practical terms, the use of a tool in clinic may be fraught. This research project has demonstrated that sleep is not a current focus of clinical appointments as other, more urgent, health problems take priority. The use of a screening tool is likely to take time to complete and then to assess. In practical terms, this may be a barrier to a sleep tool being used in clinic. Additionally, as demonstrated by this study, parents are fatigued by surveys and may be reluctant to complete them. Finally, this study has demonstrated that sleep is seldom a focus in the clinical setting, and therefore, there is little indication that clinicians would implement the use of a tool in an otherwise busy clinic. As this research has shown and was discussed in Phase Two, parents are able to identify and describe what aspects of sleep are

problematic. Instead, the design of a sleep intervention is what might be needed to create improvement in sleep for this cohort.

12.4.3 Meta-theme three: Sleep problems are complex for children with CP

The triangulation of findings from all three phases of this study demonstrates that the reasons for sleep disturbance for children with CP and their parents are as heterogeneous as the condition itself. The findings of the two qualitative phases reflect that sleep problems are multi-factorial and their causes can be complex. Parents linked their child's sleep problems to anxiety related to bullying, separation anxiety, behavioural problems, medical complexity and the myriad of comorbidities that required care overnight. Importantly, 42% of those in Phase Two (see Table 10-3) who had sleep problems reported more than one sleep problem. Reinforcing this finding was the qualitative experience of parents who described many aspects of their child's life that interfered with sleep. This aligns with the work of Horwood et al.,⁽¹⁸⁸⁾ who found that 44% of the children in their study who had sleep problems had more than one sleep disorder. Other studies^(68, 69) also report that more than one sleep problem is common for children with CP.

Several parents described aspects of their child's CP impacting on their comfort and therefore their sleep. For example, instances of tone worsening due to hip dysplasia or reflux triggering increased tone were described. Dreier et al.⁽¹⁹⁷⁾ found that pain in children with severe psychomotor impairment increased the risk of sleep problems four-fold (OR 4.13; 95%CI). This study also found that the need for repositioning and epilepsy were associated with sleep disturbance, confirming the work of others^(2, 69, 71, 77, 81, 83) that pain and repositioning are associated with sleep problems in children with CP.

Data from Phases One and Three confirm that the experience of sleep problems in this cohort is often not linear. The experiences of the parents suggest that the complexity of disability in a child means that children often do not

transition through sleep problems as a singular phase. Rather, parents described sleep problems improving and then worsening due to illness, surgical interventions, changes in family routine (for example, school holidays), or due to child or other life stressors and anxieties that impacted on sleep. No literature was found which describes the experience of sleep problems and their solutions for children over time. However, several studies support the finding that sleep problems are chronic.^(74, 75) This finding demonstrates that resolving sleep problems for children with CP may require repeated intervention over time. Any intervention for sleep in this group should incorporate this in its design.

Phase Three parents Alya, Ariel, Phoebe and Ophelia all described their child's anxiety as a factor that influenced sleep. A recent paper by Whitney et al.⁽¹⁹⁸⁾ reports that children with CP had higher odds of anxiety than their typically developing peers (OR 3.9; 95%CI 1.4-11.3). Anxiety is linked with sleep problems.^(77, 79, 190) However, the relationship between anxiety and sleep is complicated; anxiety may lead to sleep problems and sleep problems may lead to anxiety. Within the current study, Cordelia in Phase Three discussed her child attending a psychologist for anxiety, but they had not discussed sleep. It is possible that anxiety as a comorbidity that influences sleep is often overlooked; parents may interpret bedtime resistance as a developmental behaviour rather than part of a global anxiety disorder.⁽³⁶⁾ For comparison, a paper by Zupanec et al.⁽¹⁹⁹⁾ investigated causes of night-time waking in children with acute lymphocytic leukaemia. This study assumed reasons for sleep disturbance might be related to the pathophysiology of the cancer or chemotherapy. However, their main finding was that sleep problems were linked to fear, anxiety or wanting to co-sleep. There is little published research on the incidence of anxiety in children with CP; this should be a focus of future research, especially in relation to anxiety and sleep.

12.4.4 Meta-theme four: Sleep problems in a child with CP have a negative impact on parent sleep and daily life

The qualitative findings of Phase One and Phase Three of this study demonstrate that sleep problems have a significant impact on the child with CP and their parents. The association between a high PSQI and CSHQ score in Phase Two demonstrates that if a child is awake then a parent is often awake with them. The interviews revealed that parents are also often awake even if their child is asleep. Many parents described staying awake beyond their child's sleep time in order to get some time alone after the work of the day is done. Others talked about being awake anticipating their child waking up, or being unwell, or worries for their child keeping them awake. It was not within the scope of this study to explore the sleep problems of parents in isolation. It is recognised that there is scope for parents to have sleep pathology beyond their child's sleep.

As described in the literature review, several studies^(64, 65, 68, 77-79, 81) found that sleep problems in children are likely to influence the sleep of parents. In addition, a recent study by Lee⁽²⁰⁰⁾ found that mothers of children with developmental disabilities, which included children with CP, experience an average of 2.2 sleep interruptions per night, and at least a third of those interruptions were due to their children with developmental disabilities. There is little published evidence that quantifies the cost of this impact to the parents, the child and the family. The experience and impact of sleep problems for parents of children with CP were explored in both Phases One and Three of this project. It is clear from the themes *Having to Survive* from Phase One and *Bad Sleep is like Water Torture* from Phase Three that the impact of sleep problems was significant and negative. This impact was expressed in many ways; those attending night-time care were often too sleep deprived to work (which had a subsequent financial impact) and daytime routines including wanting to participate in family activities were limited by lack of sleep. For some families, enlisting extended family members to meet the daytime care needs of their

child(ren) was required. Physical and emotional health outcomes were also reported; moodiness, headaches, feeling overwhelmed. It was also clear that there was a perceived impact for children; parents reported their child's behaviour worsened due to poor quality sleep, and this attributed increased frequency of seizures and inability to cope with daily activities to lack of sleep. Chu and Richdale⁽⁵⁵⁾ found that poor sleep in mothers of children with developmental disabilities negatively impacts on maternal psychological wellbeing.

A 2017 report⁽²⁰¹⁾ on the cost of inadequate sleep in Australia estimated that in 2016-2017, inadequate sleep resulted in a financial loss of \$26.2 billion and a wellbeing loss of \$66.3 billion. It also estimated that 23% of motor vehicle accidents could be attributed to lack of sleep.⁽²⁰¹⁾ This report recommended that the impact of sleep deprivation needs to be regulated, especially for those in jobs with high levels of responsibility. This economic report quantifies the significant financial cost of inadequate sleep for Australians. On a societal level, the cost of sleeplessness for mothers is not known. Much research can be found to illustrate that parents of children with CP are tired, and that this tiredness has an impact on physical,⁽⁷¹⁾ mental⁽⁷⁸⁾ and emotional health.⁽⁷³⁾ However, this tiredness is rarely explored in the context of sleep problems; it seems assumed that it is a sequela of parenting a child with a disability. The impact of that tiredness has not been measured on a larger scale. Other outcomes like impact on relationships, between couples and between parent and child, and potential carer burnout, also need further research.

12.4.4.1 Child sleep problems: Impact on child

The three phases of this study relied on parent report of their child's sleep. Within Phases One and Three, parents described the impact of poor quality and quantity of sleep on their child. These reports included impacts on behaviour, fatigue and other comorbidities. For example, parents reported that poor sleep would result in increased seizures for their child with epilepsy. As has been described in Chapter Two, there is very little research on the impact of sleep

problems for children with CP. A very recent study by Horwood⁽¹⁸⁸⁾ found that children with CP scored two points lower on a quality of life assessment tool (PedsQL) compared to typically developing children and this decrease in health-related quality of life was associated with sleep problems. Significantly, more research is needed in this area. However, the work of Horwood⁽¹⁸⁸⁾ and the qualitative data from the current study demonstrate the potential for a significant impact of sleep on quality of life for the child.

12.4.4.2 Co-sleeping

Within this research project, co-sleeping as a means to manage chronic sleep problems was described by many of the parents in Phase One, and by Astra, Nova, Esther and Ophelia in Phase Three. As explored in the literature review in Chapter Two, there is very little evidence about the frequency or reasons for co-sleeping in families with children with CP. Jacquier and Newman⁽¹⁹²⁾ explored the incidence of co-sleeping in their cohort of 245 children with motor disability. They found that those with a motor disorder were more likely to be co-sleeping than typically developing children. Epilepsy was reported as the main reason for co-sleeping in two thirds of parents who co-slept.⁽²⁰²⁾ These data align with the experiences of Astra, Luna and Esther in Phase One, who described their child's seizures or their worry about seizures as a factor that influenced their decision to co-sleep with their child. A parent may choose to sleep with their child in order to maintain vigilance.

As was described by Ophelia in Phase Three, co-sleeping in older children is often associated with shame and stigma. However, it was the most effective solution to increase the sleep quality and quantity for that family. Underhill,⁽²⁰³⁾ in her UK based, qualitative research on sleep in CP in children, discusses that co-sleeping usually has connotations of being dangerous or a bad habit, but found the parents in her study viewed co-sleeping as a useful strategy to provide comfort when their child was unwell.⁽²⁰³⁾ Co-sleeping was identified as a factor in this thesis in the themes *Having to Survive* and *My Child Doesn't Fit in the Box*. It was not an explicit focus of this study. However, it was evident

that some parents felt shame about co-sleeping, even though they considered it a necessary strategy for optimising sleep. If sleep problems are addressed, there is potential for the need to co-sleep to be reduced. There is scope for further research, including how to educate clinicians to better support parents who choose to co-sleep out of necessity.

12.4.5 Meta-theme five: Sleep problems can improve in children with CP

Within Phases One and Three, Nisha, Nova, Vesper, Elara and Ophelia had found successful sleep solutions and reported that they were under the care of paediatricians who applied a multi-layered approach to sleep problems in their child. They described a ‘trial and error’ approach to solutions and sleep problems were revisited at subsequent appointments. Interestingly, only one family reported that they attended a sleep specific clinic. Some parents explained that finding sleep solutions was hard, and others just learnt to live with poor sleep. The Phase Two results corroborated these findings. Specifically, 38.1% (n=21) of the parents who asked for sleep help who reported they had received advice or treatment that had improved sleep for their child.

To date, there is no published research regarding what sleep interventions are effective for children with CP, specifically. Clinicians and researchers may argue that diagnostic specific sleep interventions are not necessary, and that the significant overlap between neurodisability diagnoses may mean a transdiagnostic intervention can be used. Indeed, a recent systematic review by Rigney et al.⁽²⁰⁴⁾ reviewed the effectiveness of behavioural sleep interventions for children with neurodevelopmental disorders. The majority of the reviewed studies focussed on ASD and ADHD, however, some studies included children with CP within sample groups. Rigney concluded that the current evidence suggests a transdiagnostic behavioural intervention is feasible. The findings of the current research project suggest that one singular sleep intervention is unlikely to address the needs of children with CP who have complex sleep problems. It is the contention of this thesis that the management

of sleep problems in children with CP needs to be, at least initially, individualised. As has been described by the parents in this study, an individualised approach to sleep problems allows for the complexity of the problems to be understood, and for treatment of comorbidities of CP that impact sleep to be remedied in the context of sleep problems.

12.4.6 Meta-theme six: Overnight care of children is often the responsibility of mothers

Only mothers agreed to participate in Phase One of this study. In Phase Two, 111 (91%) of the study cohort were mothers. In Phase Three, 17 of the 20 participants were mothers. The reports by the parents in Phase One and Phase Three and the theme of *A Mother's Ears are Always On*, all confirm that it is mothers who usually do the care that is required overnight. This means that mothers are the most likely parent to have their sleep impacted by the needs of their child. This research mirrors the work of other studies that have investigated overnight care in children with neurodisability.^(1, 64, 71, 77, 79, 80) This may be because night-time care is seen as an extension of daytime care and, typically, mothers are responsible for the daytime care.⁽¹⁶⁸⁾ The impact of this care was reported by Bourke-Taylor⁽¹⁸¹⁾, who found that mothers of children with a disability who experience sleep disturbance associated with their child's overnight care needs have lower subjective health and lower participation in health activities, such as active leisure and time with socially supportive others. Lee et al.⁽²⁰⁵⁾ found in their review of the literature of maternal stress, wellbeing and impaired sleep in mothers of children with developmental disabilities⁽²⁰⁵⁾, that mothers sleep poorly and this is significantly associated with depressive symptoms. Interestingly, a study by Boergers et al.⁽⁴³⁾ found that parents of children with sleep disorders reported no difference between sleep duration for mothers versus fathers of children with sleep disorders, however mothers reported significantly more daytime sleepiness. The authors⁽⁴³⁾ hypothesised that this was because mothers experienced more sleep interruptions than the fathers, thus their quality of sleep was reduced, and this was impactful. The

gendered nature of sleep care in families with children is an issue that requires greater focus in both the clinical setting and policymaking.

12.4.7 Meta-theme summary

This discussion of the six meta-themes in relation to the existing literature demonstrates that the findings of this study resonate with previous studies; sleep problems in a child with CP negatively impact parent sleep and daily life, sleep problems are complex for children with CP and overnight care is often the responsibility of mothers. These meta-themes also identify the novel findings of this study: sleep problems are prevalent and persistent and are often untreated, finding successful sleep solutions can be challenging and sleep problems can improve. The synthesis of the three phases has answered the study research questions and provided valuable information about how sleep problems may be addressed or mitigated in the clinical setting. An important aspect of addressing sleep problems is recognising the issues with the healthcare and disability systems. This will now be discussed using CST as a framework.

12.5 Critical Social Theory as it Applies to the Study

Findings

One core tenet of CST⁽²⁰⁶⁾ is the theory of false consciousness. This is the theory *“which explains the nature and process through which social member’s values and beliefs become obscured and distorted by dominant ideologies”*.^{(94)p11} The application of CST to this study’s findings is pragmatic: to understand how the study findings might be used to challenge, change or mitigate the impact of these dominant ideologies. It is not within the scope of this thesis to identify and explain all relevant ideologies. Two main ideologies have been identified as influencing the management of sleep problems within the context of sleep problems and CP: the biomedical model and ideologies of motherhood. These will now be discussed.

12.5.1 The biomedical model and sleep problems

As demonstrated in the joint display Table 12-1, all three phases of this study found that obtaining effective sleep solutions is difficult. The experience of the parents suggested that the challenges were systems based. These systemic problems resulted in parents accommodating significant advocacy and care management work to source the effective solutions for their child (related to sleep problems or for other health problems). These challenges and the perception that their child does not fit in the system might be explained by the dominance of the biomedical model within the Australian healthcare system. As presented in Chapter Four, the biomedical model espouses to the concept that all illness has a single cause, disease pathology is that cause, and that removal of that cause will cure the illness.⁽¹¹⁸⁾ This approach limits healthcare to pathophysiology, thereby excluding sociocultural and psychological factors.⁽¹¹⁸⁾ The influence of the biomedical model is evident in several areas of this study's research findings. These include the tension between a hospital-centric, acute illness focussed healthcare system and the chronic and complex nature of CP; the multifactorial nature of sleep problems and the specialised and segregated nature of healthcare in Australia; and the professional dominance of medicine which leads to an asymmetry of power in the context of clinical care. These three factors will now be discussed, reflecting on the findings from this study and supported by current literature.

12.5.1.1 The biomedical model and hospital-centric healthcare in Australia

The biomedical model has been a guiding framework for the establishment of the Australian healthcare system, and this system is structured on a model of acute care and specialisation. The Australian healthcare system has been described as hospital-centric.⁽²⁰⁷⁾ That is, the funding and structure of the Australian healthcare system are dominated by hospital care and subsequently an acute care focus. Williams⁽¹²³⁾ argues that the small percentage of total health budget (2.8%) that is spent on public health initiatives indicates the

dominance of the biomedical model in the Australian health system.⁽¹²³⁾ Standardisation and efficiency are a major focus of hospital systems. This focus can be problematic for those with chronic and complex healthcare conditions, like CP. The dominance of hospital-based healthcare in Australia also means that many specialists are hospital based,⁽²⁰⁷⁾ as is the case for the majority of children included in this study, who see neurodevelopmental and disability paediatricians affiliated with ambulatory care clinics at one of two tertiary hospitals in Victoria. The parents' access to clinical care is time limited, which creates a pressure to prioritise the most urgent problems in clinic, and those problems are often those for which there is a clear solution. As has been demonstrated by this study, sleep problems are complex and multifactorial. Additionally, hospital-based healthcare in combination with community-based allied healthcare can result in fragmented care.⁽¹¹¹⁾ This fragmentation is often referred to as 'siloing' of healthcare. In practical terms, as the parents in this study have described, this has created a system where many services are not linked either by communication or funding. This results in a system that is difficult to navigate and often this navigation falls exclusively to the parents of the children with CP.

12.5.1.2 Dominance of biomedical model: Sleep is rarely a one system problem

Sleep in CP, as has been demonstrated by the qualitative findings of this study, is rarely a simple problem with one solution. The theme *There is No Silver Bullet* demonstrates that it takes a multipronged approach over a long period of time to implement effective sleep solutions. The fragmentation of systems and the highly specialised nature of healthcare create a tension for those with chronic and complex health conditions. In Phase Three, Vela commented that her child had many conditions and each condition had an associated specialist, but she did not know whom to ask about sleep. Within the Australian healthcare system, sleep is not a separate speciality. Typically, a person with a pathological sleep problem, for example, obstructive sleep apnoea, would be

referred to a respiratory specialist. However, sleep problems that do not have a pathological cause are not assigned to any one specialty. This lack of ownership has been recognised in a recent report by the Australian Government.⁽¹⁷⁸⁾ Recommendation Ten in the report suggests that the Australian Government investigate separating the specialties of “Respiratory and Sleep Medicine” into separate specialties under the Australian Health Practitioner Regulation Agency framework. It was not within the scope of this study to investigate the perspective of the healthcare providers in regard to sleep. It is possible that a lack of delegation or ‘ownership’ of sleep within the system results in sleep being neglected as a health focus by all specialists.

12.5.1.3 The dominance of the biomedical model: Professional dominance

Synonymous with the biomedical model is the concept of professional dominance of doctors as the unquestioned leaders of healthcare, both in their professional opinions but also, more often than not, as managers and decision makers within hospitals. Pescosolido⁽²⁰⁸⁾ describes how the historical rise of doctors, as a profession, was elevated along with science. The development of germ theory, asepsis and anaesthetics all had a significant impact on society, on health and on death.⁽²⁰⁸⁾ Doctors and, in turn, medicine as a discipline, were rapidly promoted and valued within Western societies. The expertise and specialised training, associated licences and laws of medicine added to the exclusivity of the profession, which in turn allocated power.⁽²⁰⁹⁾

This power of doctors within the healthcare hierarchy creates a professional dominance. Within the context of a clinic appointment, this dominance may manifest as the doctor leading the direction of the clinic appointment, often deciding the focus of the clinic appointment.⁽²¹⁰⁾ It is important to note that this dominance is not necessarily conscious. This asymmetry of power has been researched extensively. This power is viewed as both a result of the embedded hierarchy but also as functional; the clinician needs to work to the time constraints and function of the (biomedical) system structure.⁽²¹¹⁾ Often, these time constraints are influenced by the funding of the healthcare system;

appointment times can be decided by the funding structure of the Australian Federal Government Medicare system. However, conscious or unconscious, this dominance in the clinical setting may result in the oppression of the healthcare user.

The parents in this study reported they were rarely asked about sleep within a clinic appointment. Clinicians not asking about sleep may be attributed to a lack of sleep knowledge amongst healthcare providers.^(177, 178) It might be suggested that a clinician with little knowledge about sleep would be hesitant to ask about sleep. Conversely, this lack of knowledge may mean a doctor is unlikely to follow the lead of a parent who is asking for sleep help, meaning sleep is unlikely to be addressed in the clinic appointment. Professional dominance may also influence the parent's perception of the problem. The power of the medical profession also has a history of placing doctors as gatekeepers. If parents present sleep as a problem, and the doctor does not agree, the parent is left to make a choice. That choice is to agree with the doctor or seek the opinion of another doctor. For example, Vesper, in Phase One (see Chapter Seven, Section 7.3.2.), repeatedly asked healthcare providers, including doctors, for help with sleep and was unsuccessful. After years of asking she stopped, assuming there was nothing that could be done. Thus, the professional dominance of doctors can heavily influence the focus of clinical care and potentially deescalate sleep as a priority.

Over the course of this study, the Researcher became aware of her own subconscious alliance to the biomedical model. Early on in Phase Three, Pandora confidently stated that they, as a family, did not subscribe to Western style healthcare, or the biomedical model of health. Pandora said that wherever possible, they used a homeopath or naturopath for all health issues in their family and for their child who has CP classified as GMFCS level I. It was within this interview that the Researcher realised her own assumptions about the biomedical model of care; that all children with CP and their families would interact with the healthcare systems and hospitals. When this participant

presented a contrasting opinion, one that rejects the healthcare system entirely, the Researcher was challenged to reframe all the interview questions to recognise systems outside of Western healthcare. This was a polarising experience and highlighted that even for the Researcher, who was working within a project that critically appraised the dominance of the biomedical model, the concept of rejecting it entirely was foreign.

12.5.1.4 The persistence of the biomedical model

The three sections above demonstrate the dominant influence of the biomedical model and how it may have contributed to the challenges parents in this study experienced. How these issues intersect are demonstrated in a Venn Diagram – see Figure 12-1.

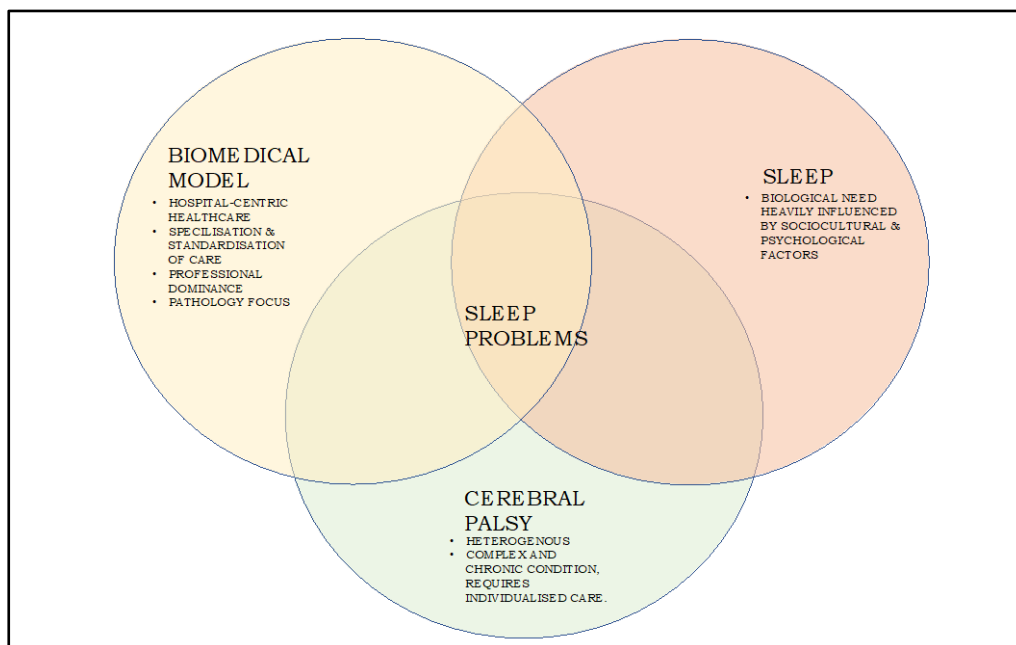


Figure 12-1 The Intersection of Sleep, the Biomedical Model and Cerebral Palsy

It is evident that the biomedical model influences healthcare on both a macro level – systems structures and funding – and a micro level – relationships and power in the clinical setting. This dominance has created a set of false ideals about what is possible within healthcare for parents of children with CP. Indeed, it has been demonstrated, through the clinicians who have provided bespoke and effective sleep solutions alongside the parents of children with CP, that it is possible to provide effective solutions. The work of what seems to be a few unique clinicians needs to be mimicked across the healthcare system.

It should be noted that many alternatives to the biomedical model have been developed, discussed and in some cases applied. One model in particular that stands out is the bio-psychosocial model, which was initially proposed by Engel in the 1970s.⁽²¹²⁾ This model is commonly referred and aspired to as the holistic model of care that includes physical, mental and social health. However, despite the popularity of Engel's model, it has had little influence in the organisation of healthcare or funding.⁽¹¹⁸⁾ That is, healthcare systems are still designed around the biomedical model. A systematic review by Tallon⁽²¹³⁾ found that the dominance of the medical model was the greatest barrier to nurses discussing the social determinants of health in the paediatric context. It is important to note certain specialties like rehabilitation, palliative care and psychiatry have adopted this model.⁽¹¹⁸⁾ It is hypothesised that this model works in these specialties, as they are frequently not hospital-based.

12.5.2 Ideologies of motherhood and sleep problems

Ideologies of motherhood, and in particular, mothering a child with a disability, may also be dominant forces that influence how adequate sleep quality and quantity for children with CP and their parents are prioritised. The concept of mothering and what it means to be a mother is a social construct; it is not determined by biology.⁽²¹⁴⁾ The amount of work the female partner does at home (in heterosexual relationships) and the division of parenting work is heavily influenced by social norms. There is an expectation within white Western

societies that biological mothers are the sole caretakers of children^{‡‡} and that motherhood and womanhood are synonymous.⁽²¹⁶⁾ As presented in Chapter Five and explained in Section 12.4.6 of this chapter, in Australia it is typical for mothers to do the majority of child care, including care overnight, despite a change in societal attitudes towards a more equal distribution of care between parents. As described in Chapter Five, sleep in Western societies is problematised and commercialised and there are many resources to help parents of young children (under 4 years) to access sleep help. The plethora of resources, services and products for sleep demonstrates the high value of good quality sleep in this society. Conversely, the findings of this study demonstrate that parents of school-aged children with CP who have sleep problems do not have access to the same wealth of resources. This stark contrast may indicate that at a sociocultural level, sleeplessness for parents of children with CP, in particular mothers, is normalised or expected. This normalisation can be attributed to three factors: 1) the concept of the ‘good mother’, 2) the expectation that mothering a child with a disability is difficult, and 3) the expectation that mothers do the emotional labour of parenting.

12.5.2.1 The ‘good mother’ and the gendered nature of caregiving in Australia

The social construct of the ‘good mother’ has been well described in the literature.⁽²¹⁶⁾ This construct maintains that mothers alone are expected to unconditionally and dutifully attend to their children to ensure their comfort, happiness and safety, regardless of the impact on themselves.⁽²¹⁶⁾ This ‘good’ mothering is intuitive and natural; ‘good’ mothers inherently know how to care

^{‡‡} These motherhood theories are dominated by the assumption that mothers are of white, heterosexual, middle class status. This dominance fails to recognise diversity in expectations of mothering due to class and cultural factors.⁽²¹⁵⁾ The Researcher recognises there is significant body of work that examines this. It is not within the scope of this thesis to explore this discussion.

for their children.⁽²¹⁶⁾ This social construct is a standard against which mothers are judged and therefore, a mother will monitor and modify herself according to these judgments.⁽²¹⁷⁾ Some have argued that mothers of children with a disability are watched more closely than those of typically developing children; the pressure to be a ‘good’ mother is higher.⁽²¹⁷⁾ These judgements may occur in person and increasingly, there is an online aspect to mothering; social media discussions and discourse between mothers and about mothers may heighten this expectation of the ‘good mother’.⁽²¹⁶⁾

Some have argued that the concept of the ‘good mother’ acts as a way of regulating women, ensuring that women take on the care of children, that family life is regulated and ‘nation building agendas’ are achieved.⁽²¹⁶⁾ Academics have suggested that while these ideologies are dominant and influential, they may not resonate with the lived experience of being a mother.⁽²¹⁴⁾ Two mothers in Phase Three of this study, Juliet and Titania, described not getting up to their awake children at night. This contrast to the other mothers was stark. Titania described how her son was often awake at night, playing and jumping on a mini trampoline for hours. Titania had installed safety equipment so her son could not leave his room, and after ensuring her son was safe, she would go to bed and sleep. In the interview, Titania explained that she understood that others might find it unusual for her to be asleep while her child is awake. Juliet described her child with severe CP, who frequently awoke distressed overnight. Due to his disability, he was unable to leave his bed. At night, Juliet would ensure her son was safe and warm but if she heard him wake, she would not get up to him. Juliet stated that she prioritised her own sleep above the sleep of her child, and he would eventually fall back asleep. The reports of Titania and Juliet polarised the accounts of the other 25 mothers. In contrast, Portia reported waking up multiple times per night, every night, to reposition her child, even though her child slept through. The contrasting choices of these mothers demonstrate how a mother’s attentiveness at night-time can be normalised as an innate duty.

The influence of the dominant ideology is clear; mothers are expected to be awake with their children and to endure this sleeplessness without assistance.

For the Researcher, as a clinician and possibly as a mother, the interviews with Titania and Juliet highlighted the dominance of the ‘good mother’ ideology. While listening to these two mothers explain why they don’t stay awake with their children, it was challenging to be aware they let their children be alone overnight. After reflection, this tension became insight; perhaps more mothers need to find ways to safely leave their children, rather than everyone be awake. This is not to say that children who are awake and require supervision and/or comfort should not receive it, but it is possible that a child’s father could have a more active role in sleep care or external resources such as carers may be employed. It is clear that the expectation that mothers always provide this care should be challenged.

The ideology of the ‘good mother’ may also influence whether sleep problems are given priority. While the impact of poor quality and quantity of sleep is significant, it might be argued that to some extent it has been normalised. Good mothers are expected to be sleepless alongside their children, as an extension of their care role. This study found that parents experienced challenges finding successful sleep solutions, and this often resulted in chronic sleep disturbance and deprivation for both the child and their parent. However, despite the chronic nature of their sleep problems, few of the parents interviewed had respite care from family members or professional carers and only a small portion of them reported help from their male partners. The Phase Two survey revealed that only two families had non-parental help overnight. That is, mothers are unlikely to receive respite from overnight care of their children. Importantly, their male partners infrequently shared overnight care. However, the impact of the sleeplessness of the mother, on her paid or unpaid work, does not seem to be recognised. From the experiences of the mothers interviewed, it seems the father’s sleep is to be protected at all costs, but no aspect of the mother’s workload or fatigue should be protected or prevented. It might be

argued that this tolerance of the sleeplessness of mothers heavily influences the prioritisation of sleep problems for children with CP.

A Swedish study⁽⁷⁸⁾ explored the night-time attention provided by parents with children with significant disability. All the families in this study⁽⁷⁸⁾ were entitled to government funded overnight respite care, but no families reporting accessing this service. This may indicate the pressure for mothers to do this care themselves, rather than outsource it, as Portia described in Phase Three of this current study.

One might argue that Victoria's health and disability systems take advantage of the expectations of a 'good mother'. As presented in Chapter Four, Australia's disability system has transitioned from institutional care to community care, but adequate financial and social supports have never been implemented. This inadequacy has resulted in families, mothers, being required to fill the gaps in the system. Mothers appear to adopt this work as an extension of their caring role, which, in turn perpetuates the inadequacy of the system. It has been suggested that the NDIS may correct some of this inadequacy, but as the mothers in Phase Three have reported, to date, the NDIS has not addressed this.

While mothers are expected to be devoted and attentive, the pressure for fathers to take on parenting work appears to be less. In the qualitative interviews in this study, the mothers explained that their male partners needed sleep in order to attend paid work. These explanations were always brief and contained very little defence, as if the mothers felt this imbalance in care was to be expected. Since the 1980s, there has been a shift toward higher expectations for fatherhood and fathers are spending more time with their children.⁽²¹⁸⁾ Larossa⁽²¹⁹⁾ argues that there is a mismatch between the cultural expectations of what parenting involves for a father compared to the actual conduct of fathers, and that fathers seldom take on a true co-parenting role. It might be argued that the expectation that mothers do the majority of the child care combined with the expectation that fathers will perform the paid work reinforce

each other. It should be noted that fathers might not necessarily be consciously participating in this gendered parenting imbalance. It is likely that workplace systems and policies make it difficult for fathers to be anything other than full-time workers. A study by Cooklin et al.⁽²²⁰⁾ found that for Australian fathers, long and inflexible work hours were associated with increased work-family conflict and this was associated with increased distress for fathers. Cooklin et al.⁽²²⁰⁾ recommended that the results of their research be used to implement ‘family friendly’ work conditions for fathers. Another Australian study⁽²²¹⁾ of 40 couples, explored men’s post-natal health and found that fathers want to be more involved in the care of their children but employment circumstances limit their involvement. It also found that those fathers with less job flexibility and less autonomy, factors that would enable them to be more available to parent, experience more unhappiness, anxiety and stress. Indeed, Charlesworth et al.^{(222)p35} argue that:

...the gendered polarisation of hours in the Australian labour market, supported by a one-and-a-half earner family strategy, undermines parents’, particularly mothers’, access to good quality jobs. It also reinforces gender inequality by making it harder for fathers to fully engage in parenting.

It is likely that fathers, as individuals, would opt to have a more equal role as parent. However, powerful labour-force pressures greatly influence their ability to do so. Thus, the gendered nature of care-giving is perpetuated through economic systems and structures. There is little research on the role of fathers in parenting children with a disability. In Phase Three of this study, three fathers were interviewed. Atlas was the father of a child who had no current sleep problems, but did experience problems with night-time settling as an infant. Atlas explicitly stated that he enjoyed the extra comfort his son needed and viewed it as an opportunity to bond. Leo was a father to three children; his partner Norma worked full-time and Leo was the primary caregiver to their children. In this family, Norma had the higher earning capacity and it was more practical for her to work full-time.

The results of this research suggest that the expectations of the ‘good mother’, combined with economic and systems structures that reinforce the gendered nature of parenting, likely influence the workload of the mothers of children with CP. This is a problem that needs greater attention from a policy level.

12.5.2.2 Mothering a child with a disability is expected to be difficult

The qualitative data from this study that represents the experiences of mothers in *seeking solutions*, and how they were dismissed or unheard, may demonstrate the potential for the normalisation of poor sleep or extreme tiredness for these mothers. Many of the mothers interviewed described asking for help with sleep, only to be told that the sleep problems were normal or acceptable for their child. Both these accounts indicate the normalisation of sleeplessness for these mothers. Further, within Phase One, when mothers were asked to describe what a ‘good’ night would be, they all reported a few solid hours of sleep would be enough, rather than a whole night of sleep.

Another aspect of mothering a child with a disability that may be influenced by societal expectations is the social construct of disability as a burden.⁽²²³⁾ This construct may influence what the mother expects to occur in regard to service provision, and also what others expect her to tolerate. However, research suggests that mothers do not perceive the care of their children as burdensome, and in fact will often describe the many benefits of having a child with a disability.⁽²²⁴⁾ It is notable that the qualitative analysis in this study did not reveal mothers describing their children’s disability as being difficult. Rather, they described their challenges as sitting within the system, which reflects the findings of other research.⁽²²³⁾

In Phase One of this study, the theme of *Having to Survive* suggested that the challenges of finding sleep solutions and the compromises mothers made to adjust to poor quality or quantity of sleep may have reduced these mother’s expectations of what a good night’s sleep is. In turn, this may have contributed to their willingness to settle for poor sleep and not seek further help. It can be

argued that the systemic lack of responsiveness disempowers and demotivates these women to seek help to change their circumstances.

In Phase Three of this study, the theme *Luck, Money or Jumping Up at Down* identified the notion that obtaining good care was a matter of luck. It is important to consider what this means for the experience of mothering a child with a disability. If coordinated and supportive care is regarded as ‘*lucky*’, what does this suggest about the mother’s expectations? The notion of relying on luck can be interpreted as a sign that parents do not have control within the system. The Researcher hypothesises that mothers expect the experience to be hard and they take on this extra care as a ‘natural’ extension of their mothering role and the emotional labour they routinely perform.

Another aspect of mothering a child with a disability to be considered is the concept that these mothers are saintly. Landsman⁽²²³⁾ described a commonly quoted newspaper article that describes “*special mothers for special children*”. This popular piece explains that the needs of a “*special*” child with a disability are designated by God and matched with a “*special*” mother who can provide for them; caring for a child with a disability is God’s work. This concept reflects a societal perception that mothers of children with disability are doing saintly work, and as saints they are expected to accept the immense workload without complaint.

Conclusively, there are many complex constructs of mothering a child with a disability that may influence expectations.

12.5.2.3 Emotional labour

Emotional labour has been presented in the discussion in several of the sections above. It will now be explored in more detail. The Phase Three theme *A Mother’s Ears are Always On* demonstrates not only the work mother’s do when their child wakes, but also the anticipating, worrying and planning that mothers may do when their child(ren) is/are sleeping. Hochschild⁽²²⁵⁾ describes the roles that working mothers take on as three shifts. The first is the day shift,

a paid work day; the second shift is the work done in the evening, domestic tasks and caring for the entire family; the third shift is that of emotional labour, a somewhat invisible workload that includes anticipating what her children and partner will need as tasks to be done and also to be happy. Emotional labour is defined as the “*labour involved in dealing with other peoples’ feelings*”.⁽²²⁶⁾ This emotional labour is also the work done to initiate and maintain relationships/friendships with those outside the home. Hislop and Arber⁽¹⁶⁸⁾ extended on the theory of Hoschild, adding a fourth shift: the work done overnight to care for children. Hislop and Arber⁽¹⁶⁸⁾ argue that this work is assumed for all mothers. Daniels⁽²²⁷⁾ describes this work as “*invisible work*” and explains, in her classic paper, that mothers do this work while making it look effortless, which reinforces the invisible nature of the work. Erikson⁽²²⁸⁾ argues that emotional labour is often considered a reflection of love or intimacy and as such the effort it requires is overlooked.

The findings of this research project reveal that the expectations of mothers regarding emotional labour are inclusive of mothers of children with CP. As Halley in Phase Three described, when her child woke, her husband would tell them to just go back to sleep. In contrast, Halley would then investigate why her child was awake and try to determine what the nature of the problem. It is possible that the gendered expectations around emotional labour with children impose significant pressure on mothers to be sleepless alongside their child. It is clear that there is scope for this labour to be shared with male parents, therefore lessening the workload of mothers.

12.5.2.4 The gendered nature of overnight care: Summary

This section has clearly described how dominant ideologies may influence the lack of prioritisation of addressing sleep problems in children. Mothers are expected to take on most of the overnight care, and subsequently be sleepless alongside their child due to this work being invisible and normalised. Pederson et al.⁽²²⁹⁾ have argued that there are clear gender-based inequities in health, but that health promotion is almost always gender neutral or gender blind. These

researchers⁽²²⁹⁾ argue that health promotion needs to be gender specific in order to address gender-based inequalities. In the case of this research, it is argued that any intervention to address the inequalities between parents needs to address mothers in particular.

12.5.3 Understanding the influence of the dominant ideologies is transformative knowledge

The application of CST to the study findings has identified key factors that may influence the lack of priority that sleep problems are given in the context of sleep in CP. These factors can be used to help inform how clinical care can be changed to improve or mitigate sleep problems, including:

- improving the parent's knowledge of healthcare and disability systems in order to empower them to source more effective solutions (sleep and other health concerns)
- mother focussed interventions that support mothers to seek respite care, share the load of overnight care and to ask for more help
- health promotion and education to increase the awareness of the importance of good quality and quantity of sleep, for both parents and clinicians

These factors have been used to inform the recommendations of this study and will be presented in Section 12.7 of this chapter.

12.6 Study Limitations

This study had several limitations, which will now be described. The limitations specific to the quantitative phase of this study (Phase Two) have already been described in Chapter Ten.

12.6.1 What is absent from the data: The worst sleepers

Within any research study, it is not possible to recruit the entire population of those being studied. In Phase Two of this this research project, only 21% of the

potential participants identified in the VCPR participated in the study. The recruitment of Phase Two consequently impacted upon the availability of participants for interviews in Phase Three. It is important to note that all parents interviewed in this study stated that their child's current sleep behaviours were significantly improved compared to past sleep patterns. That is, their child's sleep was not at its nadir. It is recognised that there are significant barriers to recruiting those who are experiencing extreme sleep deprivation. Therefore, it might be hypothesised that the findings of this study are an underestimate of the experience and impact of sleep problems for children with CP and their parents across Victoria. Nevertheless, it is important to note that this research is the first to explore sleep problems specific to children with CP in Victoria; it is the only data of its kind. It is also important to note that recruitment challenges were identified in the pilot that preceded this study.⁽²⁾ The results of this pilot informed the design of the thesis. Additionally, Phase One findings were used to design a survey that would maximise participation based on parent preferences. Despite these efforts, recruitment challenges persisted. This demonstrates the difficulty in engaging this parent cohort.

12.6.2 Critical social theory and participant engagement

Consultation with the parents in Phase One of this study was a key facilitator for the novel findings of this research. However, this consultation may be seen as relatively didactic, which does not align well with a CST framework and the aspiration to empower and emancipate through equality. It is recognised that there are many different approaches to participant engagement that may have given the participants a near equivalent relationship with the Researcher, such as, for example, a participatory action research design. The choices about the current study design were based on the limited resources of the Researcher and a PhD level project. Participant engagement is time intensive and often requires large scale research teams.⁽⁶³⁾ In addition, the significant challenges of recruitment, and the life complexity and fatigue reported by the parents in this

project, demonstrate it may have been extremely challenging to engage participants in a long-term role in the research. Nevertheless, it is clear that the methods used were effective and did generate powerful data that challenge clinical assumptions.

12.6.3 Generalisability of results

This study was Victorian based and Victorian focussed. The difference in healthcare services across the states of Australia and internationally may limit the wider applicability of these results. However, the mixed methods approach has demonstrated the benefit of asking parents about their experience of systems problems. Therefore, while the study findings may not be applicable to other locations, the study methods may be worth repeating elsewhere.

12.6.4 Potential sample bias

All three phases of this study required participants to opt in. It is possible that there is a sample bias and that the incidence of sleep problems reported in this study, particularly in Phase Two, is higher than across the entire population. Nevertheless, this research represents the only data of its kind for children with CP in Victoria.

12.6.5 Lack of participant diversity

Due to limitations in resources, this study only included participants who spoke English. Therefore, this study has not captured the experience of participants who cannot speak or read English. As presented in the Phase Two results in Chapter Ten, the demographics of respondents indicated they were more educated and on higher incomes than the average Australian.⁽¹³⁴⁾ Subsequently, the Phase Three participants had higher education and financial resources with which to navigate the healthcare system. It is likely that this research project does not represent the experiences of those less resourced. While this may limit the wider application of the research, it can be argued that this means the

results of this project are an underestimate of the challenges experienced by parents when accessing sleep solutions, or healthcare in general.

12.7 Study Recommendations

The following recommendations have been based on the mixed methods interpretation of the three phases of this study and an incorporation of the application of the theoretical framework of CST. Five recommendations have been identified in this thesis. These recommendations can be divided into the domains of 1) clinical care or 2) health policy and education.

12.7.1 Clinical care

12.7.1.1 Need for an individualised approach to care for children with CP

The application of CST to the study findings demonstrates the limitations of the biomedical model in the context of chronic and complex care. The findings of this thesis strongly support the need for individualised sleep care for children with chronic disabilities and comorbidities and should be used as an evidence base to influence clinical care. Co-ordinated or integrated care for children with medical complexity is an emerging model in paediatrics. Within these models, a central clinician, usually a nurse, provides a central point of contact for the family. This nurse becomes the conduit between the family and other clinicians and often tertiary and community settings. This nurse provides care planning education and considers the psychosocial determinants of health⁽²³⁰⁾ and their impact on the child, their family and their care. While this model of care is relatively new, research to date suggests it results in economic benefits and improvements to the child's quality of life.⁽²³¹⁾ Similar models used in adults with chronic conditions have reported benefits, including having more time to discuss healthcare needs as a nurse has more time available and a more relaxed and improved atmosphere within the clinic appointment.⁽²³²⁾ Since the commencement of this study, the RCH has introduced the Complex Care Hub (CCHUB). This is a new model of care coordination for children with medical

complexity. It provides ready access to senior nurses and a medical team. This model closely aligns with the bio-psychosocial model of health. Relevant to this thesis, there is scope for CP education and sleep awareness to be integrated within the care coordination model, specifically for advanced practice nurses to have a role in the early education of children newly diagnosed with CP and their families. Importantly, the integration of nurse-led research into the design and implementation of these models of care is vital to ensure that the changes to clinical care fit for purpose; the needs of the child and their family are met by these nuanced and time intensive care models.

12.7.1.2 Potential role for nurses and allied health clinicians in sleep and CP

It is striking that throughout the findings of this study, that school-age children with CP do not routinely have a nurse as part of their clinical care team. This means there is great scope for nursing to develop a clinical role in improving sleep health for paediatric healthcare users in Victoria. It is a recommendation of this study that health service providers consider the role of the nurse as a source of health education and support. A nurse could have a pivotal role during the time of early diagnosis in providing education about CP, assisting with navigating the health and disability systems, and potentially providing clinical support and advice about sleep health. Indeed, there is scope for a nurse-led clinic to be established in the area of sleep and disability. Sleep management and advice could be easily adapted to an advance practice nurse role. Additionally, in Phase Two of this study, allied health therapists were routinely involved in the care of the children (84% had physiotherapists, 72% had occupational therapists). However, parents did not commonly ask their therapists for help with sleep. Allied health therapists could incorporate sleep health as part of their folio of care.

These findings demonstrate that there is potential for non-medical clinicians to be involved in sleep health. Work needs to be done to explore the potential of modifying current nurse and allied health roles to accommodate sleep health.

12.7.1.3 There is an urgent need for greater access to respite

Children and their parents who have sleep problems that are refractory to individualised, skilled and sophisticated clinical care need support to obtain respite. Respite is regarded as temporary relief from caretaking responsibilities associated with a child's disability.⁽²³³⁾ This respite may be provided by professional services or a family member. Within the context of sleep problems in CP, respite may take the form of overnight care so the parent may sleep, or daytime care so the parent can rest or nap during the day. The findings from this study should be used as evidence to advocate for this respite to be considered at a policy level. It is clear from the experiences of those parents in Phase Three who received respite care, either from a professional service or a family member, that respite mitigated the effects of their child's sleep problems. This finding is supported by Gevir,⁽²³⁴⁾ who found that mothers of children with a disability who received help with care reported higher satisfaction regarding their ability to balance their time. However, the experience of accessing respite care was not universal; it seemed to rely on parents persistently advocating for access to or funding for respite care. The findings of this study should be used as evidence to support greater availability of funding for respite care. The findings also reveal a need for clinicians to be advocates for respite care for the children and parents under their care.

12.7.2 Health policy and education

12.7.2.1 Sleep health needs to be promoted and should be a priority for children with CP and their parents

It is clear from meta-theme two of this study that sleep problems are not a high priority for parents of children with CP. A recent report by the Australian Government⁽¹⁷⁸⁾ recommends (Recommendation Eight) that a national sleep health awareness campaign should be developed and implemented. The results of this study support this campaign and the need to include health promotion that specifically targets mothers of school age children, especially those children with a disability. The difficulties in engaging this group, due to their

fatigue and care responsibilities, indicate that health promotion should be easily accessible. This might include information posters on clinic waiting room walls, or simple prompts in communications, such as appointment letters or text messages to confirm attendance. The use of social media groups for parents of a child with a disability may also be effective; many mothers in Phases One and Three described accessing information from disability focussed groups in social media forums such as Facebook. The potential utility of social media as a health promotion tool is being increasingly recognised,⁽²³⁵⁾ and some evidence exists that it is effective in changing behaviours.⁽²³⁶⁾ Importantly, the message of the campaign should not focus solely on the sleep of the child, but also encourage mothers to think about their own sleep health and possible solutions.

12.7.2.2 Sleep health needs to be elevated as a priority for all clinicians

It is also clear from meta-theme two that, as per parent report, many clinicians do not prioritise sleep as a health problem in the clinical setting. This may be due to lack of knowledge and skill. As was presented in Phase Three, one parent, Ariel, reported that participating in the Phase Two survey was provocation enough for her to revisit sleep with her daughter and implement strategies that improved her sleep. This one example shows that simply asking about sleep may be an intervention in and of itself.

The findings of this study, and the parents' reports of how sleep impacts on aspects of their child's health and wellbeing, and conversely, that their child's health and wellbeing impacts on their sleep, indicate that *sleep* is a meaningful measure of clinical outcome and management for children with CP. Incorporating assessment of sleep within usual clinical consults may be instrumental in shifting perspective for clinicians (paediatricians, rehabilitation specialists, allied health therapists and nurses) involved in managing children with CP. Routinely assessing quality and quantity of child sleep may reveal information about other health problems, including those that occur across day and night. For example, pain, seizures, tone and mental health. Notably, in order for clinicians to ask these questions they may require

further education and training about the assessment and optimisation of sleep. Therefore, this recommendation is associated with the need for education programs in sleep assessment and solutions. This recommendation is supported by the recent Australian Government report,⁽¹⁷⁸⁾ which recommends (Recommendation Nine) that the sleep knowledge of GPs, nurses and psychologists be assessed with a view of developing effective training mechanisms to improve primary healthcare practitioners' knowledge in diagnosing and managing sleep problems. The findings of this study confirm that this enquiry and training should include a focus on primary healthcare services that have a paediatric focus, particularly those who work with children with disability.

12.7.3 Scope for further research

This project has provided extensive and triangulated data about sleep in children with CP that was not previously known. These data extend a very small body of pre-existing knowledge. This study has also highlighted the need for further research. The following section will present how the findings of this project may be used as a catalyst for further research.

12.7.3.1 An education-based intervention for parents of children with CP should be developed via an experience-based co-design process

As has been highlighted by the theme *Help: The Earlier the Better* in Phase Three, the descriptive experience of mothers in Phase One, and the work of previous studies,⁽¹⁸⁵⁾ parents feel better able to navigate the complexities of caring for a child with CP once they have learnt more about CP and the care system. Therefore, anticipating this learning need may help to hasten this process of familiarisation with a child's condition and care required. It is proposed that an education focussed intervention be designed that would rapidly up skill parents on both systems and CP as a condition. It is proposed that the intervention would include clinical information about CP and relevant pathophysiology and care management, in addition to how health and disability

services work in Victoria, how to navigate the systems and what do to when solutions are difficult to find. This intervention would be informed by the findings of this study, with a view to incorporating a participatory design process. For example, an experience-based co-design model could be used to ensure that the intervention created is meaningful and applicable to the participants, and feasible to the Victorian healthcare system. Experience-based co-design is an iterative research process that synthesises the experience of clinicians, healthcare users and key stakeholders.⁽²³⁷⁾ Within this process, clinicians, healthcare users and key stakeholders have an equal standing and, along with the researchers, collaborate to design a meaningful intervention.

It is proposed that this project could be a 6-12 month post-doctoral study that would involve focus groups with clinicians, parents of children with CP and young adults with CP. The findings of this thesis would be used as '*emotional touch points*' within the focus groups, as described by the experienced-based co-design tool kit.⁽²³⁷⁾ The qualitative data from the focus groups, and the feedback from clinicians, parents and young people with CP, would be used to inform the nature and structure of the intervention.

12.7.3.2 Pragmatic and clinically relevant research in sleep and CP and other CP research

The outcomes of this study demonstrate the value of a mixed methods design. The synthesis of both qualitative and quantitative research paradigms has answered the research questions by providing broad level population data (quantitative) combined with the context in which the clinical problem is occurring (qualitative). This approach is particularly significant for sleep research given the bio-psychosocial nature of sleep as a health problem. It is the assertion of this study that this research design has provided unique insight into the clinical problem of sleep. Therefore, there may be benefit in using mixed methods research more widely in service and clinically focussed research in the sphere of CP care.

12.7.3.3 Identified gaps in research

The paucity of research in sleep and CP has been clearly described throughout this thesis. The meta-themes above have identified several key areas that need further exploration:

- i. Co-sleeping: the extent to which parents co-sleep with their child, if co-sleeping is their choice, the impact of co-sleeping and the potential stigma or shame that parents feel because they co-sleep with their older children.
- ii. Epilepsy: several papers^(66, 70, 77, 191, 192) suggest that seizures are associated with sleep problems. The qualitative findings of this study support the concern that seizures can lead to overnight vigilance for parents.
- iii. The health economic impact of mothers' sleep problems: it is possible that the impact of sleep problems for mothers of children with CP has a significant societal and economic impact. Quantifying this impact may provide the evidence needed to influence a change in the priorities of policies and services for these families.
- iv. Anxiety: parent reports suggest that anxiety is an issue that impacts on sleep for children with CP. There is very little published literature on anxiety in CP. Extensive work is needed in this area.

CONCLUSION

The catalyst for this project was the clinical experience of the Researcher. This experience suggested that parents of children with CP were enduring chronic sleeplessness because of the complex care needs of their child and an assumption that poor sleep was normal. This doctoral thesis has amplified the clinical curiosity of the Researcher to create a research project with multi-layered findings that explain the frequency, impact and experience of sleep problems for children with CP and their parents. The context of sleep problems and the nuances of caring for a child with a significant disability and its

comorbidities is the strength of this study. This study has presented a synthesised account of three separate phases of research. These phases triangulate each other and have enabled an insightful and potentially transformative plan for clinical change and further research to be proposed.

This study has used an innovative design to answer a complex and poorly understood research problem. It has produced a meaningful and novel mixed methods interpretation of the three separate phases, which will be used to create clinical change. This study has demonstrated the convoluted nature of sleep problems for children with CP and its negative impact on the parents of those children.

This thesis began with a brief introduction to the physiology of sleep and the pathophysiology of CP. The position of this study was then described within the context of the narrow field of previously published literature. The theoretical framework of CST and how it was applied to the study was then described. A rationale was provided for the mixed methods design used. Following this, Phase One methods were articulated and then the findings were presented. How the findings of Phase One informed the design of Phases Two and Three were described. This sequential design that incorporated the experience of the participants illustrated the value of a mixed methods approach to answer the research questions of this project. The experience of mothers of children with CP who have sleep problems differed significantly to the clinical assumptions of the Researcher. The findings of Phase One redirected the line of inquiry of this study from exploring parent knowledge and assumptions about sleep to examining issues with healthcare and systems. Subsequently, the design of Phases Two and Three were enhanced to reflect the experience of the parents in the study. As a consequence, the results of Phase Two and Three combined with Phase One revealed previously unrecognised issues within the system: the challenges parents experienced when seeking effective sleep solutions for their children. Throughout this study, the challenges of parents of children with CP were presented in great detail through

compelling, rich and nuanced accounts from parents. It is not the position of the Researcher that parenting a child with CP is inherently harder or more work than parenting a child without a disability. Rather, that the current health and disability systems in Victoria create significant work for parents, usually mothers. It is clear that there is much scope for the systems to be changed to reduce this care load. This improvement may be through change to clinical care models, empowering parents to better navigate the system, and utilisation of nursing and allied health practitioners to become advocates for good sleep health. Additionally, changes in healthcare education and policy, increased education to healthcare providers, and the provision of financial support to employ carers to assist with overnight care or to enable daytime respite from care requirements.

This research addresses a significant gap in the literature in regard to the sleep of children with CP and their parents. It is essential that the outcomes of this complex project be translated into clinical practice as soon as practicable. Whilst this study revealed that sleep problems are often regarded as not urgent or not a priority, the cumulative effect of chronic sleep deprivation is likely to be significant. This thesis provides substantial evidence that ameliorating sleep problems has the potential to have significant positive impact on the nights and days of children with CP and their parents. It has also illustrated system structures and dominant ideologies that may contribute to sleep problems being untreated. Most importantly, this study has found that improving sleep problems for children with CP is possible.

Researcher: It sounds like a really hard few years.

*Vesper: Anyways we made it through. I guess that's why I feel so
passionate about what you are doing.*

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APPENDICES

APPENDIX A: PILOT STUDY PAPER

Petersen S, Harvey A, Reddihough D, Newall F. Children with cerebral palsy: why are they awake at night? A pilot study. *J Spec Pediatr Nurs*. 2015;20(2):98-104.

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ORIGINAL ARTICLE

**Children with cerebral palsy: why are they awake at night?
A pilot study**

Sacha Petersen, Adrienne Harvey, Dinah Reddihough, and Fiona Newall

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Search terms
Cerebral palsy, children, clinic, disability, long-term care, nursing, outpatient, pediatric, quantitative, sleep.

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Abstract
Purpose. The purpose of this study was to assess acceptability of study design and utility of assessment tools for determining causes of sleep disturbance in children with cerebral palsy (CP) and their caregivers.
Design and Methods. This pilot study explored parental report ($n = 8$) of the child's sleep using a validated sleep questionnaire, a survey, and a time use diary.
Results. The selected tools were appropriate. Study design provided challenges for recruitment. Future research should include qualitative data.
Practice Implications. Although further research is required to confirm results, sleep problems for children with CP and resulting sleep disturbances for caregivers may be an important part of clinical assessment.

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Sleep disturbance can significantly impact upon the child with cerebral palsy (CP) and his/her family. Poor quality and quantity of sleep in children with CP has been correlated with poorer quality of life for the child (Sandella, O'Brien; Shank, & Warschausky, 2011), maternal depression (Wayte, McCaughey, Holley, Annaz, & Hill, 2012), and reduced parent/caregiver capacity to participate in health-promoting activities (Bourke-Taylor, Pallant, Law, & Howie, 2013). Despite this, sleep is often overlooked as a health concern in all children, including those with CP. One potential explanation is that for children with CP, other health concerns take priority within the clinical environment.

Evidence suggests that children with CP more commonly experience sleep disturbance than their typically developing peers (Atmawidjaja, Wong, Yang, & Ong, 2014; Wayte et al., 2012). However, the majority of studies investigating sleep problems in children with CP have focused on pathophysiological reasons why they are awake, including obstructive sleep apnea, sleep disordered breathing, insomnia, delayed sleep onset, issues maintaining sleep, and nocturnal epilepsy (Atmawidjaja et al., 2014; Sandella et al., 2011; Wright, Tancredi, Yundt, & Larin, 2006). There is a paucity of research that focuses on sleep disturbance related to care and comfort needs for children with CP.

The child with CP, who is awake at night, likely has a parent/caregiver who is awake with them (Hemmingsson, Stenhammar, & Paulsson, 2009; Ikeda, Nagai, Kato-Nishimura, Mohri, & Taniike, 2012; Wayte et al., 2012; Wright et al., 2006). Chronic sleep deprivation for parents/caregivers of children with CP can have a great impact on the family, with the sleep of a child with CP being likened to that of a newborn (Wayte et al., 2012). A recent report by the Victorian Equal Opportunities Commission (Australia) lists sleep disturbance as a risk factor for relinquishment of children into state care (Victorian Equal Opportunity and Human Rights Commission, 2012). This reflects the impact of sleep disturbance on the child, the family, and the potential outcomes for the family if sleep issues are not addressed.

There is consensus that sleep issues in young people with CP are an important part of health care that requires further investigation (Bourke-Taylor et al., 2013; Newman, 2014; Newman, O'Regan, & Hensey, 2006; Wright et al., 2006). Sleep patterns should be systematically reviewed as part of a holistic assessment in order to implement appropriate interventions. To date, however, no intervention

studies have been undertaken to determine how best to improve the sleep of children with CP (Newman, 2014). Prior to designing effective interventions, the precise causes of sleep disturbance in this population must be identified. This pilot study addresses a significant gap in the current literature by focusing on problems with overnight care and comfort that could be resolved with simple changes to care regimes.

This pilot study will inform the design of a larger study, which will have two phases:

1. To quantify and describe sleep disturbance and its causes for children with CP and their families.
2. To design an intervention to decrease sleep disturbance for children with CP and thereby improve the sleep of those who care for them at night.

The primary aims of this pilot study were to test the acceptability of the selected sleep assessment instruments and assess the suitability of the study design. The secondary aim of this pilot study was to describe the nature and frequency of sleep interruption for children with CP as reported by their parents or caregivers.

METHODS

Design and sample

This prospective study used a consecutive sample to survey parents/caregivers to quantify sleep interruption of children with CP as reported by their parents/caregivers. Participants were parents or primary caregivers of children who attended the Department of Developmental Medicine outpatient clinics at the Royal Children's Hospital, Melbourne. The recruitment period spanned from May 2013 to April 2014. Parent/caregivers of children were invited to participate if the CP was classified within Gross Motor Function Classification System (GMFCS) levels IV or V, and the child was 6–10 years of age and had not previously been diagnosed with sleep pathology. The GMFCS is an internationally recognized classification system that describes the gross motor function of children with CP (Palisano, Rosenbaum, Bartlett, & Livingston, 2008). Levels IV and V represent those children who primarily rely on the use of a wheelchair for mobility. Children classified within GMFCS level IV may be able to stand to transfer or walk very short distances with physical aids. Children classified within GMFCS level V have the highest level of immobility and have

poor head, neck, and trunk control (Palisano et al., 2008). The lower age range of 6 years old was chosen to reduce the likelihood of including children with developmentally appropriate sleep problems. The upper age limit of 10 years old was selected as the Child Sleep Habits questionnaire is validated up to 10 years of age.

Instruments

Parent/caregivers were asked to complete four documents at home in their own time.

1. A short survey designed by the researchers detailing:
 - Age and sex of the child
 - Family structure
 - Typical sleep patterns for the child
 - Typical sleep environment of the child
 - History of seeking advice for sleep problems from healthcare providers

The short survey comprised specific questions from the Longitudinal Study of Australian Children (LSAC) (Australian Institute of Family Studies, 2013), a study following 10,000 Australian children investigating how social, economic, and cultural factors contribute to adjustment and well-being; these questions were in addition to demographic questions devised by the principal investigator.

2. The GMFCS Family Report Questionnaire

The GMFCS family report questionnaire is a reliable and validated questionnaire (Morris, 2014) that contains five descriptors of the GMFCS levels, and parent/caregivers are asked to select which descriptor best matches their children. This ensures an accurate report of the child's GMFCS level for data collection.

3. The Time Use Diary (TUD)

The TUD is an instrument taken from the LSAC (Australian Institute of Family Studies, 2013). For this study, the TUD was modified to only include the nighttime period between 6:00 p.m. until 10:00 a.m. in order to minimize the time burden of completing a diary over the full day. This modified version of the TUD has not previously been validated, hence, this pilot study aimed to test whether this amended instrument could reliably capture the desired data in this group of children. This diary requires parents/caregivers to indicate what their children were doing during every 15-min unit of time. If parents/caregivers shaded the section "Bathing, dressing,

hair care, healthcare," they were asked to describe the care provided via a free text section.

4. The Child Sleep Habit Questionnaire (CSHQ)

The CSHQ is a screening instrument with reliable and valid psychometric properties for typically developing children ages 6–10 years (Owens, Spirito, & McGuinn, 2000). It has 35 questions providing a total score and eight subsections: bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night waking, parasomnias, sleep disordered breathing, and daytime sleepiness. Parents/caregivers are asked to indicate the frequency with which their children show certain sleep behaviors, selecting from *Usually* (3 points), *Sometimes* (2 points), or *Rarely* (1 point). A score of 41 or greater is generally considered to indicate sleep issues (Owens et al., 2000). It is a time-efficient screening instrument for the assessment of sleep problems, but it does not explore reasons for children being awake. The CSHQ was used in this study to complement the information collected in the TUD. The information provided by each instrument was compared to determine how effectively the instruments quantified reasons for sleep disturbance in this cohort.

The TUD and CSHQ were intended to be used in partnership. The TUD was a modified form of a larger instrument used within the LSAC study. By contrasting the findings between the CSHQ and TUD, the investigators hoped to determine the suitability and sensitivity of the modified TUD.

Procedure

Eligible participants were informed about the study and invited to participate via a letter from their pediatrician. Parents/caregivers were informed via the invitation letter that they would receive a follow-up phone call if no response was received. For those parents/caregivers, a follow-up phone call from the principal investigator was made 2 weeks after the letter was sent. Parents/caregivers who agreed to participate were sent the study pack with a stamped, addressed envelope in which to return the questionnaires.

Ethical considerations

This study was approved by the Royal Children's Hospital Human Research and Ethics Committee (HREC 33039), and all parents/caregivers gave written informed consent to participate.

Data analysis

Because this was a pilot study with small numbers, quantitative statistical analysis was not appropriate. Data were analyzed descriptively, using discrete episodes of occurrence of sleep disturbance, and the feasibility of the chosen study design and measurement tools was explored.

The data collected from the TUD were compared to the recently published article by Price and colleagues (2014) in which sleep percentiles were generated and nighttime waking reported for typically developing children. Comparison was limited to identifying areas of similarity and disparity between the two studies. Results of the TUD and CSHQ were reviewed for each participant to determine their level of agreement in identifying sleep disturbance. The data obtained from the free text comment section of the TUD were used to create a list of reasons for waking.

RESULTS

Forty-one families met the inclusion criteria and were invited to participate in the study. The parents/caregivers were recruited over 10 months. Twenty families agreed to participate, four declined to participate, and no response was received from 17 families. Of the 20 families that agreed to participate, eight families returned the study documents. Of the eight completed surveys, six were completed by the child's mother and two were completed by fathers.

Demographic data describing the children are presented in Table 1. Two children were primarily cared for by their fathers overnight; four children were cared for by both mothers and fathers overnight; one was cared for by mother and grandmother; and one by the mother only overnight.

Six of the eight parents/caregivers said they had spoken to a pediatrician about sleep issues. The

remaining two parents/caregivers had not asked their pediatrician because they did not consider that sleep was an issue for their children. Of the six who asked their pediatricians for assistance, four said their pediatricians had offered solutions. Three of the eight had sought help from someone other than their pediatricians.

Results of the TUD for weeknights and weekends for the children are presented in Table 2. The children woke between zero and eight times per weeknight. On weekend nights, the children woke between zero and six times per night. Children in this study spent between 8 hr and 13 hr in bed but were asleep for between 6 hr and 12 hr. The TUD demonstrated that some children were lying in bed awake for significant portions of the night.

Table 2 details the total CSHQ scores for each participant. All eight participants scored over 41 on the CSHQ (range 46–61), indicating that the entire study cohort had sleep issues. There were two children whose TUD and CSHQ provided conflicting information. The TUD showed they slept through the night for both nights; however, they had a total CSHQ score of 55.

The tools used in combination in this study provided varied information about sleep patterns in this population. The short survey captured basic details of sleep history and the parents'/caregiver's experience of management of sleep problems by a clinician. The modified TUD captured some of the data required to inform the design of a sleep intervention and appears to be an objective measure of the actual nighttime events, including care and comfort issues. For six of the eight children in this pilot study, data generated from the TUD yielded similar results to their CSHQ scores. The combined data generated from these three sleep assessment instruments highlight that further descriptive information in regard to sleep history, and experience of seeking help for sleep problems, is required in order to inform the

Table 1. Demographics of Children and Parental Report of Sleep Location and Typical Sleep Interruption

Participant	Sex	Age (years)	GMFCS level	Where does child sleep?	Average wakes per night	Average number of nights per week child wakes
1	F	10	IV	With a parent	1	2
2	M	9	V	With a parent	5 or more	7
3	F	7	V	With a parent	2	4
4	F	6	V	Own bed in shared room	2	2
5	F	8	V	Own bed in own room	3	7
6	M	10	V	Own bed in shared room	1	2
7	M	10	V	Own bed in own room	Incomplete	Incomplete
8	F	8	V	Own bed in own room	1	3

GMFCS = Gross Motor Function Classification System; F = female; M = male.

Table 2. Time Use Diary (TUD) Number, Duration, and Reason for Wakings and Total Sleep Duration and Child Sleep Habit Questionnaire (CSHQ) Total Scores

		Child 1	Child 2	Child 3	Child 4	Child 5	Child 6	Child 7	Child 8
Weeknight TUD	Number of wakings	0	8	1	1	5	0	0	0
	Duration of waking (minutes)	n/a	15	90	60	15	n/a	n/a	n/a
	Reason for waking	n/a	Reposition	Awake Hygiene needs	Crying	Reposition Requires comfort	n/a	n/a	n/a
	Time in bed (hours)	11.5	13	12	8	11	11.5	12.5	10.5
	Total sleep time (hours)	11.3	10.3	10	10.9	9.6	8.8	12.5	11
Weekend night TUD	Number of wakings	1	3	1	0	6	0	0	2
	Duration of waking (minutes)	30	30	240	n/a	15–30	n/a	n/a	30–60
	Reason for waking	Loud noise	Crying in pain	Awake	n/a	Reposition Indigestion	n/a	n/a	Restless legs, needing comfort
	Time in bed (hours)	11.5	8.8	11	11.5	12.5	9.5	12	12
	Total sleep time (hours)	10.6	6.5	6	11.5	9.3	8.8	12	9.9
CSHQ	Average sleep per night (hours)	Incomplete	10	10	9.3	11	9	11	11.5
	Total CSHQ score ^a	61	50	51	59	55	55	51	46

n/a = not applicable.

^aCut-off score = 41 (Owens et al., 2000).

design of an intervention targeting improved sleep outcomes.

DISCUSSION

Assessing sleep in children with CP and their parents/caregivers is a complex and difficult process. The results of this small pilot study cannot be generalized to all children with CP; however, they do indicate that the sleep of children with CP is disrupted and that their parents/caregivers are often awake at night providing care to their children. It is important to note that in this study, parent sleep was not directly assessed and is an area for future research.

This study, along with prior literature, demonstrates the importance of understanding the magnitude and origin of sleep issues in this population in order to develop effective interventions. Results revealed that the study design captured sleep disturbance for the child but did not capture all aspects of sleep disturbance for the parents/caregivers of these

children. Anecdotal evidence from parent/caregiver stories during follow-up phone calls suggested the impact of sleep disturbance is significant and multifaceted. In order to gain a robust understanding of these issues, a qualitative research component would be helpful to inform a future mixed methods design study.

Sleep quantity and quality

The total hours of sleep recorded in this study are comparable to the results of Price and colleagues (2014) who reported sleep percentiles based on data from the LSAC. The LSAC data revealed that for children ages 6.5 to 9 years, the mean amount of sleep per night was 10–10.5 (± 1.8 – 2.0) hr (Price et al., 2014). The difference between results in this study and typically developing children are in the number of awakenings per night. Price and colleagues reported that the typically developing child ages 6.5 to 9 years old wakes 0.1–0.04 (± 0.2 – 0.3) times per night with 1.4 to 2.3 (± 12.4 – 21.2) min per waking.

This is in stark contrast to the children in our study cohort. While the number and duration of awakenings is higher for children with CP, their overall sleep time remains relatively typical for their ages. It is important to highlight that while the overall sleep hours for these children appears to fall within normal percentiles, the impact on the parents'/caregivers' sleep was not measured. Data collected regarding sleep disturbance within this pilot study may indicate the minimum sleep disturbance experienced by parents/caregivers.

Reasons for being awake

The reasons given by parents/caregivers for their children waking were: crying in pain, awake lying in bed, required turning, repositioning or burping, restlessness, needing comfort, hygiene needs, and awake crying. These reasons for being awake are similar to those reported in other studies (Hemmingsson et al., 2009; Wright et al., 2006), which demonstrates that these are common causes of sleep disturbance; thus, a sleep intervention for children with CP should focus on these causes.

Instruments

The modified TUD employed in this study was readily understood and appropriately completed by study participants, suggesting it is a useful instrument in quantifying sleep issues in children. The TUD provided rich data about the frequency and duration of awakenings for the children. It also provided descriptive information about the health, hygiene, and comfort care that the parents/caregivers were providing to their children overnight. The CSHQ was also an effective assessment instrument as it articulated sleep problems in its subsections. Together, the TUD and CSHQ provided good data about overall sleep issues; however, the length of these questionnaires may have contributed to low recruitment rates. The study pack contained 25 pages and, although the expected time to complete the instruments was less than 25 min, the size of the questionnaires may have seemed onerous. Contrasting the data obtained from the TUD to the CSHQ is informative. The modified TUD captures parent reports of sleep interruption and reasons for waking, while the CSHQ captures information around sleep behaviors, signs of abnormal respiratory symptoms, and daytime sleepiness. The short survey captured brief details about sleep history and experience of seeking help with sleep problems;

however, these questions may be better answered using a qualitative approach.

Study implications

Several families expressed gratitude and excitement that research was being conducted into sleep issues for children with CP because sleep was a significant issue for their children. Phone calls made to those who failed to return the study documents resulted in an illuminating anecdotal finding: parents/caregivers explained that they were just too tired or busy to participate. The recruitment phone calls provided unexpected insight into the lives of potential participants, and information was freely offered. Many families explained the study documents were in piles of unread mail, indicating that an online or telephone-based survey may be easier for participants and facilitate study participation. These phone calls also indicated that this research requires both qualitative and quantitative data collection methods to ensure sleep issues are fully explored.

Future studies should include information about how the child's sleep affects the parent's/caregiver's sleep. While this study established that parents/caregivers are awake with their children, the study design did not capture how these sleep interruptions further affected the sleep of the parents/caregivers. Finally, this pilot study revealed the care and consideration required when recruiting families of children with CP, given the high levels of family fatigue.

Limitations of the study

The purpose of this pilot study was to assess the suitability of the selected instruments and the study design rather than to produce results that could be immediately generalized. The study numbers were large enough to determine the suitability of the instruments, but the design may have impacted upon participant engagement. It is possible that those who participated experienced worse sleep than the average and chose to participate because the topic was relevant to them. Conversely, this sample may not have captured those with the worst sleep as those families may have been too fatigued to participate. Another potential limitation is that the TUD relies on parent/caregiver reporting of nighttime activity, and this potential for bias could be modified through the incorporation of qualitative data collection to explore parent/caregiver-reported data or the use of digital recording of overnight sleep patterns.

CONCLUSIONS

This study provides preliminary data quantifying sleep issues and confirms that sleep should be addressed as part of holistic health assessment in children with CP. The results are consistent with the small existing body of evidence in this area. Data arising from this pilot study demonstrate the importance of a research approach to this issue that not only measures the amount of sleep but also captures the experiences of participants. Completion of this pilot study confirms the need to adopt a mixed methods approach in future studies and confirms that further research is essential to develop effective interventions for sleep problems.

How might this information affect nursing practice?

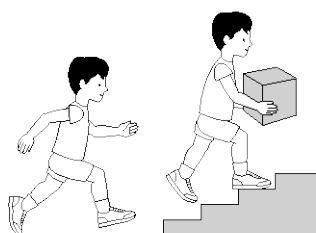
Although further research is needed to confirm the findings of this small pilot, this study highlights the opportunity for nurses to assess sleep problems as part of a holistic clinical assessment of a child with CP. Nurses can play a pivotal role in recognizing and responding to common causes of sleep disturbance and use assessment instruments and their clinical skills and expertise to improve comfort for children with CP.

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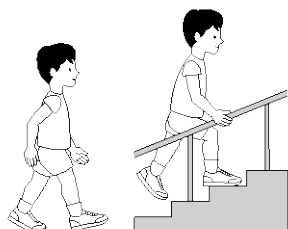
APPENDIX B: GMFCS DESCRIPTORS AND ILLUSTRATIONS

GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations



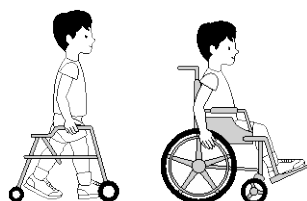
GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.



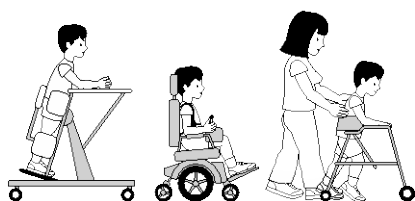
GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



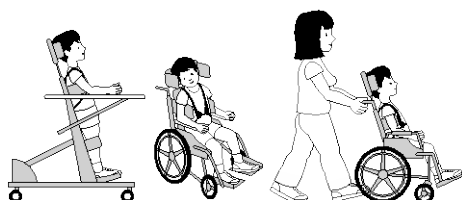
GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors: Palisano et al. (1997) *Dev Med Child Neurol* 39:214-23
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham,
The Royal Children's Hospital Melbourne ERC151050

APPENDIX C: SEARCH STRATEGY FOR LITERATURE REVIEWS

Database	Search Step	Search Term	Type of Field	Limitations
Ovid Search inclusive of Medline, Embase and Psychinfo	1.Sleep.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	Sleep (and related terms)	Keyword Heading word Original title Subject heading word Unique identifier Abstract Name of substance word Synonyms Title	All infant (0-23 months) All child (0-18 years)
	2.cerebral palsy.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	Cerebral Palsy (and related terms)	Keyword Heading word Original title Subject heading word Unique identifier Abstract Name of substance word Synonyms Title	All infant (0-23 months) All child (0-18 years)
	3.disability.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	Disability (and related terms)	Keyword Heading word Original title Subject heading word Unique identifier Abstract Name of substance word Synonyms Title	All infant (0-23 months) All child (0-18 years)
	4.developmental disability.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	Developmental disability (and related terms)	Keyword Heading word Original title Subject heading word Unique identifier Abstract Name of substance word Synonyms Title	All infant (0-23 months) All child (0-18 years)
	5.neurodisability.mp. [mp=title, abstract, original title, name of substance word, subject	Neurodisability (and related terms)	Keyword Heading word Original title	All infant (0-23 months) All child (0-18 years)

Database	Search Step	Search Term	Type of Field	Limitations
	heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]		Subject heading word Unique identifier Abstract Name of substance word Synonyms Title	
CINAHL Complete	1.sleep AND (cerebral palsy or disability or developmental disability or neurodisability)		All fields	All child

APPENDIX D: ETHICS APPROVAL FORMS AND AMENDMENTS

*Phase One*ETHICS APPROVAL &
GOVERNANCE AUTHORISATION18th August 2015

Ms Sacha Petersen
Developmental Medicine
RCH

Dear Sacha

Project Title: Bed time stories: An exploratory study of the reasons for, experience and impact of sleep disturbance for children with cerebral palsy and their parents.

RCH HREC Reference Number: 35166A

I am pleased to advise that the above project has received ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC). The project has also received governance authorisation at the Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

The Royal Children's Hospital Melbourne HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRC) National Statement on Ethical Conduct in Research Involving Humans (2007) and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

HREC Approval Date: 18th August 2015*

Please note the HREC are no longer issuing pre-determined approval periods. Ethical approval is now ongoing, subject to the submission of an annual report on the anniversary of approval.

Participating Sites:

Ethical approval for this project applies at the following sites:

Site Name
• The Royal Children's Hospital, Melbourne

Approved Documents:

The following documents have been reviewed and approved:

Document	Version	Date
Protocol	v2	4 Aug 2015
PICF	v1	28 May 2015
Survey Letter	v1	4 Aug 2015
Chailey Sleep Q're ©		2012
CPCHILD©		
Child's Sleep Habits Q're (pre-school and school-aged children)		
KIDSCREEN-10 Index, Parent Version ©		
KIDSCREEN-27, Parent Version ©		
PedsQLv2.0 (Family Impact) All		
PedsQLv3.0 (CP Module) All		
PedsQLv4.0 (QoL) All		

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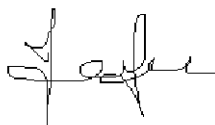
Your Health & Wellbeing SF-36v2; Sleep Disturbances Scale Child Sleep Diary		

Conditions of Ethics Approval:

You are required to submit to the HREC:

- An Annual Progress Report for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report within one month of the report is due. Failure to comply with this requirement may result in suspension of the project by the HREC.
- A comprehensive Final Report upon completion or abandonment of the project.
- Any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*.
- A formal notification should you become unable to continue as Principal Investigator.
- A formal notification should you fail to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- A formal notification of any matters which may impact the conduct of the project.
- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely



Jennifer Luplow
Senior Ethics Officer
The Royal Children's Hospital Melbourne
Phone : (03) 9345 5044
Email : rch.ethics@rch.org.au
Web : www.rch.org.au

ETHICS APPROVAL & GOVERNANCE AUTHORISATION



4 October 2016

Ms Sacha Petersen
Developmental Medicine
The Royal Children's Hospital

Dear Ms Petersen

Project Title: **Bed time stories: An exploratory study of the reasons for, experience and impact of sleep disturbance for children with cerebral palsy and their parents.**

RCH HREC Reference Number: 35166C

I am pleased to advise that your request for an extension has received ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The documents (listed below) have also received governance authorisation at the Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: 4 October 2016*

Please note the HREC are no longer issuing pre-determined approval periods. Ethical approval is now ongoing, subject to the submission of an annual report on the anniversary of approval.

Participating Sites:

Ethical approval for this project applies at the following sites:

Site Name
Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

Approved Documents:

The following documents have been reviewed and approved:

Document	Version	Date
Protocol	3.0	26 April 2016

Conditions of Ethics Approval:

- You are required to submit to the HREC:
 - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the

Page 1 of 2

approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.

- A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters which may impact the conduct of the project.
- If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes' Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).
- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely



Emma Land

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Email : rch.ethics@rch.org.au
Web : www.rch.org.au

ETHICS APPROVAL & GOVERNANCE AUTHORISATION



5 October 2016

Sacha Petersen
Developmental Medicine
The Royal Children's Hospital

Dear Ms Peterson

Project Title: Bed time stories: An exploratory study of the reasons for, experience and impact of sleep disturbance for children with cerebral palsy and their parents.

RCH HREC Reference Number: 35166 D

I am pleased to advise that the below modification has received ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The modification has also received governance authorisation at the Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: 5 May 2016

Participating Sites:

Ethical approval for this project applies at the following sites:

Site Name
The Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics)

Approved Documents:

The following documents have been reviewed and approved:

Document	Version	Date
Protocol	4.0	4 October 2016
Advertisement	1.0	4 October 2016

Conditions of Ethics Approval:

- You are required to submit to the HREC:
 - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.

Page 1 of 2

- A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters which may impact the conduct of the project.
- If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes' Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).
- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely



Eman Nafea, PhD

Research Ethics and Governance Officer (Clinical Trials)

Research Ethics and Governance

The Royal Children's Hospital Melbourne

Phone : (03) 9345 54491

Email : Eman.Nafea@rch.org.au

Web : www.rch.org.au

ETHICS APPROVAL & GOVERNANCE AUTHORISATION



04 October 2017

Ms S Petersen
Developmental Medicine
The Royal Children's Hospital

Dear Ms Peterson

Project Title: Bed time stories: An exploratory study of the reasons for, experience and impact of sleep disturbance for children with cerebral palsy and their parents.

RCH HREC Reference Number: 35166F

I am pleased to advise that the below amendment has received ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The amendment has also received governance authorisation at the Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: 04 October 2017

Participating Sites:

Ethical approval for this project applies at the following sites:

Site Name
The Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics)

Approved Documents:

The following documents have been reviewed and approved:

Document	Version	Date
Thank you letter	Version 1.0	30 September 2017

Conditions of Ethics Approval:

- You are required to submit to the HREC:
 - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
 - A comprehensive Final Report upon completion of the project.

- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
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- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely



Kelly Hoffman
Director, Research Ethics and Governance
The Royal Children's Hospital Melbourne
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Phases Two and Three

ETHICS APPROVAL & GOVERNANCE AUTHORISATION



10 November 2017

Ms Sacha Petersen
Neurodevelopment and Disability
The Royal Children's Hospital

Dear Ms Petersen,

Project Title: **Bedtime stories: sleep problems for children with cerebral palsy and their parents. Phase 2 and Phase 3**

RCH HREC Reference Number: **37300A**

I am pleased to advise that the above project has received ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The project has also received governance authorisation at the Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: 10 November 2017*

Please note the HREC are no longer issuing pre-determined approval periods. Ethical approval is now ongoing, subject to the submission of an annual report on the anniversary of approval.

Participating Sites:

Ethical approval for this project applies at the following sites:

Site Name
Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics)

Approved Documents:

The following documents have been reviewed and approved:

Document	Version	Date
Protocol	3.0	06 November 2017
Survey cover page	1.0	09 October 2017
VCPR Cover letter (Bedtime stories)	4.0	06 November 2017
Parent/Guardian Information Statement (Survey phase 2)	2.0	06 November 2017
Parent/Guardian Information Statement and Consent form (phase 3)	2.0	06 November 2017

Conditions of Ethics Approval:

- You are required to submit to the HREC:
 - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
 - A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
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- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely

**Emma Land**

Research Ethics and Governance Officer
Research Ethics and Governance
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ETHICS APPROVAL & GOVERNANCE AUTHORISATION

2 March 2018



Ms S Peterson
Neurodevelopment and Disability
The Royal Children's Hospital Melbourne

Dear Ms Peterson,

Project Title: BEDTIME STORIES: SLEEP PROBLEMS FOR CHILDREN WITH CEREBRAL PALSY AND THEIR PARENTS. Phase 2 and Phase 3

RCH HREC Reference Number: 37300C

I am pleased to advise that the below amendment has received ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The amendment has also received governance authorisation at the Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: 2 March 2018

Participating Sites:

Ethical approval for this project applies at the following sites:

Site Name
Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

Approved Documents:

The following documents have been reviewed and approved:

Document	Version	Date
Protocol	5.0	28 February 2018
Appendix F: PICF Phase 3	4.0	28 February 2018

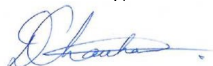
Conditions of Ethics Approval:

- You are required to submit to the HREC:
 - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
 - A comprehensive Final Report upon completion of the project.

Page 1 of 2

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- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
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- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely,



Deeptika Chauhan

Research Ethics and Governance Officer
Research Ethics and Governance
The Royal Children's Hospital Melbourne
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ETHICS APPROVAL & GOVERNANCE AUTHORISATION



14 August 2018

Ms S Peterson
Neurodevelopment and Disability
The Royal Children's Hospital Melbourne

Dear Ms Peterson,

Project Title: **BEDTIME STORIES: SLEEP PROBLEMS FOR CHILDREN WITH CEREBRAL PALSY AND THEIR PARENTS. Phase 2 and Phase 3**

RCH HREC Reference Number: 37300

I am pleased to advise that the below amendment has received ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The amendment has also received governance authorisation at the Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: 14 August 2018

Participating Sites:

Ethical approval for this project applies at the following sites:

Site Name
Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

Approved Documents:

The following documents have been reviewed and approved:

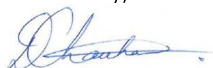
Document	Version	Date
Protocol	6.0	14 August 2018

Conditions of Ethics Approval:

- You are required to submit to the HREC:
 - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
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- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely,



Deeptika Chauhan

Research Ethics and Governance Officer
Research Ethics and Governance
The Royal Children's Hospital Melbourne
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Web : www.rch.org.au

APPENDIX E: PHASE ONE AND PHASE THREE PARTICIPANT INFORMATION SHEETS

Phase One



Information statement and consent form

HREC Project Number: HREC 35166A

Research Project Title: Bedtime Stories: Sleep problems for children with Cerebral Palsy and their parents

Principal Researcher: Sacha Petersen

Version Number: 1 **Version Date:** 28/05/2015

Dear Parent,

We know from experience in clinics that many children with cerebral palsy (CP) have disrupted sleep. This means that the parents/caregivers of those children also have disrupted sleep. We want to learn about why children with CP are awake at night and what care parent/caregivers are providing overnight. We hope that by learning about the common sleep issues for children with CP we can develop solutions. This project has two parts. We hope around 10 parents will participate in this first part. The findings from this small project will make sure that when we do a larger project as part two, we are asking the questions that are most important to parents like you.

This research project is funded by a scholarship from the Nurses Memorial Centre.

We are inviting you to participate in this first part of the project because you are the parent or caregiver of a child aged 6-12 years old with CP who has sleep problems.

We would like to interview you either by phone or face-to-face. We would like to hear about your child's bedtime routine, your experience of sleep problems and what impact sleep problems have on your life. We would also like your opinions on the survey tools we are thinking about using in the next part of this study.



The interview will be audio recorded and may take up to 60 minutes of your time. If you choose a face-to-face interview, this will take place in a quiet room at The Royal Children's Hospital. We will try to organise it for a time when you are already coming to the hospital for example, a clinic appointment.

It is difficult to say if participation in this project will be of any benefit to you or your child. Taking part will give you an opportunity to express an opinion or describe your feelings about your child's sleep problems. The information we get from you and other families will help us to create and implement some solutions for sleep issues for children with CP. This may help your child and other children in the future.

We have been careful to make sure that the questions in the interview do not cause you any distress. However, if you feel anxious about any of the questions you do not need to answer them. If the questions cause any concerns, we can refer you to a counsellor. The only expected inconvenience is the time it will take you to look at the survey tools and complete the interview.

Any information we collect and use during this research project will be treated as confidential. Only the researchers involved with this project and The Royal Children's Hospital Ethics Committee can have access to this information.

All information will be stored securely in the Developmental Medicine department at The Royal Children's Hospital. The information will be anonymous. This means we will remove your name from the information collected. Information will be kept for at least 5 years following the last publication of the project. The information collected in this research project will be used by Sacha Petersen, as part of a PhD qualification.

When we write or talk about the results of this project, parts of your interview may be quoted, but you will never be identified. At the end of this phase of the project, we will send you a summary of the group results. We expect this phase to be completed by December 2015.

Participation in this project is voluntary. You do not have to take part if you do not want to. You can withdraw from the project at any time, without giving a reason. We will not use any information already collected if you choose to withdraw from the project. Your decision will not affect access to the best available treatment options and care from the RCH.

We would like you to consider giving your permission for us to contact you in the future about other research projects that may be of interest to you. By agreeing to this, it means we will send you

information about the research, it does not mean you have to take part. Please tick the box on the consent form.

If you wish to participate in this project we will ask you to give consent before the interview takes place. If you have chosen a phone interview we will ask you to give verbal consent. If you have chosen a face-to-face interview we will ask you to sign a written consent form. If you have any questions, or would like further information about this project, please call Sacha Petersen on (03) 9345 4557 or email sacha.petersen@rch.org.au. We hope that you will take part.

Yours sincerely

Principal Investigator

Sacha Petersen

Clinical Nurse Consultant / PhD candidate

Developmental Medicine Royal Children's Hospital and
School of Nursing University of Melbourne.

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact: Director, Research Ethics & Governance, The Royal Children's Hospital Melbourne on telephone: (03) 9345 5044.

CONSENT FORM

HREC Project Number: HREC 35166A

Research Project Title: Bedtime Stories: Sleep problems for children with Cerebral Palsy and their parents

Version Number: 1

Version Date: 28/05/2015

- I have read, or had read to me in my first language, the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I voluntarily consent to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.
- I understand I will receive a copy of this Information Statement and Consent Form.

☐ I do	☐ I do not	consent to be contacted about future research projects relating to this research project.

Participant Name

Participant Signature

Date

Declaration by researcher: I have supplied an Information Letter and Consent Form to the participant who has signed above, and believe that they understand the purpose, extent and possible risks of their involvement in this project.

Research Team Member Name

Research Team Member Signature

Date

Note: All parties signing the Consent Form must date their own signature.

Phase Three

HREC Project Number: HREC 37300A

Research Project Title: Bedtime Stories: Sleep problems for children with Cerebral Palsy and their parents. Phase 2 and 3.

Principal Researcher: Sacha Petersen

Version Number: 4 **Version Date:** 28/02/2018

Dear Parent,

We know from experience in clinics that many children with cerebral palsy (CP) have disrupted sleep. This means that the parents/caregivers of those children also have disrupted sleep. We want to learn about how children with CP sleep and the reasons why children with CP are awake at night. We are also interested in care parent/caregivers are providing overnight. We hope that by learning about the common sleep issues for children with CP we can develop solutions. This is the third part of a three part project. This research project is funded by scholarships from the Australian Government, the RCH foundation and the Windermere foundation.

You may remember completing an online survey about sleep for you and your child. In that survey, you indicated that you would be interested in participating in an interview with the researchers for this project. . We are inviting you to participate in this part of the project because we would like to ask some follow up questions about your response to our online survey.

We would like to interview you either by phone or face-to-face. We would like to hear about your child's bedtime routine, your experience of sleep for you and your child. We will ask you about how your child's sleep might have affected your sleep and if you have ever asked your health care team for help or advice in regards to sleep problems. We are talking to parents of children who have both good and bad sleep. We are hoping that we can learn from you about what has helped make sleep better or worse so that we can use this information to help other children and parents with sleep problems.

The interview will be audio recorded and may take up to 60 minutes of your time. If you choose a face-to-face interview, this will take place in a quiet room at The Royal Children's Hospital. We will try to organise it for a time when you are already coming to the hospital for example, a clinic appointment. In appreciation of your time we would like to give you a \$50.00AUD voucher at the completion of the interview. If you choose to conduct the interview over the phone we will post this voucher to the address you provide during the interview. If you choose a face-to-face interview we will give you the voucher at the time of the interview. If you decline the voucher, we will donate \$50.00 to the charity of your choice, and we will send you a receipt of this donation.

It is difficult to say if participation in this project will be of any benefit to you or your child. Taking part will give you an opportunity to express an opinion or describe your feelings about your child's sleep problems. The information we get from you and other families will help us to create and implement some solutions for sleep issues for children with CP. This may help your child and other children in the future.

We have been careful to make sure that the questions in the interview do not cause you any distress. However, if you feel anxious about any of the questions you do not need to answer them. If the questions cause any concerns, we can refer you to a counsellor. The only expected inconvenience is the time it will take you to look at the survey tools and complete the interview.

Any information we collect and use during this research project will be treated as confidential. Only the researchers involved with this project and The Royal Children's Hospital Ethics Committee can have access to this information. The research team will be using a professional transcription service to transcribe the sound file into a text document. The voice recording of your interview may be uploaded to the transcription service website. The service information can be found [here](http://www.toa.net.au).
<http://www.toa.net.au>

If you object to an external service having access to your interview sound file, please tell the researcher at the time of recording.

All information will be stored securely in the Nursing Research department at The Royal Children's Hospital. The information will be anonymous. This means we will remove your name from the information collected. Information will be kept for at least 5 years following the last publication of the project. The information collected in this research project will be used by Sacha Petersen, as part of a PhD qualification.

When we write or talk about the results of this project, parts of your interview may be quoted, but you will never be identified. At the end of this phase of the project, we will send you a summary of the group results. We expect this phase to be completed by July 2018.

Participation in this project is voluntary. You do not have to take part if you do not want to. You can withdraw from the project at any time, without giving a reason. We will not use any information already collected if you choose to withdraw from the project. Your decision will not affect access to the best available treatment options and care from the RCH.

If you wish to participate in this project we will ask you to give consent before the interview takes place. If you have chosen a phone interview we will ask you to give verbal consent. If you have chosen a face-to-face interview we will ask you to sign a written consent form. If you have any questions, or would like further information about this project, please call Sacha Petersen on (03) 9345 4557 or email sacha.petersen@rch.org.au. We hope that you will take part.

Yours sincerely

Principal Investigator

Sacha Petersen

Clinical Nurse Consultant /PhD candidate

Developmental Medicine Royal Children's Hospital and
School of Nursing University of Melbourne.

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact: Director, Research Ethics & Governance, The Royal Children's Hospital Melbourne on telephone: (03) 9345 5044.

CONSENT FORM

HREC Project Number: HREC 37300A

Research Project Title: Bedtime Stories: Sleep problems for children with Cerebral Palsy and their parents. Phase 2 and Phase 3.

Version Number: 3 **Version Date:** 20/02/2018

- I voluntarily consent to take part in this research interview.
- I have read, or had read to me in my first language, the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that the interview recording may be sent to an external transcription service.
 - I do consent to my interview recording being sent to an external service ☐
 - I do not consent to my interview recording being sent to an external service ☐
- I understand that this project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.

Please detail below the days of the week and times that suit you best for an interview
 Researchers are available 7 days a week from 9:30 am to 9:30pm for over the phone interview
 Or weekdays 9:30am to 5pm for a face to face interview:

What is the best way to contact you to organize an interview time (please tick and provide contact details:

Phone call ☐

phone number:

Email ☐

email address:

Text message ☐

mobile number:

Participant Name

Participant Signature

Date

APPENDIX F: INTERVIEW TOOL PHASE ONE

Interview Guide

HREC 35166

Bed time stories: An exploratory study of the reasons for, experience and impact of sleep disturbance for children with cerebral palsy and their parents.

Obtaining recorded verbal consent in a phone interview:

Prior to starting the interview, the interviewer will go over the following consent procedures:

- a) Explain the possible effects of participating in the interview
- b) Inform participant that they are free to withdraw from the project at any time without explanation or prejudice and to withdraw any unprocessed data
- c) the project is for the purpose of research
- d) All information provided will be safeguarded subject to any legal requirements
- e) The *interview will be audio-recorded and audio-files* will be stored at The Royal Children's Hospital and will be destroyed after seven years;
- f) Participants will be referred to by a pseudonym in any presentations and/or publications arising from the research;
- g) A copy of the research findings will be forwarded to the participant should they agree to this.

The following script will then be used to gain consent:

I am now going to switch on the digital recorder and record your consent. Is that ok?

The digital recorder will then be turned on with the participant's permission and the participant asked the following:

Are you happy for me to record your consent for: **Bed time stories: An exploratory study of the reasons for, experience and impact of sleep disturbance for children with cerebral palsy and their parents.**

Just a reminder that participation in this study is completely optional. It is your choice whether or not to participate and you can withdraw from the study at any time.

- Do you feel you have had the opportunity to ask questions?
- Do you consent to the interview being audio-taped?
- Do you wish to receive a copy of the study findings?

Obtaining consent face-to-face interview:

The above protocol will also be followed in a face-to-face interview with the participant being asked to sign a written consent form.

Interview Content:

Each interview will be semi structured with a few pre-defined questions. Additional questions will be asked based on participant's initial responses. The pre-defined questions include:

1. Tell me a little bit about your family.
(prompts: who lives in house, ages, genders, weekly routine ie any carers/ out of home respite/ daily activities for the child)
2. Tell me about what happens at night time?
(prompts: bed time routine, allocation of tasks, who sleeps where, what happens when a child wakes up).
3. What troubles have you had with sleep? (child or parent)
4. Is there anything that worries you about your sleep or your child's sleep?
5. If I said I could make sleep better for you what would that look like? (prompts: sleeping through every night, sleeping earlier, sleeping separate to child, one wake up per night)
6. I am hoping to create something that will improve sleep for children with CP, at the moment I don't know what that will be. What do you think would work for you? Is there something you wish existed for sleep that doesn't? (prompts: sleep clinic, sleep training, smart phone app, phone help line)
7. I sent you some tools developed that are meant to help measure sleep and quality of life. I am thinking about using them in the next part of my PhD but I would really like you to tell me if you think they are useful. Have you had a chance to read them? Could I ask you to give your opinion on them?
8. As part of this study we wish to capture both your child's sleep and your sleep. We need to know who often you both wake up and the reason for waking. We are considering using three different methods to do this. They are

- a. **Actigraphy**

Actigraphy is a watch like device, like a fit bit, that measures your movements, including your sleep. We would use this to help us to know your movements. Specifically, if you are awake with your child, and if you are

awake when your child is asleep. You would wear it for around a week and then we would get you to post the device back to us to download the data.

b. Smart phone app or survey:

We will ask parents to report on their child's sleep via a smart phone app or survey. You will receive a text message in the morning to remind you to tell us about your child's sleep the night before via an app. The app would email the results to the researchers. Would this be something you feel you could take part in? Or would you rather a researcher call you in the morning and asking you over the phone about what you and your child's sleep the night before?

c. Phone call from a researcher.

The researcher (myself) calling you mid-morning several days over a week and asking about you and your child's sleep. The researcher would enter the data on your behalf. Your only action would be to take the phone call and answer the researcher's question.

9. Thinking about all of the options I've discussed above which do you like the best?
10. Which method do you think will be the easiest to agree to?
11. Do you have any concerns about any of the proposed methods?
12. Are there any that you definitely wouldn't do?
13. If we chose the actigraphy monitor we would also have to capture your child's sleep either through a phone call or smart phone app/survey. Do you think you would agree to this type of research?

Prior to the interview parents will be sent copies of the tools being considered for use in the study. Copies of the tool will also be brought to the interview for the parents to review before answering the question.

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Bedtime Stories: Sleep for children with cerebral palsy and their parents.

Are you employed? (select all that apply)

* must provide value

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Self-employed
- ☐ Unemployed, and looking for work
- ☐ Stay at home parent
- ☐ Student
- ☐ Retired
- ☐ Unable to work

Are you of Aboriginal or Torres Strait Islander heritage?

- ☐ No
- ☐ Yes, Aboriginal
- ☐ Yes, Torres Strait Islander
- ☐ Yes, both Aboriginal and Torres Strait Islander

reset

In what country were you born?

* must provide value

What is the main language spoken at home?

* must provide value

There are many different types of families. From the list below, please select which family type matches your family the best.

* must provide value

- ☐ - **Nuclear Family** (a family group consisting of a married couple of the opposite gender and dependent children)
- ☐ - **Extended Family** (a family group consisting of more than two generations of the same family line, living together within the same household, or very close to one another)
- ☐ - **Reconstituted Family** (a family in which two adults marry or cohabit with children from previous relationships)
- ☐ - **Single Parent Family** (a family that consists of a single parent, not living with a partner or spouse, who has the day-to-day responsibility of raising children)
- ☐ - **Same Sex Family** (a family which consists of two parents of the same sex - either a gay or lesbian couple raising children together)
- ☐ - **Other** (please specify)

What is your approximate household income?

* must provide value

The following questions are specifically about your child who has cerebral palsy.**How old is your child who has cerebral palsy (in years)?**

<https://redcap.mcri.edu.au/surveys/?s=9F8Y97H7IE>

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05/08/2019 Bedtime Stories: Sleep for children with cerebral palsy and their parents.

As you may know, cerebral palsy can be classified into different levels.

Please read the following and mark the box beside the description that best represents your child's movement abilities.

* must provide value

☐ Has difficulty sitting on their own and controlling their head and body posture in most positions. AND has difficulty achieving any voluntary control of movement. AND needs a specialty or supportive chair to sit comfortably AND has to be lifted or hoisted by another person to move.

☐ Can sit on their own but does not stand or walk without significant support AND therefore relies mostly on wheelchair at home, school and community AND often needs extra body/trunk support to improve hand and arm function AND may achieve self-mobility using a powered wheelchair

☐ Can stand on their own and only walks using a walking aid (such as a walker, rollator, crutches, canes etc.) AND finds it difficult to climb stairs, or walk on uneven surfaces AND may use a wheelchair when travelling for long distances or in crowds.

☐ Can walk on their own without using walking aids, but needs to hold the handrail when going up or down stairs AND often finds it difficult to walk on uneven surfaces, slopes or in crowds.

☐ Can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail AND walks wherever they want to go (including uneven surfaces, slopes or in crowds) AND can running jump although their speed, balance, and coordination may be slightly limited.

reset

Does your child with cerebral palsy have any siblings (brothers or sisters) living in the same house? These can be step siblings, biological siblings, or non biological siblings.

* must provide value

☐ No, they are an only child
☐ Yes, one sibling
☐ Yes, two siblings
☐ Yes, three siblings
☐ Yes, four siblings
☐ Yes, five siblings
☐ Yes, six siblings
☐ Yes, seven siblings
☐ Yes, eight or more siblings

reset

Would you say your child currently has problems with sleep?

* must provide value

☐ Yes
☐ No

reset

Children with cerebral palsy often have many different people on their health care team. Please select any of the following professionals that your child has seen in the last 12 months.

* must provide value

☐ Alternative therapist
☐ General practitioner
☐ Maternal and Child Health Nurse
☐ Nurse
☐ Occupational Therapist
☐ Paediatrician
☐ Physiotherapist
☐ Psychiatrist
☐ Psychologist
☐ Rehabilitation specialist
☐ Social Worker
☐ Speech Therapist
☐ Other

Have you ever asked a professional for help with your child's sleep problems?

* must provide value

☐ Yes
☐ No

reset

On a typical night, if your child needs attention overnight, who usually provides that care? (check all that apply)

☐ I do
☐ The other parent does
☐ Another family member does
☐ Other

<https://redcap.mcri.edu.au/surveys/?s=9F8Y97H7TE> 3/9

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Bedtime Stories: Sleep for children with cerebral palsy and their parents.

Is your child currently taking any medications to help with sleep?

* must provide value

☐ Yes ☐ No

reset

The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your child's life when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well) choose the most recent typical week.

Answer USUALLY if something occurs 5 or more times in a week.
Answer SOMETIMES if it occurs 2-4 times in a week.
Answer RARELY if something occurs never or 1 time during a week.

Indicate whether or not the sleep habit is a problem by selecting "Yes", "No," or "not applicable (N/A)".

Child's usual bedtime:

* must provide value

Expand

Child's usual wake time:

* must provide value

Expand

Child's usual amount of sleep each night (no naps) in hours and minutes:

* must provide value

Expand

Child's usual amount of sleep each day (naps):

* must provide value

Expand

<https://redcap.mcri.edu.au/surveys/?s=9F8Y97H7TE>

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Bedtime Stories: Sleep for children with cerebral palsy and their parents.

Question	Response	Problem?
1. Child goes to bed at the same time at night	☐ Usually reset ☐ Sometimes ☐ Rarely	☐ Yes ☐ No ☐ N/A reset
2. Child falls asleep alone in own bed	☐ Usually reset ☐ Sometimes ☐ Rarely	☐ Yes ☐ No ☐ N/A reset
3. Child falls asleep within 20 minutes after going to bed	☐ Usually reset ☐ Sometimes ☐ Rarely	☐ Yes ☐ No ☐ N/A reset
4. Child sleeps the right amount	☐ Usually reset ☐ Sometimes ☐ Rarely	☐ Yes ☐ No ☐ N/A reset
5. Child sleeps about the same amount each day	☐ Usually reset ☐ Sometimes ☐ Rarely	☐ Yes ☐ No ☐ N/A reset
6. Child wakes up by him/herself	☐ Usually reset ☐ Sometimes ☐ Rarely	☐ Yes ☐ No ☐ N/A reset

Child has appeared very sleepy or fallen asleep during the following (check all that apply):

	not sleepy	very sleepy	falls asleep
7. Watching TV * must provide value	☐	☐	☐
8. Riding in a car * must provide value	☐	☐	☐

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Bedtime Stories: Sleep for children with cerebral palsy and their parents.

Question	Response	Problem?
9. Child falls asleep in parent's or sibling's bed	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
10. Child struggles at bedtime	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
11. Child needs parent in the room to fall asleep	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
12. Child is afraid of sleeping alone	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
13. Child sleeps too little	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
14. Child is afraid of sleeping in the dark	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
15. Child has trouble sleeping away from home	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
16. Child moves to someone else's bed during the night (parent, sibling, etc.)	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
17. Child awakens once during the night	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
18. Child awakens more than once during the night	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
19. Child talks during sleep	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
20. Child is restless and moves a lot during sleep	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
21. Child sleepwalks during the night	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset
22. Child wets the bed at night	☐ Usually ☐ Sometimes ☐ Rarely reset	☐ Yes ☐ No ☐ N/A reset

<https://redcap.mcri.edu.au/surveys/?s=9F8Y97H7TE>

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Bedtime Stories: Sleep for children with cerebral palsy and their parents.

23. Child grinds teeth during sleep (your dentist may have told you this)	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset
24. Child awakens alarmed by a frightening dream	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset
25. Child awakens during night screaming, sweating, and inconsolable	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset
26. Child snores loudly	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset
27. Child seems to stop breathing during sleep	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset
28. Child snorts and/or gasps during sleep	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset
29. Child wakes up in a negative mood	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset
30. Adults or siblings wake up child	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset
31. Child has difficulty getting out of bed in the morning	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset
32. Child takes a long time to become alert in the morning	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset
33. Child seems tired in the morning	☐ Usually reset	☐ Sometimes	☐ Rarely	☐ Yes ☐ No ☐ N/A reset

The following questions relate to your sleep.

The following questions relate to YOUR (not your child's) sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

During the past month when have you usually gone to bed?

* must provide value

During the past month, How long (in minutes) has it taken you to fall asleep each night?

* must provide value

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05/08/2019 Bedtime Stories: Sleep for children with cerebral palsy and their parents.

During the past month, what time have you gotten up in the morning?
* must provide value

During the past month, how many hours of actual sleep did you get at night?
* must provide value

During the past month, how many hours were you in bed (on an average night)?
* must provide value

During the past month:

	Not during the past month (0)	Less than once a week (1)	Once or twice a week (2)	Three or more times a week (3)
How often have you taken medicine (prescribed or "over the counter")? * must provide value	☐	☐	☐	☐
				reset
How often have you taken medicine (prescribed or "over the counter") to help you sleep? * must provide value	☐	☐	☐	☐
				reset
How often have you had trouble staying awake while driving, eating meals or engaging in social activity? * must provide value	☐	☐	☐	☐
				reset
How much of a problem has it been for you to keep up enthusiasm to get things done? * must provide value	☐	☐	☐	☐
				reset
During the past month, how would you rate your sleep overall? * must provide value	☐ Very good ☐ Fairly good ☐ Fairly bad ☐ Very bad			
				reset

During the past month, how often have you had trouble sleeping because you:

	Not during the past month (0)	Less than once a week (1)	Once or twice a week (2)	Three or more times a week (3)
cannot get to sleep in 30 minutes * must provide value	☐	☐	☐	☐
				reset
wake up in the middle of the night or early morning * must provide value	☐	☐	☐	☐
				reset
have to go to the bathroom * must provide value	☐	☐	☐	☐
				reset
cannot breathe comfortably * must provide value	☐	☐	☐	☐
				reset
cough or snore loudly * must provide value	☐	☐	☐	☐
				reset
feel too cold * must provide value	☐	☐	☐	☐
				reset
feel too hot * must provide value	☐	☐	☐	☐
				reset
have bad dreams * must provide value	☐	☐	☐	☐
				reset
have pain * must provide value	☐	☐	☐	☐
				reset
other reason(s) (please describe in attached comment) * must provide value	☐	☐	☐	☐
				reset

<https://redcap.mcri.edu.au/surveys/?s=9F8Y97H7TE> 8/9

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Bedtime Stories: Sleep for children with cerebral palsy and their parents.

In the next phase of this project the researchers would like to interview parents who have completed this survey.

The interview can occur over the phone or in person at The Royal Children's Hospital, Melbourne, and will take between 30 and 60 minutes. The interview will take place at a time of your choice (including out of business hours).

Upon completion of the interview you will be given a \$50.00 (AUD) Coles-Myer gift card, in appreciation of your time.

Do you agree to be contacted by the researchers to discuss your participation in an interview?

* must provide value

☐ Yes, please email me.

☐ Yes, please call my mobile.

☐ Yes, please send me a text message.

☐ Yes, please call my home phone.

☐ No, I do not want to be contacted about an interview.

reset

Thank you so much for participating in this survey.

We hope the information you have provided will help us to design sleep solutions for children with cerebral palsy and their parents.

If you have agreed to be contacted to discuss an interview, you will hear from us soon. If you have any questions or comments about this study please contact: sacha.petersen@rch.org.au

Submit

Save & Return Later

<https://redcap.mcri.edu.au/surveys/?s=9F8Y97H7TE>

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APPENDIX H: INTERVIEW TOOL PHASE THREE

Interview Script: Phase 3**HREC Project Number:** HREC 37300A**Research Project Title:** Bedtime Stories: Sleep problems for children with Cerebral Palsy and their parents. Phase 2 and 3.

Prior to starting the interview, the interviewer will go over the following consent procedures:

- a) Explain the possible effects of participating in the interview
- b) Inform participant that they are free to withdraw from the project at any time without explanation or prejudice and to withdraw any unprocessed data
- c) The project is for the purpose of research;
- d) All information provided will be safeguarded subject to any legal requirements
- e) The *interview will be audio-recorded and audio-files* will be stored at The Royal Children's Hospital and will be destroyed after seven years;
- f) Participants will be referred to by a pseudonym in any presentations and/or publications arising from the research;
- g) A copy of the research findings will be forwarded to the participant should they agree to this.

The following script will then be used to gain consent:

Pi: I am now going to switch on the digital recorder and record your consent. Is that ok? (*The digital recorder will then be turned on with the participant's permission and the participant asked the following:*) Are you happy for me to record your consent for: *Bed time stories: An exploratory study of the reasons for, experience and impact of sleep disturbance for children with cerebral palsy and their parents, Phase 2 and 3.* Just a reminder that participation in this study is completely optional. It is your choice whether or not to participate and you can withdraw from the study at any time.

- This recording may be sent to a professional service to be transcribed, do you give permission for this recording to be sent to the transcription service?
- Do you feel you have had the opportunity to ask questions?
- Do you consent to the interview being audio-taped?

- Do you wish to receive a copy of the study findings?
1. Tell me a little about your family.
 - Probe for more specific detail if not covered (will be able to check against survey responses as well:
 - Age?
 - How old are your child(ren)?
 - Relationship status?
 - Employment?
 2. In the survey you indicated that you think your child has/doesn't have sleep problems. Can you tell me more about your child's sleep pattern? (Prompts. Does your child sleep through? What wakes them up? How much sleep do they get?)

If has sleep problems:	If reports no sleep problems:
Has your child's sleep always been a problem? If no – ask what changed and then proceed to other questions. If yes – What strategies have you tried to improve your child's sleep? How did you know about what to try? • Have any strategies worked? What were they?	• Has your child always slept well? • If no – use questions from sleep problems prompts.
Have you asked for help with sleep problems? – If no – Is there a reason you haven't asked for help with sleep? If yes – who did you ask? What happened when you asked for help?	• If yes – Are there particular strategies you have used for your child that have contributed to them sleeping well? • Tell me about your health care team – what are they like?

Did they help/give advice? Did that advice work?	• What happens when your child has a health problem – who do you ask? - what happens when you ask for help? - Do you get effective solutions - Have you ever had trouble getting help with a health problem?
How does/has sleep deprivation impacted on your life • Day to day activities • Relationship • Health (physical and mental) • Your own sleep • Work life • Anything else?	
How does lack of sleep impact on your child?	

One of the aims of my study is to help parents get more information about sleep problems and how to seek help.

Bad sleepers: What is/has been the best way for you to find out how to manage sleep problems?

Good Sleepers: If your child had a sleep problem – how would you try to find solutions?

APPENDIX I: ADVERTISEMENT FOR PHASE ONE INTERVIEWS

Does your child with Cerebral Palsy
have sleep troubles?



We would like to talk to you!

Do you have a child with CP aged between 6 and 12
who has sleep problems?

We are conducting research exploring the causes and
impact of sleep problems for children with CP and
their parents.

We would like about an hour of your time to talk to
you about your experience. Your experience and
stories are very important and will be used to design
the next phase of our research.

Interviews can be over the phone or in person.

For more information please email:

sacha.petersen@rch.org.au or call 9345 5447

APPENDIX J: THESIS BY PUBLICATION FORMS



PhD and MPhil students may include a primary research publication in their thesis in lieu of a chapter if:

- The student contributed greater than 50% of the content in the publication and is the “primary author”, ie. the student was responsible primarily for the planning, execution and preparation of the work for publication
- The student has approval to include the publication in their thesis from their Advisory Committee
- It is a primary publication that reports on original research conducted by the student during their enrolment
- The initial draft of the work was written by the student and any subsequent editing in response to co-authors and editors reviews was performed by the student
- The publication is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in the thesis

Students must submit this form, along with *Co-author authorisation forms* completed by each co-author, when the thesis is submitted to the Thesis Examination System: <https://tes.app.unimelb.edu.au/>. If you are including multiple publications in your thesis you will need to complete a separate form for each publication. Further information on this policy is available at: gradresearch.unimelb.edu.au/preparing-my-thesis/thesis-with-publication

(to be completed by the student)

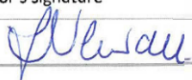
Full title	Sleep problems and solution seeking for children with cerebral palsy and their parents.		
Authors	Sacha Petersen, Kate L. Francis, Dinah S. Reddihough, Sally Lima, Adrienne Harvey, Fiona Newall		
Student's contribution (%)	70%		
Journal or book name	Journal of Paediatrics and Child Health		
Volume/page numbers			
Status	☒ Accepted and In press ☐ Published ☒ In progress	Date accepted/ published	

I declare that the publication above meets the requirements to be included in the thesis

Student's name	Student's signature	Date (dd/mm/yy)
Sacha Petersen		20.8.19

I declare that:

- the information above is accurate
- The advisory committee has met and agreed to the inclusion of this publication in the student's thesis
- All of the co-authors of the publication have reviewed the above information and have agreed to its veracity
- 'Co-Author Authorisation' forms for each co-author are attached.

Supervisor's name	Supervisor's signature	Date (dd/mm/yy)
Fiona Newall		20.8.19

The University of Melbourne
CRICOS Provider Number: 00116K

Last Updated 19 October 2017

Co-author authorisation form



All co-authors must complete this form. By signing below co-authors agree to the listed publication being included in the student's thesis and that the student contributed greater than 50% of the content of the publication and is the "primary author" ie. the student was responsible primarily for the planning, execution and preparation of the work for publication.

In cases where all members of a large consortium are listed as authors of a publication, only those that actively collaborated with the student on material contained within the thesis should complete this form. This form is to be used in conjunction with the *Declaration for a thesis with publication form*.

Students must submit this form, along with the *Declaration for thesis with publication form*, when the thesis is submitted to the Thesis Examination System: <https://tes.app.unimelb.edu.au/>

Further information on this policy and the requirements is available at:
gradresearch.unimelb.edu.au/preparing-my-thesis/thesis-with-publication

A. PUBLICATION DETAILS (to be completed by the student)

Full title	Sleep problems and solution seeking for children with cerebral palsy and their parents.		
Authors	Sacha Petersen, Kate L Francis, Dinah S. Reddiough, Sally Lima, Adrienne Harvey, Fiona Newall		
Student's contribution (%)	70%		
Journal or book name	Journal of Paediatrics and Child Health		
Volume/page numbers			
Status	☐ Accepted and In-press ☐ Published ☒ In progress	Date accepted/published	

B. CO-AUTHOR'S DECLARATION (to be completed by the collaborator)

I authorise the inclusion of this publication in the student's thesis and certify that:

- the declaration made by the student on the *Declaration for a thesis with publication form* correctly reflects the extent of the student's contribution to this work;
- the student contributed greater than 50% of the content of the publication and is the "primary author" ie. the student was responsible primarily for the planning, execution and preparation of the work for publication.

Co-author's name	Co-author's signature	Date (dd/mm/yy)
Dr Adrienne Harvey		21-08-2019


 THE UNIVERSITY OF
MELBOURNE

Co-author authorisation form

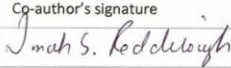
All co-authors must complete this form. By signing below co-authors agree to the listed publication being included in the student's thesis and that the student contributed greater than 50% of the content of the publication and is the "primary author" ie. the student was responsible primarily for the planning, execution and preparation of the work for publication.

In cases where all members of a large consortium are listed as authors of a publication, only those that actively collaborated with the student on material contained within the thesis should complete this form. This form is to be used in conjunction with the *Declaration for a thesis with publication form*.

Students must submit this form, along with the *Declaration for thesis with publication form*, when the thesis is submitted to the Thesis Examination System: <https://tes.app.unimelb.edu.au/>

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Journal or book name	Journal of Paediatrics and Child Health	
Volume/page numbers		
Status	☐ Accepted and In-press ☐ Published ☒ In progress	Date accepted/published

B. CO-AUTHOR'S DECLARATION (to be completed by the collaborator)		
I authorise the inclusion of this publication in the student's thesis and certify that: - the declaration made by the student on the <i>Declaration for a thesis with publication form</i> correctly reflects the extent of the student's contribution to this work; - the student contributed greater than 50% of the content of the publication and is the "primary author" ie. the student was responsible primarily for the planning, execution and preparation of the work for publication.		
Co-author's name	Co-author's signature	Date (dd/mm/yy)
Dinah Reddihough		8/8/19



Co-author authorisation form

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A. PUBLICATION DETAILS (to be completed by the student)		
Full title	Sleep problems and solution seeking for children with cerebral palsy and their parents.	
Authors	Sacha Petersen, Kate L Francis, Dinah S. Reddihough, Sally Lima, Adrienne Harvey, Fiona Newall	
Student's contribution (%)	70%	
Journal or book name	Journal of Paediatrics and Child Health	
Volume/page numbers		
Status	☐ Accepted and In-press ☐ Published ☒ In progress	Date accepted/published

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Co-author's name	Co-author's signature	Date (dd/mm/yy)
Kate Francis	Kate Francis Digitally signed by Kate Francis DN: cn=Kate Francis, ou=Murdoch Children's Research Institute, ou=CCRU, email=kate.francis@unimelb.edu.au, c=AU	07/8/19



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Co-author's name	Co-author's signature	Date (dd/mm/yy)
Sally Lima		09/08/2019

Co-author authorisation form



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Co-author's name	Co-author's signature	Date (dd/mm/yy)
Fiona Newall	<i>[Signature]</i>	20.8.17

Appendix K: Sleep Assessment Tools

SDSC

Appendix A. SLEEP DISTURBANCES SCALE FOR CHILDREN

INSTRUCTIONS: This questionnaire will allow to your doctor to have a better understanding of the sleep-wake rhythm of your child and of any problems in his/her sleep behavior. Try to answer every question; in answering, consider each question as pertaining to the **past 6 months** of the child's life. Please answer the questions by circling or striking the number 1 to 5. Thank you very much for your help.

Name: _____ Age: _____ Date: _____

1. How many hours of sleep does your child get on most nights.	1 9-11 hours	2 8-9 hours	3 7-8 hours	4 5-7 hours	5 less than 5 hours
2. How long after going to bed does your child usually fall asleep	1 less than 15'	2 15-30'	3 30-45'	4 45-60'	5 more than 60'

	1	2	3	4	5
	1 Never	2	3	4	5 Always (daily)
					4 Often (3 or 5 times per week)
					3 Sometimes (once or twice per week)
					2 Occasionally (once or twice per month or less)
3. The child goes to bed reluctantly	1	2	3	4	5
4. The child has difficulty getting to sleep at night	1	2	3	4	5
5. The child feels anxious or afraid when falling asleep	1	2	3	4	5
6. The child startles or jerks parts of the body while falling asleep	1	2	3	4	5
7. The child shows repetitive actions such as rocking or head banging while falling asleep	1	2	3	4	5
8. The child experiences vivid dream-like scenes while falling asleep	1	2	3	4	5
9. The child sweats excessively while falling asleep	1	2	3	4	5
10. The child wakes up more than twice per night	1	2	3	4	5
11. After waking up in the night, the child has difficulty to fall asleep again	1	2	3	4	5
12. The child has frequent twitching or jerking of legs while asleep or often changes position during the night or kicks the covers off the bed.	1	2	3	4	5
13. The child has difficulty in breathing during the night	1	2	3	4	5
14. The child gasps for breath or is unable to breathe during sleep	1	2	3	4	5
15. The child snores	1	2	3	4	5
16. The child sweats excessively during the night	1	2	3	4	5
17. You have observed the child sleepwalking	1	2	3	4	5
18. You have observed the child talking in his/her sleep	1	2	3	4	5
19. The child grinds teeth during sleep	1	2	3	4	5
20. The child wakes from sleep screaming or confused so that you cannot seem to get through to him/her, but has no memory of these events the next morning	1	2	3	4	5
21. The child has nightmares which he/she doesn't remember the next day	1	2	3	4	5
22. The child is unusually difficult to wake up in the morning	1	2	3	4	5
23. The child awakes in the morning feeling tired	1	2	3	4	5
24. The child feels unable to move when waking up in the morning	1	2	3	4	5
25. The child experiences daytime somnolence	1	2	3	4	5
26. The child falls asleep suddenly in inappropriate situations	1	2	3	4	5
Disorders of initiating and maintaining sleep (sum the score of the items 1,2,3,4,5,10,11)					
Sleep Breathing Disorders (sum the score of the items 13,14,15)					
Disorders of arousal (sum the score of the items 17,20,21)					
Sleep-Wake Transition Disorders (sum the score of the items 6,7,8,12,18,19)					
Disorders of excessive somnolence (sum the score of the items 22,23,24,25,26)					
Sleep Hyperhydrosis (sum the score of the items 9,16)					
Total score (sum 6 factors' scores)					

After summing the scores for the different scales report the values in the scoring sheet in order to obtain a sleep profile

Appendix B. SDSC Scoring Sheet

Name: _____ Age: _____

T score	DIMS	SBD	DA	SWTD	DOES	SHY	TOTAL	T score
100+	26+	11+	8+	21+	20+		74+	100+
99	25			20			73	99
98							72	98
97							71	97
95	24			19	19		70	95
94			7				69	94
93	23	10		18	18	10	68	93
90							66	90
89	22						65	89
88					17		64	88
86	21	9		17		9	63	86
85				16	16		62	85
84							61	84
82	20		6				60	82
81					15		59	81
80						8	58	80
79	19	8		15			57	79
77					14		56	77
76	18						55	76
75				14		7	54	75
73	17				13		53	73
72		7					52	72
70	16		5	13			51	70
69					12	6	50	69
68							49	68
67							48	67
66	15			12			47	66
64	14	6			11	5	46	64
63							45	63
62				11	10		44	62
60	13						43	60
59							42	59
58	12	5	4	10	9	4	41	58
56							40	56
55							39	55
54	11			9			38	54
53					8		37	53
51		4				3	36	51
50	10			8	7		35	50
49							34	49
47	9		3				33	47
46					6		32	46
45	8	3		7		2	31	45
42					5		29	42
41	7			6			28	41
40							27	40
38		2			4	1	26	38

CSHQ

Name of Patient: _____

Date form filled out: _____

Child's Sleep Habits Questionnaire (pre-school and school-aged children)

The following statements are about your child's sleep habits and possible difficulties with sleep. Think about the past week in your child's life when answering the questions. If last week was unusual for a specific reason (such as your child had an ear infection and did not sleep well or the TV set was broken) choose the most recent typical week.

Answer USUALLY if something occurs 5 or more times in a week.

Answer SOMETIMES if it occurs 2-4 times in a week.

Answer RARELY if something occurs never or 1 time during a week.

Indicate whether or not the sleep habit is a problem by circling "Yes", "No," or "not applicable (N/A)".

Write in child's bedtime: _____ Write in child's usual wake time: _____

Child's usual amount of sleep each night (no naps): _____ hours and _____ minutes

Child's usual amount of sleep each day (naps): _____ hours and _____ minutes

	1 Usually (5-7)	2 Sometimes (2-4)	3 Rarely (0-1)	Problem?		
1. Child goes to bed at the same time at night				Yes	No	N/A
2. Child falls asleep alone in own bed				Yes	No	N/A
3. Child falls asleep within 20 minutes after going to bed				Yes	No	N/A
4. Child sleeps the right amount				Yes	No	N/A
5. Child sleeps about the same amount each day				Yes	No	N/A
6. Child wakes up by him/herself				Yes	No	N/A

Child has appeared very sleepy or fallen asleep during the following (check all that apply):

	0 Not Sleepy	1 Very Sleepy	2 Falls Asleep
7. Watching TV			
8. Riding in a car			

PLEASE TURN OVER AND COMPLETE OTHER SIDE!!!

Page 1 of 2

Name of Patient _____

Date form filled out: _____

	3 Usually (5-7)	2 Sometimes (2-4)	1 Rarely (0-1)	Problem?		
9. Child falls asleep in parent's or sibling's bed				Yes	No	N/A
10. Child struggles at bedtime (cries, refuses to stay in bed, etc.)				Yes	No	N/A
11. Child needs parent in the room to fall asleep				Yes	No	N/A
12. Child is afraid of sleeping alone				Yes	No	N/A
13. Child sleeps too little				Yes	No	N/A
14. Child is afraid of sleeping in the dark				Yes	No	N/A
15. Child has trouble sleeping away from home (visiting relatives, vacation)				Yes	No	N/A
16. Child moves to someone else's bed during the night (parent, sibling, etc.)						
17. Child awakens once during the night				Yes	No	N/A
18. Child awakens more than once during the night Write the number of minutes a night waking usually lasts: _____				Yes	No	N/A
19. Child talks during sleep				Yes	No	N/A
20. Child is restless and moves a lot during sleep				Yes	No	N/A
21. Child sleepwalks during the night				Yes	No	N/A
22. Child wets the bed at night				Yes	No	N/A
23. Child grind teeth during sleep (your dentist may have told you this)				Yes	No	N/A
24. Child awakens alarmed by a frightening dream				Yes	No	N/A
25. Child awakens during night screaming, sweating, and inconsolable				Yes	No	N/A
26. Child snores loudly				Yes	No	N/A
27. Child seems to stop breathing during sleep				Yes	No	N/A
28. Child snorts and/or gasps during sleep				Yes	No	N/A
29. Child wakes up in a negative mood				Yes	No	N/A
30. Adults or siblings wake up child				Yes	No	N/A
31. Child has difficulty getting out of bed in the morning				Yes	No	N/A
32. Child takes a long time to become alert in the morning				Yes	No	N/A
33. Child seems tired in the morning				Yes	No	N/A

PLEASE TURN OVER AND COMPLETE OTHER SIDE!!!

Page 2 of 2

SNAKE

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Questionnaire is filled out by:

☐ mother ☐ father ☐ other: _____

General information on your child

Sex: ☐ female ☐ male

Age: _____ years **Height:** _____ cm **Weight:** _____ kg

Country of birth: _____

What diagnosis was made for your child?

What medication does your child take?

Information on the family:

Caregiver's marital status?

☐ live together

☐ divorced since: _____

☐ widowed since: _____

☐ never lived together

With whom does your child live predominantly?

☐ biological parents

☐ biological mother ☐ biological father

☐ biological mother and partner

☐ biological father and partner

☐ grandparents or other relatives

☐ adoptive parents ☐ foster parents

☐ children's home

How many children live in your household?

_____ children

**How many people live in your household
(including children)?**

_____ persons

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1. At what time did you usually put your child to bed at night?	about ____ o'clock			
2. How long did it usually take for your child to fall asleep?	about ____ minutes			
3. How many hours of sleep did your child actually get at night?	about ____ hours			
4. Please choose the one answer, which describes your child the most accurate in the past 4 weeks.				
	Never	Less than once a week	Once or twice a week	Three or four times a week
How often did your child resist going to bed (at bedtime)?	☐	☐	☐	☐
Was your child afraid of falling asleep or of being alone?	☐	☐	☐	☐
Did your child need your help to fall asleep?	☐	☐	☐	☐
How often did your child have restless sleep and rolling movements while it was falling asleep?	☐	☐	☐	☐
How often did your child wake up during the night?	☐	☐	☐	☐
Did your child have trouble falling asleep again if awakened?	☐	☐	☐	☐
Did your child sleep in your bed at night?	☐	☐	☐	☐
Did your child sleep in a room with other people?	☐	☐	☐	☐
How often did your child take medication to help him/her sleep (prescribed or "over the counter")?	☐	☐	☐	☐
name: dosage:				

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5. How long would you say your child was awake at night on average?		about ____ hours			
6. How would you rate your child's sleep quality overall?		O: very good O: good O: satisfactory O: poor			
7. Specify for the following questions how often these situations occurred in the past 4 weeks.					
a.) How often ...	Never	Less than once a week	Once or twice a week	Three or four times a week	
... were the lights switched on in your child's bedroom?	☐	☐	☐	☐	
... could noise (e.g., street noise) be heard in your child's bedroom?	☐	☐	☐	☐	
... was the radio or TV running in your child's bedroom?	☐	☐	☐	☐	
... was the door open in your child's bedroom?	☐	☐	☐	☐	
b.) How often did your child have a bad sleep because of...	Never	Less than once a week	Once or twice a week	Three or four times a week	
... pain?	☐	☐	☐	☐	
... epileptic seizure?	☐	☐	☐	☐	
... breathing difficulties?	☐	☐	☐	☐	
... repositioning?	☐	☐	☐	☐	
... medical care such as infusion, corset, respirator etc.?	☐	☐	☐	☐	
... other reason(s)?	☐	☐	☐	☐	
Please specify:					
c.) When your child could not sleep at night, what did he / she do?	Never	Less than once a week	Once or twice a week	Three or four times a week	
My child was lying restlessly in his/her bed.	☐	☐	☐	☐	

My child was crying and screaming in his/her bed.	☐	☐	☐	☐
My child was doing other things.	☐	☐	☐	☐
Please specify:				
c.) How often did your child do one of the following things while he / she was asleep at night?	Never	Less than once a week	Once or twice a week	Three or four times a week
snore	☐	☐	☐	☐
pause between breaths	☐	☐	☐	☐
tilt his/her head	☐	☐	☐	☐
grind teeth	☐	☐	☐	☐
sweat excessively	☐	☐	☐	☐

1. At what time did your child usually wake up in the morning?		about _____ o'clock		
2. Please mark the best fitting category with a cross:	Never	Less than once a week	Once or twice a week	Three or more times a week
How often did your child fall asleep during the day?	☐	☐	☐	☐
3. When your child had a bad sleep at night, how often did he / she show one of the following characteristics during the day?	never	rarely	casually	often
show physical exhaustion	☐	☐	☐	☐
fall asleep unexpectedly	☐	☐	☐	☐
become less balanced	☐	☐	☐	☐
become restless	☐	☐	☐	☐
show aggression	☐	☐	☐	☐
show other unusual behavior?	☐	☐	☐	☐
Please specify:				
4. How many hours did your child sleep during the day in total?			_____ hours	
5. Would you like to add something that you consider important for your child's sleeping behavior or activity that was not assessed with this questionnaire?				

Chailey Sleep Questionnaire

CHILD'S NAME		DATE: / /
NIGHT-TIME CARE		ACTION ✓
8	Does your child need medication during the night? ☐ yes ☐ no	☐
8a	If yes, please give details: 	☐
8b	How is the medication administered? ☐ orally ☐ rectally ☐ gastrostomy ☐ other route	☐
8c	How often, per week, is the medication given during the night? 	☐
9	Does your child need a feed during the night? ☐ yes ☐ no	☐
9a	If yes, How is the feed given? ☐ nasogastric ☐ gastrostomy ☐ other	☐
9b	Does this wake your child? ☐ yes ☐ no ☐ sometimes	☐
10	Does your child require any other night time care? ☐ yes ☐ no	☐
10a	If yes, please give details: 	☐
SENSORY IMPAIRMENTS		ACTION ✓
11	Does your child have problems with his/her vision? ☐ yes ☐ no	☐
11a	If yes, please give details: 	☐
12	Does your child have a hearing problem? ☐ yes ☐ no	☐
12a	If yes, please give details: 	☐

CHILD'S NAME		DATE:	/
ORTHOPAEDIC PROBLEMS			ACTION ✓
13	Does your child have orthopaedic problems?	☐ yes ☐ no	☐
13a	If yes, please give details:		☐
13b	Do these problems cause pain during the night?	☐ yes ☐ no ☐ sometimes	☐
13c	If yes, please give details:		☐
SPINAL CURVATURE (SCOLIOSIS OR KYPHOSIS)			ACTION ✓
14	Does your child have Scoliosis or Kyphosis?	☐ yes ☐ no	☐
	If yes,		
14a	Please grade the degree of Scoliosis or Kyphosis	☐ mild ☐ moderate ☐ severe	☐
14b	Is the Scoliosis or Kyphosis getting worse?	☐ yes ☐ no	☐
14c	Is spinal surgery planned or has it happened?	☐ yes ☐ no	☐
14d	If yes, when:		
14e	Does your child wear a spinal jacket?	☐ yes ☐ no	☐
14f	Does your child sleep in a spinal jacket?	☐ yes ☐ no	☐
BREATHING PROBLEMS			ACTION ✓
15	Has your child had a chest infection in the last 6 months?	☐ yes ☐ no	☐
	If yes,		
15a	How many chest infections has your child had in the last 6 months?	☐ 1 ☐ 2-5 ☐ 6+	☐
15b	How many of these required antibiotics?	☐ none ☐ some ☐ all	☐
15c	How many required hospitalisation?	☐ none ☐ some ☐ all	☐

CHILD'S NAME		DATE:	/
16	Is your child's breathing disturbed during sleep?	☐ yes ☐ no ☐ sometimes	☐
17	Does your child snore?	☐ yes ☐ no ☐ sometimes	☐
18	Does your child's breathing stop and start during sleep?	☐ yes ☐ no ☐ sometimes	☐
19	Does your child have shallow breathing during sleep?	☐ yes ☐ no ☐ sometimes	☐
20	Does your child struggle for breaths during the night?	☐ yes ☐ no ☐ sometimes	☐
21	Is your child's breathing at night interrupted with snorts and gasps?	☐ yes ☐ no ☐ sometimes	☐
22	Does your child gag or choke during the night?	☐ yes ☐ no ☐ sometimes	☐
23	Is your child's breathing poorer in certain sleep positions?	☐ yes ☐ no ☐ sometimes	☐
23a	If yes, what positions?		☐
24	Does your child have recurrent ear or throat infections?	☐ yes ☐ no	☐
25	Have your child's tonsils or adenoids been removed?	☐ yes ☐ no	☐
25a	If yes, please give details:		☐
26	Does your child find it difficult to recover from a cold?	☐ yes ☐ no	☐
27	Does your child find it difficult to cough?	☐ yes ☐ no	☐

CHILD'S NAME		DATE:	/
TISSUE VIABILITY			ACTION ✓
28	Does your child have problems with their skin or pressure sores?	☐ yes ☐ no	☐
28a	If yes, please give details:		☐
28b	Do these problems cause pain or discomfort at night?:	☐ yes ☐ no	☐
28c	If yes, please give details:		☐
NUTRITION & FEEDING RELATED PROBLEMS			ACTION ✓
29	Does your child have difficulties chewing or swallowing?	☐ yes ☐ no	☐
29a	If yes, please give details:		
30	Does your child have problems with feeding?	☐ yes ☐ no	☐
	If yes,		
30a	Is your child fed by nasogastric /gastrostomy feeds alone?	☐ yes ☐ no	☐
30b	Is your child fed by combination of tube and oral?	☐ yes ☐ no	☐
30c	If yes, please give details:		☐
31	Does your child experience vomiting/regurgitation during: daytime ☐ yes ☐ no night time ☐ yes ☐ no		☐
32	Is there a risk of aspiration?	☐ yes ☐ no	☐
32a	If yes, does your child require any drugs to control this?	☐ yes ☐ no	☐
32b	If yes, please give details:		☐
			Continued

CHILD'S NAME		DATE:	/
33	Does your child experience periods of constipation?	☐ yes ☐ no	☐
33a	If yes, please give details:		☐
33b	Does this cause discomfort at night?	☐ yes ☐ no	☐
SEIZURES, FITS AND NEUROLOGICAL			
			ACTION ✓
34	Has your child ever had a seizure or fit?	☐ yes ☐ no	☐
34a	How many seizures or fits has your child had in the last 6 months?	☐ none ☐ 1-5 ☐ 6-10 ☐ 11-20 ☐ daily	☐
34b	What time of the day or night do the fits usually happen?	☐ early morning ☐ afternoon ☐ evening ☐ night time	☐
34c	Please please give details:		☐
34d	How long do the fits last?	☐ seconds ☐ less than 15 minutes ☐ more than 15 minutes	☐
34e	How many different medications are needed to control the fits?	☐ none ☐ one ☐ two ☐ three ☐ more than three	☐
34f	What are the names of the medications?		☐
35	Does your child indicate that they suffer from headaches?	☐ yes ☐ no	☐
36	Does your child seem to have a headache in the mornings?	☐ yes ☐ no	☐
37	Does your child have a cerebral shunt?	☐ yes ☐ no	☐
	If yes,		
37a	Has the cerebral shunt caused any problems in the last six months?	☐ yes ☐ no	☐
37b	If yes, please give details:		☐