Survival Mode:
Mothers’ perceptions of implementing physician’s recommendations for paediatric sleep-care

by

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B.A., Simon Fraser University, 2002

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Counselling Psychology Program
Faculty of Education

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Abstract

Paediatric sleep problems are pervasive and affect optimal development. Although evidence-based treatments are available, clinical experience suggests that they are not effectively translated into practice. The experience of the clinicians at the Sleep-/Wake Behaviour Clinic at Sunny Hill Children’s Health Centre (BC Children’s Hospital) suggested that well-validated treatment protocols were not translating into clinical successes with their patients. A preliminary study in Kamloops showed that families were not implementing physicians’ recommendations for sleep-care, which raised questions about was preventing them from doing so. Therefore, the purpose of this study was to understand a) mother’s experience managing their child’s sleep problem in the context of the BC healthcare system and family; and, b) describe the meanings they make from these experiences, and in turn, how these inform mothers’ reactions to physician’s sleep-care recommendations. Mothers seeking sleep-care support from the Kamloops Paediatric Sleep Clinic were interviewed about their experiences implementing recommendations and the barriers they faced. Through an iterative process of theoretical sampling, memoing, and on-going review of the literature, I constructed a theoretical process model of mothers’ experience managing their child’s sleep problem entitled “Survival Mode.” This nascent theory was validated through negative case analysis, flip-flop techniques and member-checking, until I was satisfied that it “fit” and was a “useful” model from the participants’ perspective. Understanding the meaning of sleep problems for mothers, and the factors underlying adherence with sleep recommendations, may help increase intervention success and, inform policy/program development.

Keywords: paediatric sleep-care; treatment adherence; barriers and facilitators; physician recommendations
Thank you to the mothers who shared their stories of the love, sorrow and resilience.

Vair me o, ro van o
Vair me o ro ven ee,
Vair me o ru o ho
Sad I am without thee.

When I'm lonely, dear white heart,
Black the night and wild the sea;
By love's light my foot finds
The old pathway to thee.

Vair me o, ro van o
Vair me o ro ven ee,
Vair me o ru o ho
Sad I am without thee.

Thou'rt the music of my heart,
Harp of joy, o cuit mo chridh,
Moon of guidance by night,
Strength and light thou'rt to me.

-Eriksay Love Lilt
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## List of Acronyms

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<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>SFU</td>
<td>Simon Fraser University</td>
</tr>
<tr>
<td>SWBC</td>
<td>Sleep-/Wake Behaviours Clinic. Research clinic associated with Sunny Hill Children’s Health Centre, BC Children’s Hospital.</td>
</tr>
<tr>
<td>TRU</td>
<td>Thompson Rivers University</td>
</tr>
<tr>
<td><strong>Glossary</strong></td>
<td></td>
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<tr>
<td>----------------</td>
<td></td>
</tr>
<tr>
<td><strong>Healthcare provider</strong></td>
<td>This term refers to physicians and para-healthcare professionals, such as occupational therapists, speech and language pathologists and nurses.</td>
</tr>
<tr>
<td><strong>Physician</strong></td>
<td>This term specifically refers to medical doctors, including general physicians, family doctors, paediatricians.</td>
</tr>
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Chapter 1. Introduction

Our daughter missed 2007 nights of sleep from the time she was born until starting Kindergarten. Her brain suffered. Her body suffered. Our family suffered. Over five years she was assessed by seven healthcare professionals, including three tertiary level paediatric specialists. Along the way she received four different mental health diagnoses and experienced a severe adverse drug reaction to pharmaceutical treatment. Professionals prepared us for a dark future, where unknown mental health and addiction dangers loomed. Worse yet, without sufficient explanation, my mothering was framed as the problem, and our mother-child attachment became the primary focus. I left my job, and with it financial security and my identity, to find help for our daughter. My husband and I were terrified, and through the gruelling sleepless nights and endless days, it became difficult to find support and comfort in each other. I felt ashamed, inadequate and helpless.

In October 2012, an international group of clinicians and researchers met in Vancouver at the Peter Wall Institute, for the “Phenotyping Sleep Behaviours: Lessons from the Past, Directions for the Future” workshop. As a group, they had seen the devastating effects of paediatric sleep problems on children and families, and aimed to find ways of overcoming barriers to translating knowledge into practice. They believed that a mother’s voice would help unify and ground the conversation, and invited me to participate in the meeting. Based on my family’s experience, I was committed to bringing awareness to paediatric sleep problems, and creating a voice for families’. Since that time, I have been involved as a mother advocate for the Children’s Sleep Network (CSN), and as a clinical research assistant for the Sleep-/Wake Behaviours Research Lab at Sunny Hill Children’s Health Centre.

Through this work I have been privileged to hear many families’ and healthcare practitioners’ stories. It has become clear to me that not only do sleep problems aggravate already existing health and behavioural challenges, but they also consume emotional resources, and cause increased and inappropriate use of various health services and medication driven treatments. In other words, sleep problems lead to unnecessary suffering. Given that effective, evidence-based treatments are available,
how is it possible that so many families continue to struggle with their child’s sleep, and what can be done about it?

1.1. Statement of the problem: Disparity between research and clinical outcomes

There is a significant lack of paediatric sleep specialists in Canada (Owens & Mindell, 2006), and “very little is known about how to best increase access to evidence-based sleep-related care for children and their families” (Boerner, Coulombe, & Corkum, 2015, p.37). The Sleep-/Wake Behaviours Clinic (SWBC), operating out of Sunny Hill Children’s Health Center (an annex of BC Children’s Hospital, Vancouver, BC), is the only tertiary level care centre for children’s sleep in the province, and also functions as an internationally leading paediatric sleep research lab. Researchers at the Sleep-/Wake Behaviours Clinic (SWBC) develop sleep screening protocols to provide non-sleep specialist physicians with the knowledge and skills to recognize and manage paediatric sleep problems in the community. In the fall/winter of 2013 clinicians at the SWBC noticed that children being treated for sleep problems were not improving as expected compared to expected research-based outcomes; there appeared to be a breakdown between evidence-based recommendations and clinical outcomes.

At that time, the SWBC was testing a clinical protocol, called “Functional Sleep-/Wake Assessment” (Lipsiroglu, 2016) and decided to include an outcome evaluation with that project. The evaluation aimed to address the usefulness of the sleep-management recommendations and explain the poor clinical outcomes that were being observed. In March 2013, 20 children (between the ages of 4 and 17) with suspected sleep problems were referred by community partner agencies and family doctors for a functional sleep-/wake assessment by a paediatric sleep specialist in their home community of Kamloops, BC. During the assessment, children were screened for sleep problems and provided with a personalized sleep-care management plan, which included medication/supplementation, behavioural sleep interventions and/or additional screening. The service was consultative, and treatment was coordinated and delivered through the families’ primary care providers.

One-year post-assessment, in March of 2014, I was contracted to conduct interviews with the families about their experiences of care and the usefulness of the
sleep-care recommendations (Graham, 2015). All parents felt that the assessment experience had been positive and informative. However, 80% reported that they had not enacted the treatment recommendations and had seen no significant improvement in their child’s sleep situation. Parents reported high levels of motivation to manage their child’s sleep problem and believed they had the skills and knowledge to do so, but had either not implemented the recommendations, or had given up after a very brief (and often inconsistent) trial. This outcome came as a surprise. Based on the clinical models, the team expected that the majority of the children would show significant improvements in their sleep by the six-month follow-up (see Jan et al., 2008). By delivering expert care in the family’s community, the outreach assessment model was designed to overcome the known systems and access barriers, and the sleep-care recommendations were based on research-based treatment interventions (see Hill, 2011; Ipsirolou, 2016; Mindell, Kuhn, Lewin, Meltzer, & Sadeh, 2006).

When I asked parents about the factors that were helpful and the barriers they faced, parents agreed that the clinical assessment experience was positive and family-centered. They described feeling supported and respected by the healthcare team. This sense of safety and trust allowed them to be more transparent about their family’s challenges. Parents left the assessment feeling hopeful about the sleep-care management plan, but encountered challenges coordinating care and described encountering resistance from other members of their child’s healthcare team. For example, one set of parents reported that their child’s psychiatrist declined to make recommended medication changes, prioritizing daytime behaviour management over sleep concerns. Parents also spoke extensively about the emotional and relational barriers that they faced. Concern about how the sleep intervention would affect their relationship with their child was a serious concern for most parents, and one of the primary reasons they cited for not implementing, or discontinuing a strategy. Parents’ reports challenged existing ideas about sleep-care management.

Research indicates that behavioural sleep interventions will result in significant improvements in the sleep of approximately 84% of children treated (see Mindell, Kuhn, Lewin, Meltzer, & Sadeh, 2006; Allen, Howlett, Coulombe, & Corkum, 2015, Hill, 2011). Given their documented efficacy, clinical treatment failures are typically attributed to parental non-compliance, however, the factors affecting parents’ choices and abilities to enact recommendations have not be explored in a meaningful way (Mindell, et al.,
My conversations with parents opened up questions about how parents’ decisions are affected by social systems and relationships, and the meanings they draw from these interactions.

The inquiry also demonstrated that parents’ decisions on how to respond to their child’s sleep problem may be inconsistent with their stated care preferences. Consistent with the research literature, parents from the evaluation study reported being reluctant to use medication to manage their child’s sleep (see Russo, Gururaj, & Allen, 2003; Owens, Rosen, & Mindell, 2003; Kales, Allen, Scharf, & Kales, 1970; Richman, Douglas, Hunt, Lansdown, & Levere, 1985). However, despite stating a preference for non-pharmaceutical treatments, most parents in the clinical follow-up reported using medication and/or supplements to manage their child’s sleep. Like the single mother who used medication to manage her son’s sleep so she could get enough rest to work, parents expressed a high level of guilt about their decision to use pharmaceutical treatments and felt shamed and unsupported by others, including their family and healthcare providers, when they did so.

Participants described how the assessment had provided them with a space to share the meaning of their child’s sleep problem. Participants also reported the value of looking at sleep separately (from other health and behaviour issues) with a knowledgeable, empathetic and engaged medical partner. As a mother, I found it relieving to know that I was not alone; and as a researcher, I was curious about our collective experience — what psychological and social processes were shaping our shared experience? To fully appreciate treatment adherence behaviours, I realized that we needed to understand mothers’ perspectives, the context and conditions, and other dimensions (Schatzman, 1991) that may influence how and why mothers do or do not comply with physician recommendations for sleep care.

1.2. Research Aims

Paediatric sleep problems are widespread and can have devastating consequences for children and families. The experience of the clinicians at the Sleep/Wake Behaviour Clinic suggested that well-validated treatment protocols were not translating into clinical successes with their patients. A preliminary study in Kamloops showed that families were not implementing physicians’ recommendations for sleep-
care, which raised questions about what was preventing them from doing so. Therefore, the purpose of this study was to explore mothers’ experiences of a sleepless child, and to identify perceived barriers to and facilitators for implementing physician’s sleep-care recommendations within the family, and within the current healthcare system.

Using a grounded theory approach, I described a) mothers’ experiences managing their child’s sleep problem in the context of the BC healthcare system and their families; and, b) the meanings they make from these experiences, and in turn, how these shaped their reactions to physician’s sleep-care recommendations. Understanding the meaning of sleep problems for the mothers, and the effects they have on treatment may help inform care planning, and increase intervention success rates. Developing a better understanding of how mothers experience and manage sleep problems will also help guide health policy and program development.
Chapter 2. Background

2.1. The role of the literature in grounded theory research

The role of the literature review in grounded theory is controversial. The timing and depth of the literature review depends on the researcher’s epistemological position and experience with the topic. Giles, King and de Lacey describe “two broad perspective about the timing of the literature review in grounded theory: 1) to delay the literature review until after the data collection and analysis, or 2) to undertake a preliminary literature review prior to the study and then either expand this review or write a secondary review during the data collection analysis phase.” (2013, p.3). Researchers advocating for the first position are concerned that an early review of the literature can lead to the researcher “forcing” the data into a preconceived theory. This “empty head” position is losing favour to practices that foster an “open mind” approach (Giles, et al., 2013, p. E35; also see Bryant, 2013; Dey 2007). Proponents of the open mind approach argue that preconceptions are unavoidable, and that “Researchers must account for them in some way, and openly acknowledge the influence of prior work in their perspective of what is emerging from the data” (Giles, et al., 2013, p.E35; also see Bryant & Charmaz, 2007; Charmaz, 2006).

In consultation with my committee, I adopted the “open mind” approach. My rationale for this decision was based on several factors. Because of my previous involvement with the topic, I was already familiar with the literature; however, as a novice Researcher, I did not have the background knowledge that a more experienced Researcher would, and needed to gain critical knowledge of key concepts (Giles, et al., 2013, p.E32). Furthermore, the University research ethics board required me to provide justification, background and a framework for the study and demonstrate the potential for new knowledge. Given these conditions, I took a balanced approach, and conducted a preliminary review of the literature to provide a beginning framework for the study. This orientation process helped me to “conceptualize the background and identify theoretical knowledge gaps” (Giles, et al., 2013, p.E38). I then put it aside and allowed it to “lie fallow” (Charmaz, 2006, p.166) until I began to develop categories during my analysis of the data. My secondary review of the literature assisted me in “linking existing research and theory with the concepts, constructs and properties of the new research"
In the twenty-four months between my first and second literature review, new research provided evidence in support of my emerging theory. Although I abstained from a formal review of the literature during the data collection phase, I continued to read broadly and extensively to enhance my theoretical sensitivity (Lampert, 2007).

2.2. Paediatric sleep problems

Sleep problems are a bio-psycho-social issue. To understand mothers’ experiences, I familiarized myself with how sleep issues have been treated in medicine, nursing, pharmacology, education, and social policy.

2.2.1. Prevalence

Despite the critical role that sleep plays in children’s development and daily functioning, children’s sleep durations are steadily declining (Dollman, Ridley, Olds, & Lowe, 2007), and paediatric sleep problems are pervasive (Mindell & Owens, 2015). Overall, it is estimated that 30% of typically developing, and up to 80% of children with neuro-developmental conditions have a sleep problem (Mindell & Owens, 2015; see Appendix B, study protocol). Even so, these estimates may under-estimate the issue because the behaviours and symptoms associated with sleep-problems are frequently misdiagnosed or diagnostically overshadowed by comorbid mental health and/or neurodevelopmental diagnoses (Gruber, Sadeh, & Raviv, 2000).

2.2.2. Defining paediatric sleep problems

Sleep is a complex phenomenon, and the development of healthy sleep may be affected by a myriad of psychological, physiological and contextual factors. Depending on how sleep is conceptualized, sleep difficulty may be operationalized as a medical, psychiatric or behavioural problem. The International Classification of Sleep Disorders – Third Edition (ICSD-III) identifies 80 different conditions, including sleep disorders occurring exclusively during childhood (2005). Unlike for the adult population however, there is still considerable debate about what constitutes clinically significant levels of dysfunction or diagnostic criteria for the paediatric population (Mindell & Owens, 2015). The situation is made more complicated by phenotypic variations in sleep presentations.
among children, and their inability to describe specific phenomenological symptoms used for differential diagnosis (see Allen et al., 2003). Furthermore, cross-cultural analyses of sleep have shown significant differences between cultural groups in what is considered problematic, and in normative management strategies (e.g. co-sleeping) (Sadeh, Mindell, & Rivera, 2011). To accommodate these challenges, many clinicians prefer to regard sleep problems as clinically significant when the issue is affecting the family’s wellbeing to the point that they have sought medical advice from a healthcare provider (Sadeh et al., 2011).

2.2.3. Description of paediatric sleep problems

Disturbed and inadequate sleep, broadly referred to as “sleep problems,” can result from a variety of factors (Allen, et al., 2016). A small percentage of children’s sleep problems are the result of an underlying medical issue or physiological abnormality; whereas, the majority sleep issues stem from learned behaviour, created and sustained by the child’s environment. Sleep problems can also be a symptom or co-morbid to neurodevelopmental or psychiatric conditions. Thus, sleep is a constellation of physiology and learned behaviour. The International Classification of Sleep Disorders (ICSD-III) identifies seven major categories that include: 1) insomnia disorders; 2) sleep-related breathing disorders; 3) central disorders of hyper-somnolence; 4) circadian rhythm sleep-wake disorders; 5) sleep-related movement disorders; 6) parasomnias; and, 7) other sleep disorders.

The vast majority of children with a sleep problem present with behavioural insomnia (a sub-classification of category one insomnia disorders) (Allen, et al., 2016). Some clinicians argue that all sleep problems have a behavioural component since sleep behaviour is learned in the context of the parent-child relationship (Weiss, Driver, Bastien, Samuels, & Fogel, 2012). The broad category Behavioural Insomnia of Childhood (BIC) includes problems with sleep initiation (difficulties settling and falling asleep), sleep maintenance (staying asleep) and, waking too early in the morning (Mindell et al., 2006). Many children will have a combination of the three. According to Mindell et al. (2006), bedtime problems, most common in children two and under, include stalling and refusing behaviours (verbal protests, calling out, crying, clinging, refusing to go to bed, getting out of bed, attention seeking behaviours, multiple requests for food, drink and stories). This constellation of behaviours is believed to be related to
difficulties with parents’ limit-setting (Mindell, et al., 2006, p.1264). Children with sleep-onset association find it difficult to fall asleep without rocking, feeding or the parent’s presence. When the child awakens in the course of the night, they seek to re-create the association, and signal for their parent (through crying, calling out) (Mindell, et al., 2006, p.1264). To meet the diagnostic threshold, these problems have to occur at least three times a week, have to be been present for at least 3 months, and must cause functional impairment in more than two domains of the child’s functioning (see Appendix B, Study protocol).

2.2.4. Etiology

We live in a “sleep sick” culture (Dement & Vaughan, 1999). Health Canada reports that one in four Canadian children are not getting enough sleep (Trembley, et al, 2016), and the US Centre for Disease Control (CDC) has identified sleep deprivation as a public health crisis. Even with this knowledge, our society has a profound lack of respect for sleep reflected in Margaret Thatcher’s famous saying, “sleeping is for wimps.” Children are not immune to such attitudes, and recreation and schooling demands have increasingly pushed children’s sleep-times down over the past 20 years (Bates et al., 2002). Growing attention is also being focused on the role of omnipresent blue-light emitting screens, which are known to affect sleep by suppressing melatonin production (Foley et al., 2013).

Sleep problems are thought to result from the interaction between a variety of contextual and individual factors (Buckhalt, 2011). Infant and toddler studies demonstrate the bi-directional influence between parent’s sleep-related beliefs, attitudes and cognitions and their child’s sleep behaviour (Morrell; 1999; Sadeh, Flint-Ofir, Tirosiya, & Tikotzky, 2007; Sadeh, Tikotzky, & Scher, 2010; Tikotzky & Sadeh, 2009; Tikotzky, Sharabany, Hirsch, & Sadeh, 2010). The development of healthy sleep requires parent to have developmentally appropriate expectations, and the belief that they have the skills and knowledge to support it. Individual family-factors position some children at greater risk for sleep problems. Low socio-economic status (SES) is correlated with sleep problems, possibly due to irregular routines and non-ideal sleep situations (Bates et al., 2002; Gregory et al., 2006; Owens & Witmans, 2004). Parenting variables, such as parenting style, mental health status, and education-level also predict child sleep problems (Zuckerman, Stevenson, & Bailey, 1987).
Intrinsic characteristics also predispose some children to sleep problems. Infants described as difficult to soothe or “fussy” continue to have sleep problems throughout childhood, suggesting that temperament is closely associated with sleep (Wake et al., 2006). Similarly, neuro-developmental conditions (e.g. ADHD, Autism) are highly comorbid with sleep problems (Jan et al., 2008); and many of the medications used to treat these conditions may worsen the situation (Jan et al., 2010).

### 2.2.5. Impact of paediatric sleep problems

An overwhelming body of research points to the importance of sleep for normal development and long-term wellbeing. Extensive evidence demonstrates the impact of sleep on health, mood, behaviour, cognition, learning and social-emotional functioning (Bates, Viken, Alexander, Beyers, & Stockton, 2002; Beebe, 2006; Buckholt, Wolfson, & El-Sheikh, 2009; Liu, Liu, Owens, & Kaplan, 2005). Furthermore, child psychopathology, particularly anxiety and depression, are linked to sleep problems (Cohen-Zion & Ancoli-Israel, 2004; Ivanenko, Crabtree, & Gozal, 2005; Stein, Mendelsohn, Obermeyer, Amromin, & Benca, 2001; Stores, 1999).

The burden placed on families by children’s sleep difficulties is often not appreciated. Mothers report sleep problems as one of the more frustrating mothering issues and, more difficult aspects of raising children (Gregory, Rijsdijk, Dahl, McGuffin, & Eley, 2006). Multiple studies have traced the immediate and long-term impact of infant sleep problems on the mother child-relationship (see Bordeleau, Bernier, & Carrier, 2012; Morrell & Steele, 2003). Even short-term child sleep problems can have a serious effect on maternal wellbeing and be a source of stress on the family system (Lam, Hiscock, & Wake, 2003; McKenna, Thoman, Anders, Sadeh, Schechtman, & Glotzbach, 1993; Zuckerman, Stevenson, & Bailey, 1987). A child’s sleep problems not only interrupt mothers’ time alone for recreation and relaxation, but their own sleep is also limited by frequent awakenings and/or co-sleeping (Bates et al., 2002). Spousal relationships may suffer because of increased stress and lost opportunity for sexual intimacy (Liu, Liu, Owens, & Kaplan, 2005). Mothers’ ability to function and manage stress is also greatly reduced by sleep deprivation (Byars, Yeomans-Maldonado, & Noll, 2011), putting them at greater risk for physical and mental health disorders (Caldwell & Redeker, 2015). Health economic data also show that mothers’ work performance and attendance is negatively affected by having a child with sleep problems, putting them at
risk for workplace accidents and injuries (Hillman, Murphy, Antic, & Pezzullo, 2006). In the worst case, sleep problems can directly contribute to the breakdown of the family unit (Kelly & El-Sheikh, 2011).

2.2.6. Assessment of paediatric sleep problems

Children’s unique clinical presentations and limits to assessment protocols mean that paediatric sleep problems are routinely missed/neglected by clinicians (Ipsiroglu, McKellin, Carey, & Loock, 2013). Children with sleep disorders may present differently than adults, and even within the paediatric population, children may present differently depending on age and development. Symptoms of sleep problems in children may be paradoxical. Rather than appearing sleepy, sleep deprived children may exhibit motor activity, inattentiveness, irritability or oppositional behaviour (Chervin, Dillon, Bassetti, Ganoczy, Pituch, 1997; Owens, Opipari, Nobile, Spirito, 1998). Children presenting with sleep-related breathing concerns may go unnoticed because many clinicians are not trained to use paediatric specific testing parameters (Goldstein, Pugazhendhi, Rao, Weedon, Campbell, Goldman…& Rao, 2004). Challenging and disruptive daytime behaviours may be misunderstood as symptoms of ADHD (Sadeh, Gruber, Raviv, 2002). Finally, comorbid psychiatric conditions, like anxiety and depression, share similar symptoms to sleep problems. This shared nosology, combined with the way psycho-pharmaceuticals can exacerbate sleep problems makes differential diagnosis challenging.

If healthcare providers do not ask directly, parents may not volunteer information about their child’s sleep. Parents may not appreciate the link between sleep and challenging daytime behaviours. Socio-economic status and ethnicity also affect parental reporting. Lozoff, Askew, and Wolf (1996) described differences between white and black parent’s sleep-related attitudes and beliefs. Among families who co-slept with their preschool aged child, white parents were more likely than black parents to consider their child’s sleep behaviour to be a problem, (i.e., stressful, conflictual, or upsetting as well as regularly occurring). One explanation is that differing childrearing attitudes and expectations influenced how parents interpreted their children's sleep behaviour (Lozoff, Askew, & Wolf, 1996, p.9). Milan, Snow and Belay (2007) described similar trends, and after controlling for confounding factors found that differences in parent’s sleep-related
attitudes reflected differences in cultural values and beliefs about the parent-child relationship and family life (2007, p.20).

The first step in assessing the sleep problem is to take a thorough sleep history. A variety of checklists are available however, the Canadian Sleep Society endorses the BEARS measure which screens a child’s sleep in five domains: B = Bedtime Issues, E = Excessive daytime sleepiness, A = Night awakenings, R = Regularity and duration of sleep, S = Sleep disordered breathing [or Snoring] (see Weiss, Driver, Bastien, Samuels, & Fogel, 2012). Sleep clinicians, Mindell and Owens (2015) recommend that parents use a sleep log or diary to record details about the duration and frequency of the problem and degree of variability from night to night. To assist in this screening process, clinicians may ask parents to complete a sleep log (or diary) for two weeks. This log should include bed time, time of sleep onset, awakenings, rise time, nocturnal events, feeding pattern, naps, perceived quality of sleep, degree of alertness or sleepiness during the day, and observations regarding nocturnal events and medical or psychological stressors. The child’s sleep patterns can then be compared with typical sleep patterns for his or her age group.

There are significant limitations to parental reports. Sadeh (2008) points out that parents must be aware of the child’s wakefulness to document night-awakenings. Younger children may be quietly awake or have interrupted sleep, but if the child does not signal, then the parents are less likely to report these events (Sadeh, 1994, 1996; Sadeh, Raviv, & Gruber, 2000; Tikotzky & Sadeh, 2001). Similarly, parents may not be aware of older children’s night awakenings if the child does not seek parental attention. Since most logs must be completed over a period of weeks to months, parental compliance tends to drop over the assessment period (Sadeh, 1994).

2.2.7. Treatment for paediatric sleep problems

The Canadian Sleep Society recommends treating paediatric sleep problems using a staged-care model. At stage one parents are provided with accurate information about healthy sleep: the causes of insomnia; potential signs of sleep problems; the consequences of poor sleep; realistic sleep expectations; modifiable sleep scheduling; and, the factors that promote and affect sleep. In stage two, parents learn about sleep hygiene, or practices that promote good sleep, and how daytime practices affect sleep.
Stage three provides parents with specific behavioural strategies, which may include extinction, graduated extinction and/or positive routines/faded bedtime with response cost (see Mindell et al., 2006). If these strategies are unsuccessful, healthcare providers may move on to stage four, and consider the use of medication. This is option is a last resort, and considered only after consult with a specialist (Weiss, Driver, Bastion, Samuels, & Fogel, 2012).

Allen, Howlett, Coulombe, and Corkum developed the ABC’s of Sleeping mnemonic to capture the “constructs and practices that are commonly targeted by recommendations aimed at promoting healthy sleep”: 1) age appropriate bedtimes and wake time with consistency; 2) schedules and routines; 3) location; 4) exercise and diet; 5) no electronics in the bedroom before bed; 6) positivity; 7) independence; 8) needs of the child met during the day; equals great sleep (2015, p.2). In a meta-analysis of the empirical evidence of sleep-management practices for children ages 0-12 years they found “preliminary support” for practices consistent with the ABC principles.

2.3. Barriers to treatment of paediatric sleep problems

Despite widespread awareness of the importance of sleep in children, and a range of research-based interventions, paediatric sleep problems continue to be pervasive in Canadian children and adolescents (Mindell & Owens, 2015). Many researchers have recognized the need for further research (see Mindell & Owens, 2003; Owens, 2001), as the barriers to paediatric sleep-care are not well understood, and available research does not explicitly represent parents’ perspectives; A cross-disciplinary search of the literature (using CINHAL, PsycInfo and Medline), resulted in only one article describing healthcare providers’ perspectives on barriers to paediatric sleep-care (Boerner, Coulombe & Corkum, 2015a discussed below). To my knowledge, research has yet to specifically reflect on parents’ perspectives on paediatric sleep-care management.

2.3.1. BC healthcare providers’ experience

Boerner, Coulombe and, Corkum (2015a) surveyed Canadian healthcare providers about their perceptions of the barriers to treating paediatric sleep problems. As a group, healthcare providers identified barriers in nine domains: 1) lack of knowledge,
skills, techniques, training or education; 2) lack of resources and materials; 3) lack of
time; 4) institutional/systems-level/practice setting barriers; 5) lack of access to sleep
specialist/sleep services; 6) barriers related to parents, mismatch between parent and
health provider or setting; 7) barriers related to individual practice and professional
orientation; 8) lack of clinical or personal experience managing sleep; and, 9) other
issues (non-specified).

The barriers described in the literature have been anecdotally endorsed by BC
healthcare providers. In November 2015, I set up a booth representing the Children’s'
Sleep Network at the BC Paediatric Children’s Health Today conference. As part of a
project to understand professionals’ continuing education needs, I surveyed
paediatricians about the barriers they experienced managing sleep issues. As a group,
they endorsed all the concerns described by Boerner, et al. (2015a). The following
month, in December 2015, I hosted “Sleepy Rounds.” The meeting was a healthcare
provider community forum designed to explore and problem-solve around the needs
presented by the participants in the Functional Sleep-/Wake Assessment Evaluation.
The healthcare providers attending this session, which included paediatricians, family
physicians, clinical counsellors, child-development workers and pharmacists, shared
similar training, practice and systems-level concerns.

In these conservations, healthcare providers also described a sense of “feeling
stuck.” They were confused and frustrated by parents’ non-compliance with their
treatment recommendations. Boerner, et al. (2015a) refer to these experiences broadly
as “barriers related to parents or mismatch between parent and health provider setting.”
In their survey, 22.6% of physicians reported parental beliefs, cognitions, expectation,
resistance, and/or lack of implementation of suggested strategies as a barrier to sleep
treatment. Regardless of parental factors being recognized as a barrier, we know very
little about the processes that result in non-compliance behaviour, or the meaning
compliance behaviours hold for parents.

2.4. Parental adherence

Treatment adherence (also called compliance) refers to the degree to which a
patient follows medical advice. Non-adherence describes avoidant or resistant
behaviours which prevent individuals from accepting, engaging in, and maintaining
medical treatment recommendations. The topic of treatment adherence is extensively researched, and a great deal is understood about patients’ experiences of treatment protocols for other chronic health conditions, such as hypertension and diabetes; however, we know comparatively little about paediatric sleep-care.

Compliance and adherence are used interchangeably in the sleep literature. Medical ethicists advocate against using the terms synonymously, suggesting that compliance “connotes a paternalistic relationship between the physician and patient and that the noncompliant patient performs deviant behavior or exhibits weakness of character.” (Miller, Hays, 2000, p.177). Alternatively, adherence “better represents the more complex web among patient, provider, and [treatment] and reflects the fact that following a [treatment] regimen is not necessarily a simple choice (Miller, Hays, 2000, p.177).

The paediatric sleep literature generally treats parents’ behaviour as non-compliant, attributing intervention failures to parent’s ineffectual limit setting (Mindell & Owens, 2015). Mindell and Meltzer describe the initial phase of behavioural treatment as “generally intense,” and report that many parents find the “strict adherence” to the treatment protocol challenging (2008, p.276). As early as 1990, Durand and Mindell suggested that further research was required to understand the processes underlying non-compliance, hypothesizing that poor limit setting may be influenced by factors such as maternal depression and marital stress. Since that time, Allen, et al. (2015) have described the influence of relational and other non-specified “contextual” factors, such as maternal mental health, the emotional environment of the home and the parents’ ability to meet their child’s emotional needs; but, as of yet, researchers have not described how these factors shape parents’ adherence to sleep interventions.

2.4.1. Parents’ perspectives of sleep-care management

Our understanding of parents’ perspectives on adherence is extremely limited. Tse and Hall (2007) described the barriers reported by parents implementing psychoeducation-based sleep intervention strategies for typically developing infants aged 6-12 months. These parents described difficulty persevering with new strategies or adhering to new routines; how other caregivers under-mined the intervention; and, concerns about neighbours hearing their child’s crying. Beresford, Stuttard, Clarke, and
Madison (2015) reported similar concerns from parents of school-aged children with neurodevelopmental disabilities participating in a supported behavioural intervention. Parents in this group described factors that helped and hindered their ability to implement the sleep intervention. Parents identified the following as facilitating their ability to implement the intervention: 1) affirmation of their existing knowledge and behaviour; 2) awareness that other families have sleep problems; 3) increased understanding of sleep and specific management, and how sleep problems relate to their child’s health conditions; and, 4) receiving on-going support to persevere and maintain changes in behaviour. In contrast, parents reported barriers related to: 1) inadequacies in the educational element of the sleep management intervention; 2) impairment and disability factors (periods of ill health; comorbid and challenging behaviours); 3) the demands the intervention placed on the parents/caregiver (difficulties changing or sustaining new sleep management strategies, the importance of consistency across caregivers); and, 4) externally imposed disruptions or barriers (changes and disruptions in usual routines, the home environment).

Blunden and Bails (2016) are the first researchers to seek out parents’ opinion and attitudes about their “view and limitations” implementing behavioural sleep recommendations for their preschool aged children (p.8). Parents reported how extinction methods (crying it out and controlled crying) were incompatible with their parenting style. Parents in this study also reflected on how their “choices and preferences had been at the least undervalued and at worst judged as ‘wrong’ by healthcare providers” (2016, p.8). Furthermore, consistent with McKenna and Gettler’s (2008) findings, parents describe a lack of “sufficient emotional support” during the intervention, which may have been particularly helpful to “maintain compliance” (2016, p.8).

2.4.2. Emotional and relational barriers affecting parental adherence

There is a robust literature linking infant sleep with maternal mental health. Interventions specifically focus on improving mother’s wellbeing, with the belief that improving the quality of the mother-child attachment relationship and mother’s sense of competency will create the emotional conditions required for healthy sleep to develop (see Appendix B, Study protocol) (Adam & Snell; 2007; Bates, Viken, Alexander, Beyers, & Stockton, 2002; Bernier, Belanger, Bordeleau, & Carrier, 2012, 2013; Byars,
Yeomans-Maldonado, & Noll, 2011; Hall, Zubrick, Silburn, Parsons, & Kurinczck, 2007; Martin, Barajas, Brooks-Gunn, & Hale, 2011; Minde, Popiel, Leos, Falkner, Parker, & Handley-Derry, 1993; Reid, Hong, & Wade, 2009; Rosen, Kirchner, & Redline, 2005; Spilsbury, Storfer-Isser, Drotar, Rhoades, Leve, Harold, Mannering, Neiderhiser, & Shaw, 2012). The focus on emotional and relational factors disappears from the conversation as children enter school age. At this point, the literature reframes the issue as a problem of limit setting and discussions about mothers’ experience of the problem or meaning it holds for them is displaced with behavioural models. There is however a movement to introduce relational considerations into research on older children. Beresford et al.’s (2016) description of parent’s lack of self-efficacy and relationship distress and guilt points to the need to extend our understanding of the role of attachment into the school-aged years. Likewise, Blunden and Bails’ (2016) pilot study opens questions about the impact of parenting style preferences, shame and lack of support.

2.5. The need for further research

Despite being identified as a need more nearly thirty years ago, research has not addressed the barriers to paediatric sleep-care. With high prevalence rates, and a growing understanding of the impact on child development and family functioning, there is clear need to understand how to most effectively provide sleep-care to Canadian children. The literature is heavily weighted toward our clinical understanding of sleep and treatment protocols. Physicians face a translational research issue, in that we do not know what real-life barriers families face managing their child’s sleep.

Since I undertook my first review of the literature, the sleep-research community has taken the first steps to understand parents’ perspectives. These studies offer novel insights into parents’ experiences of adherence. Like the mothers in the Functional Sleep-/Wake Evaluation, these studies are a critical starting point for understanding the relational and emotional processes that shape parents’ choices about adherence behaviours. As clinical treatment-evaluations these studies have two significant limitations: a) they address parents who have already accessed sleep assessment services; and, b) they are limited to parents participating in clinical interventions supported by clinicians. Insofar, this research provides important, albeit atypical and narrow perspective of parents’ experiences of adherence.
By presenting mothers’ perspective, this study addresses substantive gaps in the sleep-literature. This study aimed to describe real life experience of families accessing sleep care services in British Columbia, with the purpose of describing the processes that inform parental non-adherence.
Chapter 3. Methodology

This chapter presents an overview of the methodology used in the present research, including the selection of grounded theory as a research method. This is followed by a description of the research site and participants. I then address the construction of the interview protocol and procedures, and coding process. The chapter finishes with an outline of the criteria used in order to ensure both the rigor and quality of the research project.

3.1. Grounded theory methodology

The current understanding of paediatric sleep management is primarily informed by quantitative research. By design, these methods control extraneous variables to create an extremely narrow, but clear view of the problem. In my experience, sleep problems are messy. My choices about methodology were informed by this experience. Understanding mothers’ adherence behaviours calls for a research method that is able to capture the complexity of what is going on behind those adherence behaviours (Charmaz, 1990; Foley & Timonen, 2015; Glaser & Strauss, 1967). Grounded theory research seeks to explain novel, poorly understood patterns of human behaviour and social processes, to build a new theory or adjust a theory that has been shown to be in deficit (Glasser & Strauss, 1967; Hurley, 1999 in Foley & Timonen, 2015, p. 2).

3.2. Positioning myself as a grounded theory researcher

Glaser and Strauss (1967) initially said the Researcher “discovers” theory; more recently Charmaz (1990) has argued that in fact we “construct” theory. I align myself with a constructivist position. I am not neutral-- the very selection of this topic comes from a profound and painful personal experience; and it could be said that my previous work on the topic creates a priori biases. As a researcher, the way I approach the data, and the methodological choices I make are inextricably tied to my experience and perspective. I do not see this as a liability. Instead, I consider my status as an insider as an asset to the study, allowing me to serve as a cultural translator between lived experience and clinical knowledge. Based on my previous work in the sleep community, I expected that my study would broach sensitive topics for participants. A grounded theory approach
allowed participants to invite me into their experience. The fact that grounded theory has been successfully used in other healthcare research to access hard to reach and vulnerable populations provided me with further confidence that it would be a good fit (Foley & Timonen, 2015). I believed being transparent about my insider status would help create emotional safety for the participants, granting me privileged access to their private perspectives (see Glaser & Strauss, 1967; Hoare, Mills, & Francis, 2012).

3.2.1. Fostering change and social justice

I took on this research project with a commitment to represent parents’ voices in sleep research, with the goal of effecting change for other families. Grounded theory methodology provided a platform to achieve this goal. Thus far, sleep-care research has marginalized parent’s views in favour of expert and authoritative voices (Nagy Hesse-Bieber & Piatelli, 2012). This void creates a view of non-adherent mothers as “deviant” and “weak” (Miller & Hays, 2000, p.177). I believed that my research should open a space for mothers’ living knowledge, and present their perspectives in a way that would be accepted as legitimate by a diverse audience (see Wicks, Reason & Bradbury, 2008; Williams & Keady, 2012).

Thus, as a researcher, I was faced with the task of selecting a qualitative method that would be consistent with the medical community’s epistemological positivist orientation. Grounded theory provided a bridge between positivist clinical research and participant’s lived experience (Nagy Hesse-Biber & Piatelli, 2011). Because the grounded theory approach uses a larger number of participants, and employs structured procedures for data analysis, it is generally seen as the qualitative approach that allows for the greatest degree of transferability to other contexts (see Charmaz, 1990; Lincoln & Guba, 1985). Grounded theory has been widely adopted in healthcare research, particularly nursing (Pawluch & Neiterman, 2010); in fact, some of Charmaz’s (1990) ground-breaking methods were developed understanding patient’s experiences of chronic illness. Today, grounded theory is extensively used to understand a variety of health experiences, including “barriers and facilitators” of behavioural healthcare management programs (see Mills et al., 2006; Pagoto et al., 2007; Ogedegbe et al., 2005).
3.2.2. Researcher characteristics and expertise

Grounded theory is well-suited to me as a Researcher. With a background in medical anthropology, and extensive experience interviewing patients, I felt well-prepared to use this qualitative approach. My training as a counsellor also prepared me to be attuned to participants’ lived experience, and look for shared themes.

3.3. Planning the study

3.3.1. Obtaining ethics approval

Approval for this project was obtained from the Simon Fraser University Research Ethics Board (REB), and Thompson River’s University’s REB on behalf of the Kamloops Paediatric Sleep Clinic. Copies of the study protocol, and ethics approval documents are included in Appendices B-E. Research was conducted with oversight from the Mr. Les Matthews, Associate Professor with the Respiratory Therapy Program.

3.3.2. Developing the interview protocol

Development of the interview protocol was informed by my previous experience working on the Functional Sleep-/Wake Assessment Evaluation project; an informal survey of BC Paediatricians at the Sleepy Rounds Healthcare forum; a review of guides to conducting grounded theory research (e.g. Charmaz, 1990; Cobrin & Strauss, 2008; Creswell, 2007; Glaser & Strauss, 1967); discussions with my senior research supervisor; as well as through the initial review of the literature. In particular, I was instructed by Boerner, Coulombe, and Corkum’s “Barriers and Facilitators of Evidence-Based Practice in Paediatric Behavioral Sleep Care: Qualitative Analysis of the Perspectives of Health Professionals” (2015). To ensure that the findings would be useful, I consulted with healthcare partners specializing in paediatric sleep problems (see Appendix A, Mentorship and Consultation Team).
3.3.3. Identifying the site for study

**Kamloops paediatric sleep clinic**

Participants were recruited from the Kamloops Paediatric Sleep Clinic at Thompson Rivers University (TRU). The clinic is a partnership between the Respiratory Therapy Program and a local paediatrician specializing in sleep. Opened in March 2016, the clinic grass-roots project that developed in response provided through the the Functional Sleep-Wake Assessment project. It is housed in Thompson River University’s Respiratory Health and Sleep Science Centre. The clinic offers assessment, treatment and case management services for children with sleep problems. The program is the only service in the province offering community-based, interdisciplinary sleep-care. Children are referred to the clinic by their family physician or general practitioner, and receive care from a paediatrician and team of respiratory therapy students. Unlike tertiary level care options, the Kamloops Sleep Clinic does not require the child to have a specific neurological diagnosis or evidence of medical pathology to access care. Physician services are covered through British Columbia’s Medical Service Plan (MSP), and TRU provides administrative and clinical support under the umbrella of the respiratory therapy teaching program.

The Kamloops Paediatric Sleep Clinic offered several advantages as a research site. As a group, Kamloops physicians report low levels of confidence managing paediatric sleep problems (see Boerner et al., 2015a). Healthcare providers reported a sense of professional vulnerability opening up about their challenges and feelings of inadequacy managing children’s sleep problems. I have established myself as a credible and trustworthy partner in the Kamloops community, and have effectively facilitated meaningful change for families and healthcare practitioners. I expected that this insider status created a sense of safety for physicians and families.

**The region**

Kamloops is a city in south central British Columbia, Canada. It is the largest community in the Thompson-Nicola Regional District, and part of the Interior Health Authority. The surrounding region is commonly referred to as the “Thompson Country.” With 85,678 residents, Kamloops is ranked 37th on the list of Canada’s 100 largest metropolitan areas (Kamloops, n.d.). Kamloops is ideally suited for investigating the
individual and contextual factors affecting sleep care. As a mid-sized city, Kamloops provided an opportunity to investigate how sleep is managed in urban and rural healthcare settings and diverse family situations.

**Healthcare system**

In preparation for this research, I set up a booth at the Children’s Health Today paediatrics conference in October 2015 to survey paediatricians about their sleep-care practice needs. BC paediatricians endorsed previous findings, and agreed that they lacked adequate time in their practice or skills and clinical knowledge to effectively manage children’s sleep problems. Urban and rural paediatricians reported differences in their level of confidence managing sleep problems. Whereas urban physicians preferred to refer or consult with specialists, rural physicians were more likely to request training to manage the issue within their own practice. This information suggests that sleep-care is managed differently in urban and rural locations. Whereas urban family’s may receive assessment and care for a sleep issue from multiple care providers, rural physicians appear more likely to act independently. Kamloops is the region’s healthcare hub, and provides services to both urban and rural families. I expected sampling a mix of urban and rural families would allow me to understand how systems, practice and access factors may affect mother’s experience.

**Population characteristics**

The population of Kamloops has a broad cross-section of families from different socio-economic and cultural backgrounds, including a large First Nations population. Previous research has linked non-adherence with parents’ individual characteristics (e.g. parental mental health, socio-economic status, education level). My aim was to move away from the individual family, to describe a larger phenomenon (Glasser & Struass, 1967; 1999). To do so, I sought a sample that represented family’s diverse experience. Ultimately, I hoped that sampling from this population would result in a richer and more ecologically valid model that could inform programs and services.

**3.4. Recruiting the participants**

All families attending the Sleep Clinic were invited in-person or by phone to participate in the study. The majority of participants were invited to participate by the
I also made two trips to the research site and spoke to four families in-person. Prospective participants were provided with a brief overview of the study, and if they expressed interest, were given a study package (containing a letter of invitation, informed consent document, and a small portfolio of articles detailing my family’s experience with paediatric sleep problems and my related advocacy work). I hoped that personalizing the invitation would make families feel more connected to the study and comfortable with me as a Researcher. Participation in this study was completely voluntary; families received the same level of care from the Kamloops Paediatric Sleep Clinic regardless whether they chose to participate in the study. A copy of the recruitment materials is included in Appendix C, Participant invitation portfolio.

In grounded theory research, the findings from early interviews often guide the Researcher to select specific kinds of participants. My study originally sought to explore the experience of parents however, on reading the early interviews I realized that the experiences of mothers and fathers were quite different. Rather than “forcing” the data, and risk diluting participants’ experience, I made the decision to revise the scope of my research and focus exclusively on mothers (Charmaz, 1990; Corbin & Strauss, 2008; Glaser & Strauss, 1967, 1998; Hoare et al., 2012).

3.4.1. Obtaining consent

Participants reviewed and signed a copy of the Informed Consent document; in cases where the recruitment happened by phone, the TRU clinic staff used a verbal protocol. Both protocols are included in Appendix E (Participant consent) and C (Participant invitation portfolio) respectively. Contact information for the study team was included in the document, and participants were invited to contact the Researcher for more information about the study prior to making their decision. The Clinic team emailed an electronic copy of the signed Informed Consent document to me. This email was password protected, and the original document was stored in a locked filing cabinet at the clinic; the signed consent documents were collected at the end of the study. Once I received the Informed Consent, I contacted participants by phone and/or email, and answered any questions they had.
3.4.2. Potential risks and benefits of participation

The risks associated with participating in the study were identified as minimal. In my experience, mothers have found relief speaking about their experience however, it was possible that some participants could be triggered by the experience. Families participating in the study were in the care of a family physician and paediatrician, who monitored their functioning, and if necessary provided appropriate support and referrals for distress. As a precautionary measure, I included information for local crisis services in my informed consent document.

The study design offered participants confidentiality, however, as a mid-sized city, there was the chance that individuals could potentially be identified based on descriptions I provide. All participants were provided with a draft copy of their interview and invited to edit details. I also asked participants to consent to the final version of the document. Participants were given the option of withdrawing their consent at any time. Through this collaborative process, I hoped that participants will felt free to share according to their own comfort level.

The Kamloops Paediatric Sleep Clinic is operated by a small group of staff, led by one local paediatrician. I offered them confidentiality in the report, but one could easily identify them if they so desired. We had a conversation about the personal and professional risks, and they were comfortable participating. They were also aware they could withdraw their consent to participate at any time.

3.4.3. Data generation and collection

Concurrent data collection and constant comparison using codes and categories are essential features that differentiate grounded theory from other qualitative methods (Birks & Mills, 2015, p. 90). Through a systematic process of inductive and abductive thought, the grounded theory Researcher moves low level concepts into medium and finally high-level concepts that result in a theoretical explanation of the phenomenon under study (Birks & Mills, 2015). I followed the methods outlined by Bryant and Charmaz (2007): initial coding and categorization of data, concurrent data collection and analysis; writing memos to articulate my developing theoretical observations, theoretical
sampling, constant comparative analysis, identifying the core category, advanced coding, and theoretical integration.

3.4.4. The interview protocol

The interview protocol was developed in consultation with my clinical collaboration partners (listed in Appendix A, Mentorship and Consultation Team). Boerner et al’s (2015) dephi study, and experience working with the BC Paediatric Society guided me inquire about issues related to the medical system and physician’s preparation to manage paediatric sleep problems. I also relied on my experience working as an advocate in the sleep community to direct my questions about mother’s experience in the context of the family. The open-ended questions were designed to invite mothers to reflect on their experience managing their child’s sleep across time and in different contexts. A copy of the sample interview questions is included in Appendix F.

Because of the geographic distance between myself and the participants, interviews were conducted by phone. The interviews typically lasted about one-hour, although some were much longer or shorter. The participant’s interviews were audio recorded and I transcribed the recordings to closely reflect the spoken conversation. I chose to include false starts and disfluencies, which helped me to see connections and patterns in participants’ experience. After the interview was complete, a copy of the transcript was emailed to the participants for their review and consent.

3.4.5. Purposive Sampling

From a theoretical perspective, sleep is a learned behaviour that is co-regulated within the mother-child relationship. Regardless of the age, all evidence-based sleep care recommendations involve some parental involvement and oversight to be successful.

For the purposes of this study, the term “Mother” was understood broadly as referring to a child’s primary female-caregiver. Additionally, based on observations made about families attending the Sleep-/Wake Behaviours Clinic, I was aware that a disproportionate percentage of children with sleep problems may be living in non-
traditional family arrangement (e.g. with grandmothers). So as not to overlook these families, I included non-biological mothers.

**Mother-reported sleep problem**

To accommodate diagnostic issues and differences in cultural norms and attitudes towards children’s sleep, many clinicians prefer to regard sleep problems as clinically significant when the issue affects the family’s wellbeing to the point where they have sought medical advice from a healthcare provider (Sadeh et al., 2011). Therefore, for the purposes of this study, I adopted the broad definition, and considered “parent-reported sleep problems.”

Limiting the sample to mothers seeking help from a physician contextualizes the problem within the healthcare system, and links mothers’ experience directly to other known barriers. By situating the data within one shared experience—contact with the physician—I believed common patterns may be easier to locate. Additionally, Sadeh et al. (2011) have suggested that using help seeking behaviours as a measure of perceived distress may overcome differences in cultural perceptions of sleep problems.

**Medical status**

There is considerable controversy in the literature about the relationship between neuro-developmental disabilities and sleep, and debate about whether missed/undiagnosed sleep problems may be frequently mistaken and treated as psychiatric conditions (Ipsiroglu, 2008). To manage this controversy, most studies exclude children with neuro-developmental disabilities and/or who are taking psychotropic medications (e.g. CIHR’s Better Days, Better Nights, Better Days). However, the purpose of this study was not to differentiate between diagnostic categories or investigate the effects of medication on sleep. As a grounded theorist, I was concerned with thickening our understanding of sleep problems, and believe that this could be best accomplished by identifying shared experiences and needs. Hence, I invited all families, regardless of their child’s medical status to participate.

**3.4.6. Initial coding and categorization of data**

I recorded the interviews on my personal IPad. During the interviews, I took detailed notes, and later transcribed them myself. The labour-intensive transcription
process allowed me to attend to the participant’s tone of voice, pacing, silences, laughter and sighs (Artinian, Giske, & Cone, 2009). These types of data provide important context for discerning the meaning of participant’s words. I then read the transcripts “moving swiftly [through] to open up the data by identifying conceptual possibilities” (Birks & Mills, 2015, p.92). Next, I re-read the transcripts, first studying individual words, then lines, and finally segments.

As I did this, I asked myself: What is actually happening in the data? What is the main concern being faced by the participant? What accounts for the continuing resolving of this concern? (Strauss & Corbin, 1998, p. 148; also see Charmaz, 2014; Corbin & Strauss, 2008; Glaser & Strauss, 1967). My experience coding was far from easy and fluid. Like Laurie Goldsmith reported, my coding experience “demanded time, anguish and mental gymnastics” and I tried out a few storylines before I found one that fit (Goldsmith in Birks and Mills, 2015, p.117). The coding process took place over nine-months, in three intensive phases.

Through this process, I identified key segments of data and wrote them on separate cue cards, which I then sorted into 53 initial code categories and placed in manila envelopes. Wherever possible I used participant’s in vivo language as codes.

Even at this early stage, it was evident that participants were describing the same systemic barriers identified by previous Researchers. However, I was struck by the additional dimensions of time, context and, relationship. There was a recursive quality to the stories. Even though my focus was on their current experience in the healthcare setting, participants focused on their experiences prior to and outside of the present sleep intervention. Moreover, they described how the sleep problem existed in multiple contexts: the family, community and, society. Even with gentle guidance, participants consistently re-directed the conversation. It was as if they were trying to describe their story’s prologue. More than the frustrating systemic barriers that prevented them from accessing supports and services, participants wanted to talk about the relational dimension of sleep problems. Participants’ stories were live with emotion, and regularly punctuated with laughter and tears. This intense emotionality brought to life sanitized clinical descriptions represented in existing research. Although their decision-making process remained unclear, it was evident that understanding the source and meaning of participants’ emotions was necessary.
3.4.7. Memo writing

Grounded theorists use memoing to develop written records of their thinking during the research process. Memo writing is an ongoing activity, starting from the very early stages of planning a study through to its completion. This continual process helps the Researcher raise the data to a conceptual level and develop the properties of each category, and eventual the integrated theory itself.

I used a variety of strategies for memoing. Initially, I was quite prescriptive about my memoing process, writing my thoughts in my research journal. I found this process frustrating and inconvenient, since most of my insights happened in relation to my clinical work or just as I went about my daily life. I quickly switched to recording my memos on my phone, and later using voice recognition software to transcribe them.

As a Researcher, I was “acutely aware that my objectiveness and perspective could be skewed as a result of existing prejudice and bias derived from a pre-understanding borne from my own previous experience and personal insights of the phenomena in question” (Hinton in Birks & Mills, 2015, p.92). Thus, during this phase I was mindful to participate in reflexive practices (Glaser, 1978): I completed a nine-month supervised clinical counselling practicum working with families; participated in a structured sleep intervention as a parent through BC Children’s Hospital; and, continued to actively collaborate with professionals in the sleep community. These experiences provided me with opportunities to reflect deeply about the data and my emerging interpretation of them (Saldona, 2013 in Birks & Mills, 2015).

3.4.8. Constant comparative analysis and theoretical sampling

Theoretical sensitivity

I started data collection in the summer of 2016, an in the interim completed a counselling practicum working with families from a trauma informed attachment model. As part of this learning experience, I engaged in training, read extensively and clinically observed how mothers and fathers are differentially affected by parenting role issues; issues of selfhood; and, how attachment related trauma manifests. As part of my own growth and clinical supervision experience, I was exploring my own experience of shame.
(heavily influenced by Brene Brown, 2008). I had not planned the study this way, but in the end, a prolonged data gathering phase added a depth and richness to my analysis: my clinical experiences; exposure to a diverse literature, and intensive and structured reflexivity sensitized me to emergent themes and core concerns that I otherwise may have overlooked.

The decision to focus my study on mother’s experiences came nine-months into the project. At this point, I had interviewed three fathers and three mothers. As I reviewed the transcripts, I noticed different themes and concerns between the two groups. Specifically, mothers described more attachment-related distress and their narratives reflected themes which I believed may be related to cultural discourses around mothering specifically.

**Attachment-related distress**

Mother’s narratives focused on attachment and relationship related themes. Whereas, fathers described similar themes, they were not central to their experience, nor did they describe the same level of emotional activation or distress related to the sleep problem. Although behavioural models do not differentiate between caregivers, my previous experience and early literature review sensitized me to the importance of attachment, and its relationship to self-efficacy and mental health, making me wonder about the continuing effect on treatment compliance.

**Cultural discourses**

Unlike fathers, who focused primarily on issues of access to services, mothers seemed to be negotiating multiple and competing cultural discourses around ‘motherhood,’ ‘autonomy,’ and ‘care-taking ethic.’ To understand and represent their experience I needed to examine how mother’s everyday lives and experiences are organized by social processes, and I felt that this was best accomplished with a feminist lens (Nagy Hesse-Biber & Piatelli, 2011). That is not to say that fathers are not affected by these cultural and societal factors, but to keep my project manageable, I decided to avoid “abstract wonderment” and focus exclusively on mothers (Glaser, 1992, p.22, in Birk & Mills, 2015, p. 21).
**Pragmatism**

Even though my recruitment was open to all parents, mothers were the ones responding to my study invitation. I confirmed with the TRU Sleep Clinic staff that proportionately more mothers are the attending appointments with their children. This demographic trend made me consider the ways gender roles may at work in sleep-care.

### 3.4.9. Focused coding

Focused coding was the second major stage of data analysis. After breaking apart the data, I focused on developing thematic categories. I did this by linking sub-categories and developing a range of properties and dimensions (Birks & Mills, 2015, p.12). Through this process, I identified 53 categories.

In the interviews, mothers identified with societal tropes, such as the “mombie,” as reference points for their experience. I scanned social media to identify memes that seemed to capture the themes and concerns described by mothers, and used these to cluster categories into four categories: *Have Enough; Safe Enough; Powerful Enough, and Good Enough.*

In May 2017, I travelled to Kamloops. As part of this trip, I consulted with clinicians at the Child Development Centre (a referral source for the sleep clinic), and participated in a sleep support group for parents put on by the centre. Although this session was not formally considered a focus group (the impromptu session did not provide time for ethics approval), it was an excellent opportunity to reflect on my emerging theory. Parents attending this group were at various stages in their sleep management journey. Some were just questioning whether there was a problem whereas, others were already engaged in treatment. These conversations helped me to recognize sleep management as a developmental experience. At this point, I was focused on mother’s experience, but this was the first time that I had the opportunity to see couple’s shared perspective. These observations confirmed my belief that mothers were differentially affected by cultural messages and gender role demands.
3.4.10. **Identifying a core category**

In grounded theory, the core category encapsulates and explains the grounded theory as a whole (Birks & Mills, 2015). At this point in my research, I was participating in a sleep-intervention for my own child through BC Children’s Hospital. Like the mothers in the study, I was irresolute about enacting the recommended interventions, despite pursuing specialist intervention over a number of years, and having high motivation for improving my child’s sleep situation. This parallel process helped me to identify the experience of *ambivalence* in mother’s stories.

3.4.11. **Advanced coding and theoretical integration**

Advanced coding is the final step toward theoretical integration. Charmaz describes it as moving the “analytic story in a theoretical direction” (2014, p. 150). There is considerable debate in the grounded theory community if theoretical coding is necessary. Charmaz (2014) asserts that it is not necessary for most projects, but agrees with Glaser and Holton (2013) that the theory will “appear more plausible, more relevant, and more enhanced when modeled by an emergent [theoretical code] (p.3).

Entering the theoretical coding phase, I believed I had a coherent theory, but wanted to shape it in a way that linked it to the extant literature, and provided a felt sense of the participant’s lived experience. By translating my theory into what Strauss and Corbin refer to as (1990, p.116) a *storyline*, I hoped to create a coherent analysis of the theory, that was also digestible to the reader (Birks & Mills, 2015, p. 115; also see Charmaz & Mitchell, 2001).

As engaged in this process, I watched for variation, or instances when an individual participant’s storyline did not match, which Morse (2007) calls *negative cases*. Rather than disregard these inconsistent narratives, they added depth and dimension to the story, and pressed me to find other places where there were still gaps (Corbin & Strauss, 2008).

I experimented with participant’s metaphors, eventually settling on *survival mode*. The phrase survival mode had been used by several participants and embodied the core experience of ambivalence. By definition, the term survival refers to the state of continuing to live in spite of difficult circumstances. Mothers were explaining how their
mothering, relationships, wellbeing and sense of self were strained by the circumstances of the sleep problem. This experience created a deep sense of sorrow and a despair, that was in tension with their committed to their child. The idea of Survival suggests a protracted experience, which helped me describe how feelings of ambivalence developed over time. Finally, Mode captures how mothers learned to cope with ways of being, which eventually became their version of normal.

3.4.12. Participant Profiles

In total, I interviewed ten parents (4 fathers and 6 mothers) but analyzed only the interviews with mothers. All 6 mothers lived in Kamloops or one of the rural communities in the regional district, and were parenting with a male partner. At the time of the interview, all of had met with the sleep clinic at least once for an assessment and, were in the process of implementing sleep-care recommendations.

Penelope

Penelope has two children, a son Oliver, age 4 1/2 and Charlotte, age 3. She parents with her husband, Liam. Oliver had a serious illness as an infant, requiring lengthy hospital stays and on-going therapeutic treatments. Penelope first became aware of Charlotte’s sleep problems when she turned two, but feels that they may have been present earlier, but she had been overwhelmed by Oliver’s health needs. Both children have an Autism diagnosis, and Charlotte also has been diagnosed with global developmental delay. Penelope is a stay-at-home mother. Her days are filled with multiple behavioural and medical appointments. Her biggest concern is Charlotte’s inability to get to sleep independently and stay asleep; most nights Penelope sleeps on a mattress on the children’s bedroom floor.

Rose

Rose is the mother of eight children. Her youngest, Joel, 3 1/2, has always had difficulty sleeping. Two of her seven older children have a diagnosis of Autism Spectrum Disorder (her older son is moderately affected and her daughter is non-verbal and has global developmental delays). Joel was also being assessed for developmental delay. The family recently relocated from Alberta, and Rose spends a great deal of time coordinating assessment and treatment services for her three children. Rose does not
currently work outside the home, but in the past, was very involved supporting the church community. She home-schools her children. Rose is concerned with Joel’s inability to fall asleep independently, frequent nighttime awakenings, and challenging daytime behaviours.

Anna

Anna has two sons, Charlie, 6 years-old and Nathan, 3 1/2 years old. She describes Charlie as having always been a restless sleeper and snoring as an infant. She works 3/4 time as a nurse. Her husband is currently starting up his own business, which means long and unpredictable hours. When Anna is at work, her in-laws help with child care. Charlie attends a mainstream school. Charlie does not have any neurodevelopment diagnosis however, his impulsivity, aggression and inattention are challenging to manage. Anna’s biggest concern is Charlie’s difficulty falling asleep, early waking and challenging daytime behaviour.

Lilly

Lilly is raising her grandson, 10-year-old Tyler, with her husband, Rex. Tyler has a dual diagnosis of ADHD-Autism; as well as significant sensory difficulties and anxiety. Tyler slept well as an infant, but since a disturbing incident when he was 4 years-old, has had difficulty sleeping independently. Tyler continues to be very anxious at night, and is highly sensitive to noises in his environment. Most nights, Tyler sleeps with Lily. Lilly and Rex started their family in their early 20’s. Lilly was the primary caregiver then however, Rex has recently retired, and they now share the caregiving responsibilities for Tyler. In addition to parenting, she is also the primary care-giver to her aging parents, and is an active grandmother to her other grandchildren. Tyler attends an alternative school program, and participates in an intensive behavioural intervention, occupational and speech therapy program. Lilly’s primary concern is understanding and treating the underlying sleep problem as she believes Tyler’s daytime behaviour and ability to benefit from behavioural interventions is directly linked to his sleep. Lilly is primarily concerned with understanding and treating conditions underlying the sleep problem.

Juliet

Juliet has four children; her 15-year-old son, Chase is the second child. Juliet describes Chase as always having sleep problems; she noticed since infancy that he
flailed around and snored. As he became older, he was lethargic, irritable and was prone to gaining weight, which interfered with his ability to participate in sports. Juliet feels that these symptoms are directly related to a sleep-breathing condition. Because of bullying problems at school, Juliet chose to home-school Chase for a year in grade seven, but he now attends a mainstream high-school. Juliet is currently being assessed for a sleep problem herself. Juliet works full-time outside of the home as a manager at a medical clinic in a rural community. Juliet is employing recommendations made by the sleep clinic.

**Iris**

Iris has two children, 7-year-old Sydney, and 14-year-old Riley. Iris conceived Sydney when she was peri-menopausal, and identifies as a "geriatric mother." As a "preemie" baby, Sydney was treated for sleep apnea in the NICU, and according to Iris, continued to suffer from sleep-breathing difficulties since then. Sydney had her first seizure just after her third birthday; her recovery included a lengthy hospital stay. Iris believes Sydney’s sleep problems are directly related to her epilepsy; she also strongly believes there is a disordered breathing component, and advocated to have Sydney’s adenoids and tonsils removed. Iris is a hairdresser who works from home. Iris believes that Sydney’s anxiety, seizures and chronic fatigue are a result of her sleep problem. She attended the clinic once, and has not completed the paperwork for a sleep apnea referral.

**3.4.13. Evaluation of the grounded theory**

Charmaz (2014) identifies four criteria for evaluating the quality of a grounded theory. The credibility of this study comes from the logic and conceptual grounding in the data. The originality of the model support and expand on our current understanding of the management of paediatric sleep problems, and adds mother’s voice to the research conversation. The collaborative approach ensures that the findings resonate with and have meaning for mothers and clinicians. Finally, the study is designed to provide useful recommendations that can be immediately applied to improve children’s health outcomes.

To ensure that the theory was emerging from the participants, and not being forced into my own ideas, I engaged in methodical coding, theoretical sampling, constant
comparison and memoing processes described above (Charmaz, 1990; Cullingworth, 2014, p. 31). I also employed validation procedures, specifically constant comparison and negative case analysis, to test my emergent theory. This is where early interviews with the fathers helped to validate my emerging theory about mothers’ experiences. My consulting team provided ongoing opportunity to validate and triangulate my research (Charmaz, 1990). Following the interviews, I shared a copy of the transcript with the participant for their review and approval. I invited participants to a member checking event in May 2017, where I intended to share my emerging theory, and ask for their input; however, I did not receive a response from the participants. A final copy of the draft manuscript was also shared with the participants, and again, I did not receive any response.

Throughout the coding process I practiced disciplined reflexivity to manage my multiple roles. My role as a researcher put me in a position of authority and power over the participants. As a heterosexual, married, white, middle-class, educated woman, I was also aware that I enjoyed hidden privilege, such that my experience was not necessarily representative of other mothers’ experience. Furthermore, I was mindful that the experience of mothering is informed by multiple cultural identities, and ways of performing motherhood (Horwitz, 2003), and that my experience would necessarily be different from my participants.

My research design did not ask participants to disclose information about their identity. Through the interviews, participants offered information that led me to believe they were similar to me in terms of culture and socio-economic status. Participants however ranged in age from young mothers to experienced grandparents raising children. Potential participants were provided with a newspaper article describing my family’s story, which included a picture. It is possible that participants self-selected out of the study based on their perceptions of me as a Researcher and what I represent.

I believe that conducting the interviews over the phone was a useful strategy for managing power dynamics and overcoming cultural assumptions. Because I did not have any visual cues about the participant, I was forced to be curious and check assumptions that I may have otherwise made based on visual information.
In addition to memoing, I sought supervision from my senior supervisor and engaged in my own counselling through the research and writing. This process helped me to see where my own experience paralleled the participant’s and where it differed. Through member-checking process, I specifically sought feedback on issues of power and cultural sensitivity.

Determining transferability is the role of the study’s reader, as only the one who can know if their content is sufficiently similar to the one described in the theory to make the transfer of findings appropriate (Cullingworth, 2014, p. 30; also see Lincoln & Guba, 1985). To this end, I have attempted to provide the reader with adequate description of the micro and macro contexts under study so that readers may decide whether the findings are transferable to their individual situation and concerns. Credibility comes from making my steps clear: through generating the interview protocol, into selecting an appropriate site for study, and to selective sampling. In coding, I made an attempt to illustrate participant’s views using their own words as possible in order to keep the theory truly grounded in the data.
Chapter 4. Findings

4.1. Overview of Survival Mode process model

In this chapter, I present my analysis that led to the development of the Survival Mode process model, which explains mothers’ meaning-making of their child’s sleep problem and how strategies for managing it develop over time and in response to cultural values, relational threats and systemic barriers. This theoretical model captures the reality that mothers’ responses to sleep problems exist in multiple and interactive dimensions, and appear to follow a developmental pattern. The matrix-model comprises two parts: (1) time-task and (2) assets. I first provide a brief overview of the elements of the model. This is followed by greater elaboration regarding the data that informed each element.

As concerns the time-task dimension of the model, mothers’ descriptions of their experiences with a child’s sleep problems could be categorized as falling into one of five stages: Pre-problem, Questioning, Help-seeking, Assessment and, Intervention. Each of these stages was found to be associated with specific tasks related to managing their child’s sleep problem.

The Pre-Problem stage was a period in a mothers’ life when her child’s sleep was not yet a concern. This was a time when mothers enacted cultural beliefs and attitudes that shaped their expectations about children’s sleep, and they established their preferred mothering narrative. Mothers relied on previous mothering experience and general sense of self-efficacy to construct the belief that they were able to manage their children’s sleep. In the pre-problem stage mothers became aware they could be vulnerable to judgements about their mothering, and they tried to mother in ways that were considered acceptable.

During the Questioning phase mothers started to consider whether their child had a sleep problem. They assessed what was normal with regard to sleep and actively researched and tried out different management strategies. Mothers began to experience judgement because their experience did not fit with cultural norms and attitudes about children’s sleep. Managing their child’s sleep problem drained mothers’ physical, emotional, social and time resources, such that the demands exceeded mothers’
capacities. This created a state of internal tension for mothers because their *Survival Mode* behaviour became incongruent with their beliefs about how to enact their preferred version of *Good Mothering*.

In the Help-Seeking phase, mothers actively sought assistance for their child’s sleep problem. This often occurred concurrent to, or as part of help-seeking for challenging daytime behaviours, which made it difficult to get sleep recognized as a specific and legitimate concern. Mothers were challenged to stay resilient and continue to advocate for care as they encountered systemic barriers and dismissive responses from physicians.

In the Assessment phase, mothers continued to encounter reluctance from physicians to have sleep problems recognized as a serious and independent health issue. In continuing to advocate for their child’s sleep, they had to resist problem conceptualizations that blamed and shamed them for their child’s sleep behaviour, and advocate for care and services specific to their child’s sleep.

In the Intervention phase, mothers evaluated and made choices about enacting physician’s sleep care recommendations. Mothers experience living in Survival Mode resulted in the belief that physician’s sleep-care recommendations would potentially have a low return-on-investment and would be beyond their capacity to enact. Their prior experience managing their child’s sleep made them feel vulnerable, and they were cautious to avoid further blame and shame. These beliefs were incongruent with their beliefs about Good Mothering, which was formulated around an unyielding and self-sacrificing commitment to their child. The tension between these two schema were experienced as *ambivalence*: Good Mother beliefs compelled mothers to enact the recommendations for their child’s benefit; whereas, previous experience had created the belief that the negative relational and capacity costs of enacting the recommendations were too great. Physicians interpreted this ambivalence as non-adherence.

It became apparent that in their daily interactions and encounters with healthcare providers, mothers employed various strategies to negotiate relationships, systems, and beliefs that made the sleep problem more or less challenging to manage. It was found that these strategies clustered around four assets: (1) *Have Enough*, which refers to the mothers’ time and energy resources, sense of self-efficacy, and ability to enact her
various roles; (2) Safe Enough, which relates to mothers’ sense of psychological safety, being loved, and belonging; (3) Powerful Enough, which captures mothers’ sense of power (or lack thereof) in their ability to access services; and, (4) Good Enough, which relates to mothers’ ability to perform their preferred version of mothering. These assets served as protective factors that enabled mothers to stay perseverant and resilient.

4.2. Pre-Problem phase

The Pre-Problem phase describes a time in a mother’s life when her child’s sleep was not a serious concern. The phase may be real or imagined. Some mothers had older children for whom sleep was not a problem, and for others it was as they anticipated the birth of their child. Insofar, the length of this phase is unique to each mother’s situation. The Pre-Problem phase is a formative period when mothers enacted beliefs which informed how they made meaning of, and in turn, responded to their child’s sleep. Mothers believed that sleep issues were a normal and transient part of infancy. They relied on their previous mothering experience and professional identities to inform the belief that they were adequately resourced to handle their child’s sleep problems. In this section, I identify the cultural messages and practices described by mothers that set them up to feel as though they must be perfect, and the ways that they engaged in self-management to avoid judgement. Finally, I describe the “good mother” narrative, and explain the ways it informed mothers’ responses to their child’s sleep.

4.2.1. Have enough

In the pre-problem phase mothers believed that they had the resources and confidence to successfully manage their child’s sleep. These beliefs arose from a variety of experiences, but prior mothering experience and professional competency were two of the most influential.

Previous experience and successes managing children’s sleep gave experienced mothers, like Rose, a sense of confidence and competence around sleep,

Yah, so it’s like, this is my eighth, so I should know what I’m doing. I’ve had kids where I let them cry themselves to sleep now and then. You know, that stuff has happened before, and it worked just fine. (Rose)
Like Rose, mothers anticipated that sleep could be a challenge, especially early in infancy, but expected that any problem would be transient. They believed that sleep issues were a normal (albeit unpleasant) part of infant development, which their child would eventually outgrow. With her older children, Rose learned that although intense effort was sometimes required to manage a baby’s sleep, the effort would only need to be applied for a short-period of time before being rewarded. As an experienced mother, Rose had successfully managed her children’s intermittent sleep problems successfully, but she felt ineffective when it came to her son, Joel:

I’ve had kids where I let them cry themselves to sleep...that stuff has happened before this, and it worked just fine, but with Joel, he would drive us all crazy because we didn’t know what to do. (Rose)

None of the mothers expected that their child’s sleep would be a sustained issue requiring long-term intervention.

Mothers also referred to their professional experience as evidence of their competency, capacity, and resourcefulness to handle challenging situations. In the following statement, Anna reflected on her expectation that the skills and confidence she had developed as an emergency room nurse would transfer into her new role as mother,

I’m a nurse, you know, I should be able to handle this! I can manage crisis. I can manage care plans. I can manage. I can manage things. (Anna)

Anna experienced herself as being able “to manage things,” and applied this self-confidence to her new role as mother.

4.2.2. Safe enough

Mothers’ experiences of managing their child’s sleep, and the meanings they made around it were informed by a mothering culture, which they understood as expecting near perfection. In order to “fit” in this culture, mothers felt pressured to engage in constant self-development, undertaking mothering as a skills-based project. During this time, mothers became aware of feeling vulnerable to judgement and blame related to their mothering.

Mothers explained how they were constantly exposed to messages about how they should mother. This was most apparent in social media spaces that were
constructed around images and messages concerning Good Mothering. These messages created a great deal of anxiety for mothers,

I feel like between Facebook and Pinterest giving some ideas, and everyone googling things, it just seems like mom now-a-days, and this could all be in my head, you’re supposed to like have it all together a bit more. (Penelope)

In this statement, Penelope was sharing the pressure she felt to fit a particular mold. Performing mothering in culturally endorsed ways allowed Penelope to feel that she belonged and reinforced her social identity as a good mother. Mothers expressed fears about stepping outside this prescriptive and limited style of mothering. For instance, Penelope described using “elemental water” (a product sold at the health food store) which her sister-in-law reported had helped with her child’s sleep. Penelope believed that it, along with other trendy strategies, like “sleep bugs” (sound emitting nightlights) and “jade teething necklaces” (said to help with fussiness associated with teething) were just a type of “snake oil.” Even though she believed the strategies were frivolous and ineffective she felt pressured to use them, and worried that she may be judged critically by other mothers if she did not.

4.2.3. Powerful enough

Mothers’ previous experiences engaging with the healthcare system shaped their expectations of their ability and need to advocate for care and support. When mothers had had favourable experiences, they expected the healthcare system would be accessible and provide timely and appropriate services. Alternatively, negative experiences resulted in mothers’ believing that only through their commitment to and advocacy for their child would their child receive the help they needed.

Penelope’s experience provides a positive example. Her son was born with a life-threatening medical condition. After a rapid initial assessment, Penelope’s son was immediately started on treatment. She described the care team as communicative and attentive to her son’s medical needs and the family’s emotional needs. During his treatment and recovery, the family stayed at the Ronald McDonald house so they could focus on their son and not have to worry about practical needs and stresses. As a mother, Penelope felt well-supported by her healthcare team and embraced by a community of compassion. Experiences such as Penelope’s led mothers to believe that
the system would recognize and respond to their child’s needs with minimal need for advocacy on their part.

Other mothers had negative experiences accessing health services that left them feeling disempowered and dismissed. Iris described a time when she was unsuccessful in getting care for her older son.

[Iris] So, um, and you know, I wasn’t an advocate obviously because if I couldn’t get the Ear Nose and Throat doctors to do his job, I should have thought, you know, maybe I should get somebody else to have a look at [her son]

[Researcher] The idea of advocacy, and just pushing through, and not taking no for an answer, and being persistent and resilient. That’s come with experience?

[Iris] Yes, I think so. I think I’m much more confident [advocating for healthcare] now, and that’s come from age and experience.

Based on this experience, Iris learned to anticipate resistance and barriers in the healthcare system, and expected that she may well need to advocate for her child. She learned not to be passive with her healthcare provider, and when she encountered barriers to receiving care she recognized the need to be assertive.

4.2.4. Good enough

In the Pre-Problem period, mothers established a preferred mothering-narrative, which they identified as a being a Good Mother. Through this story, mothers told themselves about the type of mother they wanted to be. Each mother’s narrative was individualized to her personality and circumstance however, they all shared common features that can be captured by the following description:

A Good Mother is selfless. Her children come before herself and any other need or commitment. She is ever-present in her child’s life, most certainly when they are sick or unhappy. A Good Mother monitors her child’s wellbeing and seeks expert care when necessary. The Good Mother’s commitment never waivers, and she believes that she alone is ultimately responsible for her child (see Chase & Rogers, 2001, p. 30 in Horwitz, 2003).

Iris’s version of the Good Mother is apparent in the following statement,
There was one weekend in particular in June when we were in hospital. It had been (my daughter’s) worst seizures yet. ... And, uh, I was sitting awake for 72 hours just watching her. Just watching her. And I was beside myself because like, I already had like very little sleep. ... the nurse said, I’ll come and watch her, I want you to go to sleep. And, I’m like I can’t go to sleep. (Iris)

The Good Mother narrative served as an important hermeneutic for how mothers made meaning of their child’s sleep problem. Iris described mothering as,

Just doing what you have to do. Sometimes you just put one foot in front of the other. (Iris)

When I asked Anna to offer an image as a metaphor for her experience of mothering, described herself “sitting on her son’s bed crying, and him happily peeking around the corner.” She called the image, “Driven to insanity.” When I asked her what this image meant for her, she talked about a sense of depersonalization, deprivation and self-sacrifice. Anna

Being a Good Mother involved a sense of depersonalization, deprivation and self-sacrifice,

I thought I was very more go with the flow, carefree...and then I had kids. (Anna)

As part of the interview process, I asked participants to summarize their experience as if it was a newspaper headline. Rose suggested the term “Mombie,” taken from a t-shirt her daughter had purchased for her as a joke. The meme poked fun at mothers who were sleep deprived and overly focused on attending to their children’s needs. The metaphor immediately resonated with other participants; in fact, it was not until the writing process, that I realized I had also used the term in an earlier work to describe my experience. (Graham, 2014)

4.2.5. Summary

In this section, I have outlined the foundational beliefs and values that mothers applied to their experience managing their child’s sleep problem. During this period, mother’s beliefs and experience were congruent and they felt adequately resourced to handle their child’s sleep.
4.3. Questioning phase

During the Questioning phase mothers began to consider whether their child had a sleep problem. They assessed the normalcy of their child’s sleep, and actively researched and tried out different management strategies. In this section, I describe how mothers started to doubt their self-efficacy and framed sleep as a skills-based issue. I discuss where mothers sought out information on sleep-strategies, and describe the resource and relational barriers mothers encountered when they attempted the interventions. I then explore mothers’ experience of judgement, and the resulting sense of isolation and loneliness. Lastly, I explain how mothers’ behaviours towards their child undermined their sense of being a Good Mother, and the strategies they used to maintain their preferred identity.

4.3.1. Have enough

During the Questioning phase, mothers’ sense of having the resources necessary to cope with their child’s sleep problem began to be challenged. In contrast to their expectation that sleep problems were a transient issue, their child’s sleep problem persisted beyond what mothers considered to be normal and significantly impacted their functioning. This unexpected experience eroded mothers’ sense of competency,

Um, so I was raised around babies and small children all my life...so I felt totally prepared to have my own...and was totally unprepared when I turned into an, um, just unknowing, self-conscious, self-doubting...lost basket case. (Anna)

Like Anna, mothers felt lost and lacking in confidence, and tried to regain a sense of control by framing the situation as a deficit in their skills and knowledge. They started to educate themselves about children’s sleep, and became discerning consumers of sleep information, looking to parenting groups, parenting books, and guidance from family and friends for ideas on how to manage their child’s sleep. Mothers quickly found that there was a lack of information and resources to support older children’s sleep. Lilly said it was like the “wild west out there” trying to find reliable and consistent information on older children’s sleep. In the end, like Lilly, mothers found themselves “banging around on the internet.”
Mothers invested a great deal of time and energy “going through a list” (Penelope) of potential reasons why their child was not sleeping, “trying to get a good grip on the problem.” (Rose)

She’s upset for over half an hour before she calms down. And, once she calms down she just sits up, and she’s like Mommy, Mommy, like she starts talking and wanting to play. Yah, but you know there’s nights when you go in, and then she’s upset and it’s like you give her blanket and soother and, she turns around and curls up and like passes out, and you’re like, huh?! (Penelope)

Ultimately this process of “playing detective” (Rose) was unrewarding and futile because there did not appear to be a consistent pattern to their child’s behavior.

At this point, mothers “started to get religious” (Penelope) around scheduling and routines, and making the environment conducive to their child sleeping. For example, Penelope changed her children’s sleeping arrangements by having her son sleep in her and her husband’s bedroom so that her daughter with sleep problems could sleep alone. She also modified her daughter’s bedroom by putting cardboard on the windows and installing a fan. Anna also changed the family sleeping arrangements putting a mattress on the floor in her children’s room where she could sleep. In addition to changing the physical sleeping arrangements, mothers also reported implementing new behavioural strategies such as “crying it out” and “taking nap time off the table.”

Despite mothers’ high motivation to resolve the sleep problem, their ability to implement these strategies consistently was compromised by a lack of time and energy. Mothers attempted to be structured with their child’s sleep, but it was difficult to remain perseverant, especially when their child did not respond or the response was inconsistent. For instance, Anna believed that if she was methodical and patient she would be able to identify the source of the problem so it could be solved, but this guessing game was ultimately unrewarding,

Does he have too many blankets? Does he have not enough blankets? Should he have a pillow? Should he not have a pillow? I’ll turn on the fan for white noise. Well, maybe the fan is disrupting him. You know, you know, like I’ve gone through kind of all of it...and really, I’ve found nothing! (Anna)

Lilly also described feeling despondent when a strategy that was gaining momentum suddenly stopped being effective. After a great deal of trial and error, Lilly discovered
that a humidifier helped her son’s sleep. Then, suddenly, and without any warning, the strategy stopped working because he became inexplicably frightened of the noise,

It is at the point where the humidifier or the white noise made some spooky noises in the background too, so we’ve had to take that away now. (Lilly)

In addition to the frustration of seeking the elusive “magical solution” (Anna) mothers were conscientious of the impact that the intervention had on the other members of the family. They viewed the family as a living system that functioned in a precarious homeostasis, and considered the sleep problem as a stressor that had to be managed and contained. For instance, Anna was sensitive to how her son’s behaviour created a stressful emotional environment for his 6-year-old sibling,

My six-year-old is very sensitive, and so when his younger brother is freaking out, and melting down, um, it’s almost like it makes my six-year-old anxious. (Anna)

Anna was reluctant to try any intervention that would heighten tension or exacerbate anxiety in the family. Her approach to sleep was to manage the problem in a way that minimized the impact on her other child. As a result, she and her husband played “musical bedrooms,” moving themselves and the children around throughout the night.

Mothers reported that their child’s resistance to sleep intensified when they tried behavioural interventions. As a result, they had to choose whether to prioritize managing their child’s sleep or doing what it took to ensure that they all got adequate sleep. This is evident in Lilly’s description of trying to get her son to sleep in his own bed,

I put him back in his own bed and stuff, but half the time it’s just not worth it...because if I get up and take him back, and I lay with him for ten minutes, and I go back to my room, guaranteed he’s right back. (Lilly)

No matter how committed Lilly tried to stay, her son would still arrive back in her room. They would go through this dance each night, and inevitably she would become so tired that she was not able to return her son to his bed. When it was time for Lilly’s son to go to bed, she was faced with the choice of allowing her son to co-sleep, so she could get some sleep herself, or being constantly interrupted through the night to take her son back to bed. Night over night, this pattern wore at Lilly’s resiliency, and she made the
decision that the cost of trying to get her son to sleep independently was too great. Mothers all agreed with Lilly that trying to intervene was “just not worth it.”

Mothers commented on the effect of cumulative stress and never-ending demands had on their mental health and general sense of well-being. They described what it was like to live with chronic sleep deprivation,

Like, I know that, I’m just, I’ve been just, I been just almost...sleep deprived with her. There are days where I’m functioning, I know off less than four hours of sleep, and I’m going out in the world...I don’t know what this is doing to my health; I don’t know what it is doing to my mind... (Penelope)

Penelope had been so focused on her children, and getting through each day, that she had not considered the toll that sleep deprivation had her. Penelope’s experience was so long-standing that coping with chronic sleep deprivation had become her version of normal.

The timing of sleep interventions required mothers to recruit their limited resources at the end of the day, when their exhaustion was most intense. Already tired from a full-day, mothers described how they then had to face an equally difficult second shift without any reprieve. Anna talked about the difficulty of working in a demanding job in healthcare, and how at the end of the day she does not have the emotional or energy resources to be patient with her child’s sleep,

I work in a hospital, and I’m you know, I’m on cell phones and land lines, and Vocera [secure clinical communication], and I’m paged over-head and I’m dealing with patients. And, I’m talked to and yelled at and stimulated all day. And when you come home, and you have little people that have missed you, and they’re a lot of energy themselves. So, you’re just really counting on that time leading up to bedtime. I think you’re counting on it so much, that when it doesn’t go smoothly it’s like you’ve reached the end of the fuse of dynamite...Just be quiet! And, it’s not angry, it’s just over-load. Just for the love of god, please shut-up and go to sleep! (Anna)

What is evident in Anna’s experience is the gap between her child’s sleep-related demands and her own capacity. Anna very much wanted to be patient with her child, and had the intent to provide a calm and structured nighttime routine that involved settling her son in his own bed. However, by bedtime “all her sweet mommy patience has left the building” and she was willing to do whatever to took to get her son to bed, including using a screen to help numb her children into sleep,
This sounds awful, and I’m cringing as a parent saying it, but one of the best ways to interrupt the craziness is to turn on Paw Patrol [a children’s cartoon]. It like freezes [the boys] and they stop moving. (Anna)

Anna was aware that screens interfered with healthy sleep, and felt guilty for using them as a coping strategy. She was exasperated with her son’s high needs, but angry with herself for not having more to offer, as if a good mother would have unlimited capacity and patience.

All the mothers in the study were parenting with a male-partner, however, as the mother, they felt they performed the majority of care for the sleep problem. Indeed, Rose described the job of managing her child’s sleep as “dirty work.”

And it’s usually me doing the [sleep] strategies...so cause my husband is a very sound sleeper...and so I’ve historically always been the one getting up with the kids, ’cause he just doesn’t, he just doesn’t hear it...I think for the most part, it’s me doing them on my own. (Anna)

Mothers described their husband as caring and supportive, but because they lacked the first-hand experience with the sleep problem, mothers felt that they had difficulty understanding mothers’ perspective and reactions. Anna’s husband thought she was simply making a big deal, and could not understand why she needed to be so rigid around sleep. Anna’s husband would participate in interventions, but only with her insistence, and even then, was likely to make exceptions or excuses to prioritize spending relaxed and playful time with the children over the sleep routine,

I think he, he, kind of supports me...when I tell him what I’m going to do, and it’s like ok...you down, so for him he doesn’t always see the really, really big deal...and, but I think that because he’s not the one home... he’s not the one dealing with the day-to-day impact, so it’s easier to minimize sort of, how the consequences of not implementing some the strategies.

This dynamic left Anna feeling like she was responsible for being “the total enforcer,” a role that she resented,

And that’s something that I’ve already thought about, you know, now that school is starting back again...to sit down and have a conversation with him, and be like, this is the window of time where you are not allowed to step foot in the house...so you either have to make sure that your home well before this time, or after this time...but if you step foot in the house during that window of time, I will shoot you...or I will walk out, and you will be left with the kids, and I’ll come back after a glass of wine with friends. (Anna)
None of the mothers had specifically discussed bedtime parenting roles and expectations with their partner. Mothers assumed the care-taking role by default, however, there seemed to be an unspoken assumption that as mothers they were better resourced to handle the problem,

I feel like I deal with it because my husband doesn’t have the patience (Penelope).

Mothers also saw themselves as having special parenting knowledge. Iris described this as a sort of intuition that her husband did not have access to,

Well, I think dads just don’t have the same mechanisms as moms do. Yah, and my husband doesn’t have the same, I don’t know sensitivity...(Iris)

All the mothers referenced some version of special knowledge that could be described as maternal intuition. Mothers felt that they were picking up on more and different information than their partner, and perhaps also experiencing a powerful felt sense about the problem. Because of this special knowledge, mothers assumed greater sense of responsibility for decision making around sleep.

4.3.2. Safe enough

During the Questioning phase, mothers’ relationships and associated sense of belonging began to be challenged. Mothers described how this process began with their child, expanded into their relationship with their partner and, then out into their family and friends.

The impact of the child’s sleep difficulties on mothers’ relationships with their child was one of the most difficult and stressful aspects of the sleep problem. Anna felt “driven insane” by her son’s sleep behaviour. Rationally, she recognized that it was outside of his control, but it felt very punishing,

Oh my gosh, [her son] called me for the sixteenth time and I banged the door open and I yelled at him, what! What! What! What! (Anna)

The challenges felt relentless. Day and night, Anna was struggling, without reprieve or positive interactions to help off-set the negative interactions.
These experiences of resentment and anger, created anxiety for mothers because they felt that sleep was undermining their relationship with their child. Rose expressed this as “not knowing how to how to change everything without making [her son] cry.” In this statement, Rose was describing how she felt caught between two positions: she believed that the promoting healthy sleep was in her son’s interest, but also believed that providing him with a nurturing and calm bedtime was equally important. Anna also explained how she was cautious about implementing any strategy that would place further strain on her relationship with her son,

I just can’t do anymore. I’m just like, oh, yah, I know I should do it, and then feeling guilty that I didn’t do it, but oh well, you know, like, you know he went to bed, he went to bed happy, I guess, so it’s ok. (Anna)

Mothers knew they should adhere to the sleep routine, but it meant they would finish the day in conflict with their child. After a day of managing the children, mothers wanted to feel close and connected to their child. Putting them to sleep calmly and peacefully helped them regain a sense of comfort and feeling of closeness that they were missing.

The dilemma over relational guilt also applied to mother’s other children. Iris worried that her other son felt overlooked because of the time, attention and resources commanded by her daughter’s sleep problem,

Well it’s hard on him [other child]. Like here we are, we’ve got this child who demands so much, and he’s like what about me? Like, why is it always about his sister? … I understand that pain; I understand what he goes through, but what do you do? (Iris)

Mothers felt that the sleep problem made it difficult to fairly distribute emotional and time resources to their other children, and like Iris, they worried that the situation might create long-standing feeling of disparity and resentment between siblings. Penelope described the losses associated with this situation,

My parents just bought property at a lake. And, all my siblings have gone up there, and we’ve gone up for a day, and come home. And, they’re like oh, trailers, tents, and I’m like no, you’ve got to be kidding if you think we’re sleeping in a tent where at like the five o’clock sun is going to wake this child up, you’re out of your mind. And, like we used to camp all the time, but since we’ve had Charlotte, we don’t go camping anymore. Like we just stay at home all summer… so I kind of feel like yah, in so many areas of our lives we’re missing out. (Penelope)
Penelope felt guilty that her son was missing out on experiences because the family was prioritizing their daughter’s sleep needs. Penelope had a hard time reconciling prioritizing one child’s needs over the other, but found herself defaulting to managing the sleep because of the immediate impact on the family’s overall wellbeing and stress.

At first mothers were somewhat tentative to talk about the impact of the child’s sleep problem on the spousal relationship, but once I opened up about my own experience, they shared enthusiastically. According to Penelope, sleep problems put the parent’s relationship on the “back burner.” Prolonged bedtime routines, co-sleeping/sleeping separately, and frequent nighttime awakenings interfered with mothers’ time alone with her husband. Chronic exhaustion meant that mothers would frequently fall asleep with the child or soon after, contributing to the couple having very little time alone together. Rose spoke about how her son’s need to have her present to fall asleep and stay asleep impacted her relationship with her husband,

Well, there has to be an impact because a lot of the times I end up [in my son’s] room. You know, sometimes intimacy is hard. I mean, especially when he’s in the room, right? That made it all the more difficult...Like I say, we take what we can get. I do like get resentful because I just want to sit down. I’ll sit down with my husband to watch a show or whatever. Even if I fall asleep through the show, I'll sit there. I’m still sitting with him...You know there does come a little bit of resentment Like, why are you sleeping? You know, I’ll want to go sit with Daddy!...He’s [Rose’s husband] has been good about it. I mean, yah sure, he gets frustrated too because he has to get up super early...Yes, so he’ll just go to bed. Then I’ll feel like oh, I’ve failed you know. [Her husband] is going to bed, and he’s like no, I’m just tired, and goes to bed, but I still feel like I let him down. (Rose)

Rose’s anxiety and guilt came partly from her own need to connect with her partner, but also from the pressure of his expectations. It was important for Rose’s husband that they spent time together as a couple at the end of each day. So, when her son’s sleep interfered with this time, Rose felt torn between attending to his needs or her husband’s.

Diminished opportunities and energy for sex not only meant that couples were missing out on pleasure, but important opportunities for emotional intimacy and connection. Mothers were initially reluctant to talk about how the sleep problem affected their sex life, but when they were invited to do so it was a major concern and source of frustration in their relationship,
Well there has to be an impact because a lot of the times, I end up in his room...you know, that it is sometimes the intimacy is hard...I mean, especially when he was in the room, right...that makes things all the more difficult. (Rose)

Mothers appeared grateful for the opportunity to freely discuss the topic, and revealed that they had been reluctant to discuss it previously because they feared being perceived as complaining, as a good mother always prioritizes their child’s needs, certainly above her sexuality. Mother’s also feared that others would assume that they were crossing taboo boundaries by engaging in sexual intimacy when their children were near.

Trying to manage the sleep problem socially isolated the family. For Penelope managing her daughter’s sleep meant sacrificing participating in social events and severely limiting their lifestyle,

You know, for things like family birthdays and stuff, before if we were like oh, you’re not having cake until six, whatever. Now, we’re like ahhhh, when are you bringing desert?! Like, we went to a birthday this summer, and it was like 6:30, and they haven’t done cake yet, and I’m kind of like this show needs to get on the road, like we’ve got bedtime! (Penelope)

Penelope’s family members did not understand why she felt the need to be so strict around bedtime, and were unwilling to accommodate their family’s schedule. Sticking to a bedtime routine meant leaving functions early or avoiding them all together because their early departure often ended in conflict and hurt feelings. Penelope described this experience as her “lonely reality.” She wished that people around her could understand the magnitude and depth of her experience and not brush it off as an over-blown inconvenience,

It’s the going out, and once you’ve told somebody our daughter doesn’t sleep all that well, it’s like then people are like, oh, is she sleeping now? And, you’re like no. But, it’s just like something about it, where it’s almost like most people, just don’t understand, or they don’t try to understand, or they half-heartedly give you this advice. But you almost feel like there’s this sense of you’re not trying hard enough. Or, you’re making too much of a deal about nothing. (Penelope)

According to Iris, those around her do not even try to empathize with her experience,

You know, we have friends that make fun of us because we go to bed so early. Like holy crap, do you want my life for a bit?! (Iris)
Iris was describing the way that her child’s sleep felt out-of-step from what was considered developmentally normal and accepted. Unlike those around her, Iris described how she was still coping with unrelenting exhaustion that is usually considered to be a problem limited to infancy. This liminal experience felt like a barrier in her relationships and contributed to her sense of loneliness and isolation.

Mothers quickly learned that disclosing information about their child’s sleep was socially dangerous. According to Rose, “everyone [was] an expert,” and people (even strangers) felt entitled to criticize her mothering practices regarding sleep, you know, you get all the well-meaners, like you know, oh he’s just a baby, you got to make him go to sleep at night. Um, or, you’re still nursing him too much, or don’t do that, do this. (Rose).

Anna shared how others’ responses suggested that her child’s sleep problem was a result of her mothering, which could be solved if she did something differently. In the following quote, she conveyed how she felt judged by friends and family when they were present for child’s bedtime routine,

I would get very sensitive, like if we were having people over to the house...like for dinner...I’d like be struggling to get my son into bed, and get him asleep...and to stay asleep and not call me seventeen times...and, you just feel like you’re getting there’s a lot of unspoken conversation happening you know, with the other people in the room...you know, she’s gone in for like the seventeenth time, and...you need to sort of justify it, and make excuses and all, you know— ‘it’s so weird, they don’t do this. (Anna)

Anna summarized the experience of judgement and mother-blame as “generational amnesia.” For her, it felt as if mothers with older children had forgotten their own challenges around sleep or chose to attribute their success to their superior mothering. Rose also identified with the idea of generational amnesia, and shared how she had felt judged for her “soft” mothering. Mothers in this study acknowledged the ways that their parenting practices may have differed from those of older generations, and were open to the idea that maybe they were being too lenient, but wanted the opportunity to figure out practices and approaches that worked for them without being shamed or blamed for their child’s sleep problem. Rose preferred to take a gentle approach to putting her son to sleep, and was unwilling to let her son cry it out like the older women from her church community suggested,
I by no means coddle my children, but I’m sorry, there are things I just won’t do. And, just because I won’t take your advice doesn’t mean I’m a bad person!... (Rose)

More than sharing their experience and offering suggestions, mothers experienced “generational amnesia” as a form of social pressure.

Mothers learned to protect themselves from others’ judgements by not talking about the sleep problem,

After a while, I just realized, you know, I just stopped talking to people because it’s just making me look like I don’t know what I’m doing. (Rose)

4.3.3. Powerful enough

Questioning a sleep problem started out as a “niggling,” (Rose) that grew over time into a general sense of concern. When they first became concerned about their child’s sleep, mothers typically could not articulate the specific concern despite strong feelings that there was a problem,

Like as a baby, he would moan and groan, and roll around, and like move. And before he could even move around, flail and moan and groan, and stuff. (Juliet)

As children got older, abnormal patterns of behaviour emerged. Juliet recalled the early signs she noticed in her son’s behaviour,

He was too tired. Struggling too much to get up and get going. Didn’t have the energy he should have. Things like that...Sometimes he talks in his sleep. He sometimes walks in his sleep. He sometimes yells in his sleep. He sometimes has whole conversations. He often wakes up, like you know, on the floor, or completely turned around in his bed—that kind of thing. And, that’s like, it just seemed more than just, to me, more than what would be considered a bad dream, like you know what I mean? Like it’s so often. (Juliet)

As part of the questioning process, mothers queried whether their child’s sleep behaviour could be explained by their developmental stage (nightmares common in the pre-school years) or their temperament (a strong-willed child), or whether it was a consequence of their parenting (laying down with their child to settle them to sleep). Finding answers to these questions was difficult because as sleep had always been a problem for their child, mothers did not have a point of reference for differentiating what
aspects of their child’s behaviour were developmentally typical, and what was cause for concern. Rose’s previous mothering experience provided her with comparative data that framed how she understood her child’s sleep.

“This isn’t right, this isn’t normal. [At her son’s age] my kids were sleeping through the night...So, it’s just too abnormal for me. (Rose)

Mothers’ accounts suggested that sleep could not be isolated as the specific problem behaviour. The point at which mothers determined that sleep was a problem was when their child’s daytime behaviour started to significantly affect the family’s wellbeing. The problem went far beyond getting their child to sleep and maintaining sleep throughout the night. In fact, mothers spoke relatively little about the nighttime situation and were more concerned with what it meant to live with their child’s daytime behaviour. Anna and Penelope both likened their sons’ daytime behaviour to the “exorcist,”

[He’s] like the exorcist, where his head is just spinning around, and it’s meltdowns every two minutes. (Anna)

Similar to Anna and Penelope, mothers pointed to their child’s mood swings, excessive motor activity, inattentiveness, irritability or oppositional behaviour as evidence that the sleep situation was problematic.

It was at this point that mothers raised concerns with their healthcare provider. They addressed the issue with their family doctor/paediatrician and in some cases with specialists and para-health professionals. Juliet described how because her son was physically thriving, and hitting the appropriate developmental milestones, that the physician dismissed her concerns about sleep, proclaiming him “healthy,”

Honestly, but there’s like the doctors, they’re like you know, you get your immunization, you get your height and weight...and he says, yah, he’s healthy, he’s normal, he’s on task for where he should be. ... like all the way along everyone kept saying, yah, he’s good. (Juliet)

The irritation and frustration of being told to “just keep doing what [she was] doing” was still apparent in Juliet's voice ten years after the fact.

Mothers reported how physicians enacted gender stereotypes as part of their evaluation of the child’s functioning. This was particularly applicable to boys. Juliet and Rose described how their sons’ dysregulated/challenging behaviours daytime
behaviours and delayed development were dismissed as typical boy behaviour. When mothers brought their concerns forward to physician they were benevolently dismissed,

We’d been told along the way, he’s fine. That’s how boys are. Boys don’t always perform at school. Why are you worried about it? You know, that kind of thing. (Juliet)

Mothers were in a difficult position because they could not offer any specific or contradictory evidence to dispute the physician’s evaluation that they were over-reacting, or that their child’s behaviour could be explained as part of normal development or gender-typical behaviour. This experience activated mother’s belief that their child’s health depended on their ability to advocate for access to services.

4.3.4. Good enough

Mother’s ability to enact their preferred version of Good Mothering was compromised by their attempts to manage the sleep problem. In the statement below, Anna described her preferred intensive mothering style,

I always wanted my kids to have the confidence and feel reassured that you know, mom is there, if they need me for any reason, whatever, I’m there. (Anna)

In saying this, Anna was conveying her belief that she should be unconditionally available for and patient with her children, however, her exhaustion and frustration made it difficult for her to consistently behave in this way,

When he was a bit younger, and trying to get him to sleep, and get him to stay asleep, and I would like find myself yelling, at a toddler! And, you think, what the!? Or like physically holding him down in bed- like you need to stay here! (Anna)

Anna’s commitment to being an available and nurturing mother made it difficult for her to be compassionate with herself when she was anything less. As a result, she felt a deep sense of shame about her actions. She could not reconcile that a Good Mother would allow herself to do such things to her child. Interestingly, Anna was eventually able to be gentler with herself as concerned her challenges with parenting. This occurred when she contrasted her experiences in her profession (nursing) with her experiences as a mother. As nurse, Anna felt confident and competent and questioned why she could not feel this way as a mother. In recognizing that in her professional role she was
surrounded by team members, protocols and other supports but, as a mother, she did not have the same resources, she was able to appreciate that her home situation was far more chaotic than an emergency room crisis. In seeing this, she was able regain her sense of humour and offer herself more compassion.

Well, and then, I kind of approach it, finally, kind of with this sense of humour and, just realize, being a parent is unlike any other experience on the planet, and If I have a difficult patient in the hospital that I can’t get to sleep, well then I phone the GP and I get a sleeping pill. I just can’t do that with my children. (Juliet)

Mothers also sought out affirming social support to normalize their experience and manage their experience of not meeting their own expectations,

I’ll usually turn to one of my cousins who has three kids, and I’ve got a couple of good friends that have kids my age, and so we’ve sort of created this unofficial pact of non-judgement...where we can just really, just bare it all. And, talk about what I call sort of our less than stellar parenting moments, where you, where you literally do what you need to do to survive and get through the day. I think some of it just would come blurring out because I was in such a state of frustration or anxiety. And, then as soon as it came out of my mouth, I think oh my gosh. You kind of wait for the reaction. And, I’ve been lucky enough that, the people that’s come blurring out to will look at me and go, oh my gosh! The same thing happened to me last week. Or you go, oh my gosh, I’m not alone! (Anna)

Developing this sense of security in her “pact of non-judgement” took some time for Anna, but it was relieving to be authentic and still feel unconditionally accepted and supported. Mothers who had this type of resource appeared to feel more connected, confident and, resilient, than those who did not.

4.3.5. Summary

In this section, I described the foundational beliefs of Survival Mode. I presented the high resource costs of sleep management strategies, and the conflicts created by mothers’ multiple roles. I then discussed how mothers perceived sleep strategies as threatening to their family relationships and sense of social belonging. I described the ways that mothers identified their child’s sleep problem, and how their concerns were minimized and dismissed by physicians. Within this, I provided examples of how mothers used reframing as a form of resistance. Finally, I discussed the dissonance between mothers’ actions toward their child and their preferred Good Mother narrative, and the
ways that mothers used humour, relationships and self-compassion to mitigate feelings of shame.

4.4. Help-seeking phase

During the Help-seeking phase, mothers actively sought help for their child’s sleep problem. In this section, I describe the barriers mothers faced accessing information and services, and how this process was emotionally and labour intensive, and compromised mothers’ ability to perform their other roles. I explain the assets mothers deployed to stay resilient and advocate for care. In their encounters with healthcare professionals, mothers felt exposed and vulnerable, but sought ways to negotiate invalidating systems and responses. Finally, I discuss how mothers reconciled their experience of failure with their belief that Good Mothers attend their child’s health needs.

4.4.1. Have enough

Mother’s first obstacle was accessing information about where to get help for children’s sleep problems. Unlike other child-health issues, mothers reported that there were no information campaigns or community resources that directed them where to go for help for sleep issues,

The road to help was so cloudy and bumpy; [that] nobody knows how to drive it. I can see young parents just standing there and looking around, and thinking, well, what do I do, and then they give up. (Lilly)

Mothers found alternative strategies for finding sleep care. Lilly described how she became an informal mentor for other parents in the Autism community looking for sleep-help,

Even going to these support meetings [for families of children with Autism]. Nothing against [the organizer], but she really was not a lot of help, and I found going to these meetings and finding other parents in the same situation as me and [husband], I would hand them my phone number, and say call me...I know, looking there were three ladies, in fact I had given my name to because I remember me, me being that one across the table— well what do I do? Where do I go? How do I get help? (Lilly)
In fact, three of the five mothers in this study learned about the Kamloops Paediatric Sleep Clinic’s services through these informal networks,

So, this lady who did the infant development here in Kamloops, she like you know, there’s this pediatric sleep clinic that’s going to get started. (Penelope)

The three mothers attached to child development support services reported using this informal strategy to access care. However, mothers were careful to point out that their experience was an exception to the rule. Indeed, Juliet described her experience as “Rural Kid Gets Sleep Help” to describe how she believed her experience was an exception to the rule. All participants in the study were connected to either child development and support services and/or involved in the healthcare system in a professional capacity. Participants believed that these connections provided them with opportunities and contact with professionals not available to other mothers.

Rose talked about how difficult it was for the family to search for help when there was “already so much going on.” In addition to the routine stressors of family life, like weddings and dealing with lice after summer camp (Rose), half of the mothers were also pursuing help for their child’s comorbid health condition(s). Rose, Penelope, and Iris’s children were being investigated for Autism,

[My daughter] got her assessment, and she came back with an Autism diagnosis, and they also diagnosed her with global developmental delay...just like one extra thing, and now they’re like no, she also has this, and I’m like great, now she has multiple things! Now, [her son] has multiple things (cancer and Autism)...How am I supposed to wrap my head around that?! (Anna)

Finding the time and energy to pursue help, while balancing busy family life was overwhelming for mothers. Penelope went on to describe how embarrassed she felt about this outburst, but it was an example of how thinly stretched she was by the constant demands of seeking help for her children’s health needs,

I’m like bringing my son to his [autism] therapy, when I’m like dropping him off for three hours, and he has the cast on his foot because he’d just had [cancer] surgery...I didn’t have it, and they’re like where’ the special shoe for the cast? I’m like – I have no idea!! Usually I won’t talk that way to somebody that is employed in a professional manner... (Penelope)
Mothers expressed concern about the impact that their child’s sleep problem had on their ability to engage in the workforce. Three mothers had paid employment outside the home; and the three mothers who were staying at home with their children reported that their decision to do so was influenced by challenges related to the sleep issue. Being too tired, not being able to find suitable childcare (particularly to cope with their child’s challenging behaviour), or needing to take significant time off work to manage the medical appointments were all cited as reasons why some mothers were not actively employed. Juliet described what it was like to cope with chronic exhaustion at work,

It’s such a big deal [the impact of sleep problems on daily functioning]. It changes who you are when you don’t sleep. I know personally, like I can barely keep my eyes open at my desk. I don’t perform very well at my job. (Juliet)

4.4.2. Safe Enough

Being open and transparent with physicians was difficult for mothers. Iris described feeling rushed and dismissed by her physician when she tried to bring up concerns about her son’s sleep,

I’ve actually found that children’s sleep problems are seen as no big deal [by physicians]. I don’t know, they [physicians] just don’t even seem to really care?...I believe that our doctors are so overworked, and especially in Kamloops (Iris)

Based on their interactions in the Questioning phase, mothers anticipated that discussing sleep could expose them to criticism. In order for mothers to feel comfortable sharing their concerns (particularly with respect to the impact that the problem had on their own functioning and coping mechanisms), they needed to feel secure and trust their physician would listen and respond to their concerns in a non-judgemental way.

Mothers accessing healthcare through walk-in clinics felt particularly vulnerable because they lacked the safety and security of an established relationship and the physician. Rose talked how the risk of reaching out for help for her son’s sleep problems because of previous contact with social systems. The previous year, her older daughter, living with non-verbal Autism, had broken her leg and social services had investigated for child abuse. The allegations were proven false, but the fear and shame of being labelled a dangerous mother left Rose feeling vulnerable when she accessed healthcare
for her children. Rose carried these fears into her encounters with professionals about her son’s sleep problem,

I have to you know, choose my words wisely. I’ve learned to choose my words wisely...I don’t have a family doctor here in town because there’s just none, and we go to walk-in clinics...I was just so nervous taking [her child] to the walk-in because you have to go through the whole rigmarole, explaining this and that, and the other. I just had this dread [bringing her child for assessment at a walk-in]...like the bile rising up in your throat. (Rose)

Rose carried the fear that her mothering would be questioned about her mothering again, but also wanted to seek help for her son’s sleep issue,

I just, you know, they’re my babies...I want the best for them, but then on the same token, I like I said before, I don’t trust people, and I don’t trust a lot of professionals. You have to gear up for it. Bare up under it. (Rose)

Of all the aspects of the problem, mothers reported that co-sleeping with their older child was the most difficult topic to disclose to their physician,

Nobody really seems to want to talk about it [co-sleeping] after they’re older...Especially if they’re coming into your bedroom, that’s taboo...If I was to tell people that [our daughter] came into our bedroom when she was like ten, they’d be like what?! Because eventually people are like is she still in your bedroom when you have sex, and now you’re letting your pre-pubescent child come in?...You just adapt, but yah, you don’t tell people. (Penelope)

Iris equated co-sleeping with older children to other taboo mothering practices,

Well, it’s like if you know, if you breastfeed your baby over six-months. You know, like a year or two years, it’s like eww, that’s kind of weird. You know, just don’t talk about it. (Iris)

Disclosing that their older child still co-slept with the parents was an essential part of describing the child’s sleep problem, but mothers believed that it was dangerous information to share because the practice suggested an inappropriate and sexualized relationship between parents and child.

Mothers were frustrated by the lack of support available to families managing children’s sleep problems. Penelope viewed sleep problems as a hidden disability that required support equal to other chronic health conditions. When her son faced a critical health condition (cancer), the family was assigned a social worker who provided them
with support and normalized the stress that couples face when they have a child with a medical condition,

Each family has their own social worker...they were there for like various resources and the social worker would also sit down with us...and like be like how do you guys feel about what’s going on, and it was also like a counselling session. (Penelope)

Penelope went on to share how helpful these services were for her family’s wellbeing and ability to manage the complex health condition. They were treated with compassion and provided with support and resources. Moreover, they felt that the care team recognized the physical and emotional impact that they were experiencing, and cared for the parents’ needs (as they recognized the family’s wellbeing was a key factor in her son’s recovery). However, with regard to her son’s sleep, Penelope felt ignored by the healthcare system.

4.4.3. Powerful enough

Mothers struggled to communicate their “fully unexplainable” (Penelope) experience of the sleep problem to physicians in ways that would be accepted as valid. This was likely, at least in part, a consequence of the way medical appointments were structured (15 minutes, one issue per visit). In such a short time-frame mothers were unable to engage in lengthy explanations of their experience and physicians are unable to engage in deep listening. Under such circumstances, Juliet found it difficult to get her physician to “see the big deal” about her son’s sleep,

[The doctor] felt like he was doing just fine: he’s attending school; he’s playing some sports; he’s in 4-H. He must be fine. Away he goes. (Juliet)

Because Juliet’s son was “coping just fine” (Juliet) the physician deemed that sleep was not a problem that required further assessment. This was frustrating as Juliet recognized the ways that her son was compensating and recognized that his functioning and wellbeing were significantly compromised. She wanted her son to thrive, not just cope.

Mothers were unwilling to accept the idea that sleep was not a problem. All reported some sense of intuition, or as Rose put it, “spidey sense,” which told them to keep pursuing the issue. The challenge was identifying measureable evidence to
communicate this felt sense that something was wrong. Describing her daughter, Iris said,

She always looked tired. She always. She’d get this cloudy look in her eyes. (Iris)

Iris’s subjective evidence of “tired eyes” was not seen as clinically significant by physicians. Mothers felt disadvantaged and powerless because their knowledge of, and forms of evidence they used to assess, their child’s well-being were not viewed as legitimate or sufficient by physicians.

Physicians also rejected mothers’ concerns because they did not view sleep to be part of their scope-of-practice. For example, Iris’s daughter was connected to a paediatrician for her epilepsy. However, once this condition was sufficiently managed, she was discharged from the paediatrician’s care even though Iris raised concerns that the seizures were related to her sleep problems,

They just don’t care about it [sleep] anyway. They are there to deal with that one issue [epilepsy]. Like our paediatrician just signed off on us, right? Um, it just blows me away. So, you’re not going to take care of [my daughter] anymore? Like, I understand we’re like, I’m fine, she’s graduated. She’s fine now, she doesn’t have any major health issues, and there’s a lot of children who do need care, but I still know that there is an issue. You know, she doesn’t get a quality sleep. She doesn’t sleep through the night, so there’s got to be something; there’s definitely got to be something wrong. (Iris)

Mothers reported that specialist physicians (such as paediatricians, Ear Nose and Throat doctors) were not prepared to continue caring for their child once the referring condition was addressed. As a result, no healthcare provider had access to all the relevant sleep information, nor was anyone case managing the issue.

Mothers lacked a general sense of agency and ability to advocate for help for their child’s health. Juliet’s professional role as a Medical Office Assistant afforded her unique access to healthcare services, and the ability to influence healthcare professionals to gain access to sleep-care services,

So, then what happened, and this is funny, because this would not happen to most parents. And we wouldn’t be any closer to any answers if it didn’t happen. I went to um, some education [in her role as manager for a medical clinic], in an educational seminar here in Kamloops, and they were talking, and they were both paediatricians with access to
paediatric care, and um, [local sleep specialist pediatrician] was there and she said, just in her whole talking, there is this really interesting link between kids that don’t sleep well and behavioural issues or slipped grades at school. You know, they can’t function as high as they could, because if their sleep was better managed, and then she went. And so, at the break time, I said to her, I know you don’t really want to talk about cases at education, but I just want to know if it would be; if you would accept a referral for my son. This is a little of his story. You know, we’ve had all this testing done and his pulse ox [oximetry] was normal, but he walks, he talks, he’s thrashing around at night. He wakes up tired you know. We had oximetry done and everyone says he’s normal. And she says, yah, yah, I’d love to; get a referral. So, I went back to my family doc. And said, I want a referral to her and he did it. Right, um, had I not been at that educational seminar, we would be nowhere. (Juliet)

In contrast to others, Juliet ability to access services depended on her being involved in the medical community, having a good relationship with her doctor, attending an event, where she connected with a specialist, and having the confidence and knowledge to advocate for a referral. As noted by Juliet, without such connections “the average person would get nowhere…just would get nowhere.”

4.4.4. Good enough

By the Help-seeking phase, mothers struggled to reconcile how they could maintain their identity as a Good Mother given their lack of success in getting help for their child’s health needs. Penelope described how she interpreted roadblocks as evidence of her failure as a mother,

Always trying this...always trying that, like I feel like I just have a laundry list of failures. (Penelope)

Rose also described how the help-seeking process eroded her sense of self-worth as a mother. Rose had successfully sought treatment for two of her older children’s special health needs, which included navigating specialist services in two different provincial health systems and re-establishing services in their new community, but she was unable to do the same for her son’s sleep problem. The inability to successfully get help for their child eroded a core part of mothers’ identities as one who is attends to the needs of an ill or unhappy child.
Mothers relied on their commitment to their child’s future to help them persevere through failure. They viewed sleep as a critical factor in their child’s development, and worried about the long-term implications of not getting healthy sleep,

I know when a child does not get sleep it affects them. It will affect him in the long-run as far as learning; as far as his whole countenance, you know? It’s just if he doesn’t get sleep, you know, he could get sick. We all need sleep; our bodies need that time. (Rose)

Like Rose, all mothers described a goal of raising a healthy adult as a source of motivation. They were willing to endure hardships in the present for their child's healthy development.

4.4.5. Summary

In this section, I presented the experiences mothers faced as they sought help for their child’s sleep problem. Within this discussion, I described the time and energy mothers invested into the help-seeking process. I then discussed the vulnerability that mothers experienced when they opened up about their situation to physicians, and the conditions that made this experience feel more or less dangerous. Within this, I identified the assets mothers deployed to resist invalidating responses from physicians. Finally, I described how mothers’ experiences of failure undermined their Good Mother identity, and how mothers relied on an unyielding commitment to their child’s long-term wellbeing and hope to persevere.

4.5. Assessment phase

In the Assessment phase, mothers focused on getting a diagnosis for their child’s sleep problem. This process involved providing the healthcare provider with information in a structured clinical interview. In the following section, I describe the burden of the healthcare manager role that mothers took on. I then present how healthcare provider’s clinical approach and attitude toward sleep was perceived by mothers to reinforce a mothering-blaming narrative, followed by a discussion of how mothers’ felt their knowledge was discounted and delegitimized. Finally, I conclude with a discussion about how mothers applied the Good Mother narrative to find strength to persevere.
4.5.1. Have enough

Mothers identified as the primary manager for their child’s healthcare. This role included making and attending healthcare appointments, collecting and providing information to the physician, and coordinating services and sharing information between providers. Lilly “was tired and ready for a break” and grateful that her husband had recently retired and was able to share more of the responsibility. She reflected on what it was like to for other mothers, who were managing the role on their own, on top of the other role demands,

I see other people with jobs and going to work and, they’re just frazzled and bagged at the end of the day … (Lilly)

At this stage, it was common for mothers to feel as though their efforts were futile, and even want to give-up. As Juliet said, “you just learn to cope,” and it did not seem as if their efforts and perseverance was paying off. For instance, Iris had not completed the paperwork for her daughter’s specialist referral and she questioned whether she had the resources to continue,

So, I’ve wondered why the heck are we here [at the doctor’s seeking help]. Why the heck are we here, and what are we doing here, if [the doctor] is not going to do anything—why are we here? I’ve been to so many wasted appointments, that I don’t really need to [be at]. Like, why am I here?! (Iris)

This statement speaks to Iris’s waning self-efficacy. Whereas, at the beginning of her sleep journey, she felt confident in her ability access care for her child, she questioned their idea that her efforts would be rewarded with a solution for her child’s sleep.

4.5.2. Safe enough

Mothers perceived that physician’s conceptualization of the sleep problem were constructed around mother-blaming interpretations of the problem. Anna entered the assessment process feeling vulnerable and insecure in her mothering, and felt that the types of questions and data collected by the physician was intended to “shine a spotlight” on her mothering. For Iris, it felt as though she could “never do anything right in [the physician’s] eyes,”
I don’t think they [the doctor] understands the anxiety piece. In don’t think they get that she’s got high anxiety because, you know, she doesn’t get enough sleep...so, the conversation goes, like we’ve got this and this for you know, anxiety, and stuff like that, and you know, to teach you how to be a better parent. And with those things, I’m like I don’t think I’m a bad parent! Some of my coping skills, are you know, um...yah, I don’t know...The last time I was at [the doctor’s office], they said, maybe if you take these anxiety classes, and learn how to deal with you know anxiety, or you know, what have you, maybe then you’d be you know, a better parent, right? So, I’m like ok. And, you know, you walk away from that conversation going, wow, I didn’t do anything about it [refute the doctor’s position]. Why didn’t you actually look in to it further, because you know, why? (Iris)

Iris interpreted the physician’s suggestion that her mothering might be contributing to the sleep problem as harsh criticism, that validated her fears and insecurities. Rose echoed her concern,

I got this from a healthcare professional because they knew when I took him for his lisp program, and they’re like you know, stop nursing him at night, you know, like he shouldn’t be doing that, you know, for teething, you know. (Rose)

A medical diagnosis was important to mothers because they imagined it would reframe the problem as a legitimate medical issue, and not a function of inadequate mothering. Rose reflected on the sense of relief and hope she gained from a diagnosis for her older son,

When they gave [Rose’s older son] his [Autism] diagnosis... All of a sudden, it was not my fault!... It’s not because anything I did. But, I felt al, you know, like you don’t love hearing that your child has Autism, or some issue, but it’s a starting point from which to work with. And as you know then, it’s nothing you’ve actually did or didn’t do, or did I do this right or not? You know like you’re flailing when you don’t know what’s going on. (Rose)

Like Rose, mothers hoped that a medical diagnosis would shift their social identity from bad mother, deserving of blame, to a good mother who required support and compassion.

4.5.3. Powerful enough

Similar to the way mothers found it difficult to communicate their concerns about sleep in the help-seeking phase, mothers struggled to present their evidence of their child’s sleep problem within the physician’s assessment model. The types of screening
tools and physician’s assessment approach did not allow mothers the opportunity to share their expert knowledge.

Physician’s questions required mothers to provide information about their child’s symptoms and behaviours in a way that seemed to over simplify the problem and not capture its complexity. Whereas, the physicians were asking for specific symptoms and patterns the reality was that the sleep problems presented in very complex and often unpredictable ways.

Yah, I don’t think there’s any real…you know I don’t think I can give you a pattern because I don’t think there is one. (Iris)

Indeed, Anna and Rose both referred to their child as “Dr. Jekle and Mr. Hyde” to describe their son’s random and unpredictable responses and moods.

According to mothers, part of the difficulty identifying a pattern was that there were “just too many things in the air—like too many other variables” (Anna). Trying to differentiate a causal relationship between variables (particularly in the context of busy family life) was challenging, and mothers were uncertain how sleep was connected to other developmental issues,

He’s ok for a while, that he, and, I don’t know, if it’s also night time toilet training, but he’s waking up in the middle of the night, and he wakes up really early. (Anna)

Differentiating sleep-related behaviours from other behaviours was even more difficult for mothers of children with other developmental concerns. For example, Lilly’s grandson was being treated for anxiety, Autism and a peripheral vision deficiency. It seemed impossible to tease apart the different sleep symptoms and triggers, as the lived reality of his conditions was not neatly organized.

Mothers wished that their child’s sleep could have been explained with a diagnosable medical condition, like sleep apnea, but most children presented with a constellation of non-specific behaviours and symptoms that could not be tested,

Like they would bring up, like does she snore? Does she do this? Does she do that? And, I’m like, no. It’s just frustrating. She’s just a terrible sleeper. Yah, so, I kind of feel like some of the things that maybe they were prepared to say, like oh, you know, like if she snores, it could be the things and we could like do like this for her. I’d be like oh, yah. I almost wished she snored. (Penelope)
Iris was “super frustrated” by how slowly the assessment process moved, and her physician’s cautious approach to diagnosis. By the time mothers reached the assessment stage, mothers felt a sense of urgency,

Like for a year and a half, we’ve been waiting. So, finally, I said to the girl [part of sleep clinic team] the last time she called me, I don’t know, like a couple of months back. I said to her, you know, ok, you know what, I don’t want to waste any more of your time. I think you people are lovely, I said, but look, I’m super frustrated, about I said, you know, look, I want my daughter to have a sleep apnea test. What is it going to take? (Iris)

The physician’s practice of eliminating different conditions to make a differential diagnosis was frustrating for mothers, and they could not understand why screening for various conditions could not be completed concurrently. Moreover, mothers were concerned that the physician was focusing on the symptoms of the sleep problem, and not looking for the underlying etiology of the sleep problem. Lilly put this as wanting to, “fix the foundation, not just repair the roof” (Lilly). Mothers felt trapped by what they perceived to be an inefficient assessment process and a slow-moving system, however, they could not see alternative ways to advocate for faster assessment.

4.5.4. Good enough

The assessment experience presented mothers with a double-bind. The slow-moving process left Lilly wanting to “smash her head against the wall,” and reinforced their insecurities that they “weren’t trying hard enough” (Penelope) as a mother; but, the thought of giving up felt like abdicating on her commitment to her child’s health. Insofar, mother’s self-interest was set in opposition to their child’s health needs, such that mothers felt that any response would result in failure. This dilemma was apparent in mother’s continued investment in the process despite their doubts about the outcome and feelings of vulnerability.

Mothers’ formulation of the situation as a double bind was informed by their previous interactions with physicians. In the following statement, Lilly recalled how she almost lost her older daughter because she deferred to a physician’s authority,

We’ve been through a lot of medical things with our older kids...We almost lost our middle daughter and they [the doctors] just kept telling us oh, you don’t know what you’re talking about. You’re young parents,
blah, blah, blah. And we both said, nope, nope, nope, and we almost lost her. If we had listened to those friggn’ specialists, right?...If we believe something in our hearts, we follow it through. We don’t let anyone tell us otherwise. (Lilly)

Lilly’s story was an example of withstanding pressures and the desire to give up however, mothers also used stories of regret, and used the guilt and shame as motivation to behave differently this time. Mothers used stories of loss and redemption of their Good Mother identity to either reinforce their conviction to prioritize their child’s health needs, or as a warning to never again allow their own needs and interests to supersede their child’s.

4.5.5. Summary

In this section, I have presented perceived structural and attitudinal barriers mothers encountered in the assessment process, and how their experience of the sleep problem and ways of making meaning about the problem were incompatible with the types of assessments used by the physician. I have discussed how Mothers felt blamed and shamed by physician’s conceptualizations of the sleep issue, which framed the problem as a mothering issue, and presented the ways they resisted by normalizing their actions, and re-framing the sleep problem as health issue. I then described mothers’ reasons for pursuing a medical diagnosis, in the hopes that it would give them direction and re-establish their status as a Good Mother. Finally, I offered the ways that mothers experienced the assessment experience as reinforcing Survival Mode beliefs and, described the assets they relied on to recast themselves as a Good Mother.

4.6. Intervention phase

In the Intervention phase, mothers evaluated, selected and enacted physician’s sleep-care recommendations. Despite the long journey to this point, and high motivation for change, mothers described feeling ambivalent about enacting recommendations. In fact, mothers reported that they had only attempted about half of the recommendation, and of those they had tried, mothers admitted they had not consistently adhered to the treatment protocol.

Mothers reported that physicians made a variety of types of recommendations that could be grouped into six categories: a) behavioural modifications, around sleep
timing, routine, parental-response to resistant sleep behaviours, and daytime activities; b) sleep hygiene, related to the child’s sleep environment; c) medication targeted at sleep and adjustments to other psychoactive medications; d) supplementation such as iron and melatonin; e) parent management training, related to anxiety; and, f) in a few instances treatment for sleep disordered breathing.

Mother’s decision to enact the recommendations was the result of a complex cost-benefit evaluation. They evaluated the potential effectiveness and efficiency of recommendations, and compared this against their available assets. In most cases, mothers opted to implement low-barrier, low-resource cost interventions, specifically pharmaceutical treatments. However, this choice of action was incongruent to their narrative of Good Mothering, which compelled them to “fight for [their] kids” (Rose), regardless of the costs. Mothers experienced the tension as ambivalence. In this section, I describe how mothers evaluated physician’s recommendations in the context of these competing motivations.

4.6.1. Have enough

Coming into the clinic, mothers had a long history of attempting behavioural recommendations. In fact, mothers reported that they had tried some variations of the behavioural recommendations suggested. Based on their experience, mothers perceived behavioural interventions to have high investment costs and low returns.

I would say, the most we would gain from cutting out the nap, if we gained anything, it would maybe be half an hour or forty-five minutes. And it would be the same if we tried, you know, if he’d napped then we kept him up a bit later, we’d, the most I would gain is maybe instead of getting up at five, he’d get up at six...It’s totally not worth it! (Lilly)

Lilly believed that behavioural modification required intensive and sustained effort, and that new behaviours were vulnerable to regression the moment that she backed off from the routine. She described there being “no respite,” and the pressure to stay consistent and committed was wearing and unrealistic given the multiple behaviours she was trying to manage on a daily basis. Lilly offered the example of setting limits around eating with the TV on,

Well routine, right? So, you know, say we got into a habit, of letting him eat in front of the TV instead of at the table, say for breakfast...because
it made it easier for you...So, and then, it was hard to get him to do anything, so we brought him back to the table. Well now you have to eat at the table, you know in order to get your TV or iPad time or whatever... So, that's one example. Ok, we've got this under control, everything is going good, the rules are enforced, and then you think, oh, you know, one time. I'm going to do it. And then you go right back. (Lilly)

The timing of the intervention was also a barrier for mothers. Behavioural sleep strategies required that mothers recruit resources at the end of the day when their capacity was the lowest. By nighttime, Anna wished for "as smooth a glide into bed as possible." Mothers described themselves as just surviving and, as not having the energy, patience, time or emotional resources to withstand any additional stress. Rose talked about how her anxiety mounted around bedtime,

I can't seem to deal with it very well. I take something called mental calmness...and it works fine; it works well. I, you know, it brings me back to reality because just the day has been so busy, and then by nighttime, I think of the things I didn't do. (Rose)

Mothers also considered how the sleep intervention would impact the family system as a whole. Rose felt as if she was trying to manage multiple and competing needs of each family member,

My one daughter, my twenty-year-old, she's got a transform migraine, post-concussive thing. She can't handle the screaming [that her son does when he is left to go to sleep on his own]. She can't handle that. That just shoots her off. Her eyes almost bug out of her head [when her son screams]. (Rose)

Rose's decision to enact a sleep strategy was dependent on the family's fluid and changing needs. She was constantly evaluating the situation, assessing the needs of each family member, and then adjusting her strategy to meet their needs. She likened responding to sleep as a "game of whack-a-mole" (a reference to a game where the player is tasked with bonking random targets at an impossibly fast rate),

"That's like when we found out a couple weeks ago [laughter], that my one daughter came back with lice from cadet camp...but it's just like the whack-a-mole thing. Ok, I just got this, we're kind of on a roll here and boom! Something else hits you." (Rose)

For interventions to be successful, mothers had to have the family's buy-in and support. This was a particular challenge for mothers with older children who were resistant to the treatment. Iris's daughter refused to take the medication prescribed,
They thought her iron was low, so we started some iron, and like [the child] said, Mom, I’m not taking this. It tastes like crap! (Iris)

Rose also encountered opposition from other family members about the treatment. She discontinued the melatonin after only a brief trial period because her mother and husband disagreed with her son taking the supplement (because they perceived it to be “drugging” (Rose) the child to sleep,

With the melatonin, it just didn’t make sense. It made things worse instead of better. That’s why I stopped it. I talked to my husband and mom, [who was staying with the family] and I got this sense that yes, it’s not working from everybody’s perspective, so I didn’t make the decision lightly. (Rose)

Rose justified discontinuing the supplement after a very short trial period by looking for evidence (e.g. agitation) that the treatment was ineffective. This strategy allowed her to reduce tension in the family system and avoid feeling that she was non-compliant with the treatment recommendations.

Sometimes interventions were in conflict with mothers’ other goals for their child. For instance, Juliet felt reluctant to enforce the no-screen recommendation. As part of sleep hygiene (optimizing the sleep environment), the physician suggested that her son should limit his exposure to blue light two hours prior to bedtime. However, for Juliet’s adolescent son, this intervention had the negative side effect of socially isolating him from his peers,

Their friends are like, hello, hello, hello, why aren’t you answering me?...because everyone does it [is constantly connected]. They say, you’re the odd kid out when you don’t do it. (Juliet)

Juliet’s anxiety about limiting her son’s use of the phone at bedtime was rooted in her hope that her son would eventually “have a best friend” (Juliet). Juliet described how her son’s sleep condition had made him a target for bullying so, she was reluctant to set limits that may interfere with his acceptance in his peer group. Juliet wanted to promote healthy sleep conditions, and understood the reasons why her son should limit his exposure to his phone, but she also recognized the social pressures on him to be available and connected with his peers.

Mothers’ ambivalence also came from recognizing their own limits. To this point, they had been so focused on finding help, and maintaining hope for a solution, that they
had not paid much attention to their diminished wellbeing. In the following statement, Iris recognized her limits and struggled with the idea that she needed to start prioritizing her own health,

Um, it happened about three of four weeks ago...My blood sugars were at 17.9 a few weeks ago...Yah, it was horrible. So, I realized at that point, that you’ve got to do something. You’ve got to do something or you’re not going to be here long enough to even worry about it. And the anxiety, that I started to have has started causing palpitations, and that’s been happening for the last three or four weeks, so you know. Sorry, the last, it’s been happening for the last three or four years, like since [daughter] got really sick, I’ve started to have the heart palpitations, the sweating, just the anxiety, you know. It will come on for no apparent reason. So, I’m like no, I’ve got to start taking care of myself. But, I’m a giver so, you know I need to I’ve back to myself. I need to take care of myself. I need to love myself. I need to give a crap about who I am, so that was my tipping point. So, I’m there. Setting boundaries and all of those things. So, you know, just getting more-healthy minded myself. (Lilly)

Lilly realized that she had been neglecting herself, and wondered how much longer she could sustain herself under the stress and demands.

4.6.2. Safe enough

Mothers were uncertain whether their relationship with their child could withstand the additional stress of an intervention. Anna explained how she was cautious about implementing any recommendations that would place further strain on her attachment relationship with her son. Anna needed the bedtime situation to go well to assuage the tension in her relationship with her son and feelings of guilt that had built up over the day and worried that the “muss and fuss” (Rose) of behavioural intervention would threaten this opportunity for positive connection,

I just can’t do anymore. I just, and I’m just like, oh, yah, I know I should do it, and then feeling guilty that I didn’t do it, but oh well, you know, like, you know he went to bed, he went to bed happy, I guess, so it’s ok. (Anna)

Because mothers were feeling so vulnerable and inadequate, they needed acceptance, compassion, and as Rose put it, a “place to vent,”

I’ve accepted that this is a challenge that we’re going to have, and that my son has. And, hey, I really need some support and understanding to get through this part, and that’s what I’m asking for support. (Anna).
4.6.3. Powerful enough

Despite mother’s clear preference for a long-term solution, they were unable to access supports and services that would assist them in implementing the behavioural interventions. This dilemma was most apparent in the families who had a child without a diagnosed developmental condition. The three mothers of children with Autism had access to supports and services that enabled them to more easily implement behavioural interventions. In contrast, mothers of children without a diagnosis or non-supported diagnosis, like ADHD, did not have the same access to funds or services that would support them in implementing non-pharmaceutical recommendations. In these cases, mothers reported that they were more likely to use medications to manage their child’s sleep even though this was not their preferred option.

Mothers viewed pharmaceutical treatments as attractive because they offered the possibility of an immediate effect, but they expressed concern about treating the problem symptomatically, and preferred a long-term solution. Lilly sought to “fix the foundation,” and resolve the underlying sleep issue(s),

There’s this thing in the back of my head that I don’t want to like drug my kid to sleep every night. Like this isn’t...for the next five years, I like want to find something where she can actually like learn to put herself back to sleep. (Penelope)

Mothers expressed concern about unknown long-term health effects of using pharmaceuticals that have not been extensively researched in paediatric populations or off-label uses of over the counter drugs/supplements,

Well, what’s the long-term effect of giving her Gravol every night? And you know you’re still giving her, I mean, you’re still giving her a drug, right? You know, like what are the long-term effects? Melatonin never worked for her. You know, that was one thing, that you know, we were told to do. But, you know, our paediatrician said try Benadryl or Gravol, and the lesser of two evils I felt, in my own heart and mind, was to give her Gravol, right? (Iris)

4.6.4. Good enough

During the Intervention phase, Mothers struggled to “come to a place of acceptance” (Rose) that their child's sleep problem may not be resolved (despite their efforts),
I’m not asking for a solution necessarily, because at this point, I’ve given up on a solution. (Penelope)

This realization and sense of hopelessness created a deep anxiety for mothers because the thought of giving up the fight was incongruent with their established beliefs about Good Mothering,

I fight for my kids. I’ve always fought for my kids, for what’s best. (Rose)

To resolve this tension mothers reworked their definition of Good Mothering to accommodate imperfection.

Rose talked herself through this process. In the first part of Rose’s narrative, she described her Good Mother commitment to be gracious, grateful and patient with her children, “You know, I take each day as a gift...” (Rose). But, the stresses of the sleep problem, on top of daily life, wear her down, and she behaved in ways that she regretted, “I’ve just sometimes, I just feel bad for if I get upset, or I lose my cool…” (Rose). Rose then went on to give evidence that affirmed her belief she was failing as a mother, and chastised herself for pitying herself when she compared her situation to families facing critical illness. When it all became too overwhelming Rose felt paralyzed by the pressure and demands,

I do it, day by day. I don’t think about what I have to do for the whole week, or the whole month. I just sit down and do nothing... (Rose)

Rose then regained her sense of humour about her situation, and used self-compassion to reassure herself that there could be a positive outcome (even if she sometimes failed to live up to her exacting expectations), and cited her older children as evidence,

I mean, like my older daughter that’s married lives in [nearby city], and she’s like super bubbly; she’s just a happy person you know. Everyone is attracted to her. So, she’s told me a few times, you and dad need to go on holiday [with the offer that she would take care of the children]...You almost want to tear up and cry because I didn’t do such a bad job. (Rose)

Her older children’s caring nature reassured Rose that her mothering was good enough. She used this as evidence to challenge the belief that her less than ideal mothering was irreparably damaging her child.
4.6.5. Summary

In this section, I described how mothers’ experiences prior to the intervention phase resulted in ambivalence about enacting physician’s sleep-care recommendations. I have referred collectively to this set of experiences as Survival Mode. As a result of these experiences, mothers expected that the sleep-care recommendations would likely not be effective, and certainly not worth the relational and energy costs. In contrast, Good Mother beliefs compelled mothers to prioritize their child’s interests above their own needs.

4.7. Summary

The purpose of this study was to explore mothers’ experiences of a sleepless child, and to their identify perceived barriers to and facilitators for implementing physician’s sleep-care recommendations within the family, and within the BC healthcare system. Using a grounded theory approach, I have presented the Survival Mode process model to demonstrate how mothers’ experiences prior to engaging with physician’s sleep-care recommendations shaped their beliefs about specific interventions, and in turn the likelihood that they would implement them.

These findings were presented as a time/task-asset model. I found that mothers’ approaches to their child’s sleep problem developed over-time, which I have presented using five stages: (1) Pre-Problem; (2) Questioning; (3) Help-Seeking; (4) Assessment; (5) Intervention. I have described how mother’s decisions regarding physician’s sleep-recommendations were the result of understandings which developed in response to her experience of: (1) having enough, (2) being safe enough, (3) being powerful enough and, (4) feeling good enough. In each of these phases, I discussed assets that mothers enlisted to help them maintain a sense of hope, and stay resilient and perseverant.

As a result of these experiences, I have suggested that mothers develop a set of Survival Mode beliefs, which led mothers to predict that physician’s sleep-care recommendations would: (1) exceed her time and energy resources, and ability to enact her various roles; (2) threaten her relationships; and, (3) compromise her ability to enact her preferred mothering style. This belief system was problematic because it was incongruent with mothers’ idea of Good Mothering, which was formulated around an
unyielding and self-sacrificing commitment to their child. Mothers experienced the tension between these two belief systems as ambivalence: Good Mother beliefs compelled mothers to enact the recommendations, whereas, the threat of additional negative consequences made mothers avoidant of or non-adherent to the recommended actions. Thus, mothers’ choices to enact physician’s sleep-care recommendations were based on their evaluation of their assets and capacity to implement the strategy, and do so in ways that did not compromise their identity as a Good Mother.
Chapter 5. Discussion

This study is one of the first to describe mothers’ lived experience of managing their child’s sleep problems, and presents a theoretical model explaining their decision-making related to physician’s sleep-care recommendations. While researchers have repeatedly called for further investigation into the barriers to parents implementing paediatric sleep-care, the literature thus far is heavily weighted toward clinical understanding of sleep and treatment protocols, and physicians are unclear as to the real-life barriers families face managing their child’s sleep. Moreover, mother’s perspectives are largely missing from the literature, and any representations are limited to the experience of a specific clinical intervention and focused on the infant population. This study has addressed these gaps, presenting the complex reality of managing paediatric sleep problems in the context of the family and British Columbia healthcare system.

I have described mothers’ ambivalence toward physician’s sleep recommendations in the context of the Survival Mode process model. In this section, I discuss this model both in relation to issues identified in the current literature and new factors identified in this study. This discussion is presented by way of the model’s assets: good enough, powerful enough, safe enough and have enough. In each section, I discuss the barriers mothers encountered and summarize their resilience strategies.

5.1. Good enough

According to Ribeiro, Mendes, Stiles, Angus, Sousa, and Gonçalves, (2014, p. 702), “ambivalence is the cyclical movement between two opposing parts of self that keep feeding into one another, dominating the self alternately and producing distress as they go” (2014, p. 702). In attempting to manage their child’s sleep, mothers were caught between two aspects of self – being a good mother and the need to survive their daily reality.

Mothers identified with a style of mothering described as the “Good Mother” in the literature. This cultural discourse refers to a set of expectations and acceptable behaviours for mothering in mainstream Western culture (Thurer, 1994; Eyer, 1999 in Horwitz 2003). Chase and Rogers (2001) describe the Good Mothers as follows,
We all know the ideal of the good mother. Above all, she is selfless. Her children come before herself and any other need or person or commitment, no matter what. She loves her children unconditionally yet she is careful not to smother them with love and her own needs. She follows the advice of doctors and other experts and she educates herself about child development. She is ever present in her children’s lives when they are young, and when they get older she is home every day to greet them as they return from school. If she works outside the home, she arranges her job around her children so she can be there for them as much as possible, certainly whenever they are sick or unhappy. The good mother’s success is reflected in her children’s behavior - they are well mannered and respectful to others; at the same time, they have a strong sense of independence and self-esteem. They grow up to be productive citizens (Chase & Rogers, 2001, p. 30 in Horwitz, 2003).

The mothers in this study were strongly committed to this narrative so strongly that even as their capacity was challenged and they experienced negative consequences, they subverted their own physiological, emotional and social needs in the interest of their child. When mothers were unable to consistently enact this style of mothering, they became highly distressed and experienced feelings of shame and inadequacy. Regardless of the costs, mothers were motivated to be “good mothers” if it meant that their child would become a healthy and happy adult. Their child’s wellbeing was mothers’ source of hope and resilience, and the fear that they may fail them was their greatest source of sorrow.

Mothers enacted Good Mothering using what has been referred to as attachment parenting practices. This approach, popularized by William Sears in 2001, is predicated on maximal parental responsiveness. Proponents of this method advocate for practices such as on-demand breastfeeding, co-sleeping and baby wearing. As an example of how attachment parenting is applied to sleep practices, Weissbluth (2015) instructs parents to put their child’s sleep needs at the centre of the family routine and immediately respond to children’s distress cues. Although Weissbluth was referring to sleep practices with infants, mothers in this study strongly identified with and tried to adhere to these practices, even as their child aged well beyond infancy. Mothers continued to describe wanting to be available and present to respond to all their child’s emotional needs. They also continued to arrange the family routines around their child’s sleep.

In contrast to this intensive style of mothering, the behavioural sleep strategies typically recommended by physicians required mothers to not respond or to respond in a
very controlled way to their child’s sleep-related behaviour. Mothers felt torn between attending to their child’s immediate emotional distress and implementing these behavioural interventions to manage their child’s sleep. In this circumstance, mothers were caught between two Good Mother directives -- being emotionally present for their child and cultivating a healthy happy adult (through good sleep). In other words, behavioural sleep-care recommendations created a dialectic in the Good Mothering narrative, in which mothers were pressed to prioritize either their child’s immediate emotional needs or their long-term wellbeing. Mothers’ inconsistent limit-setting as concerns sleep seemed to reflect this conflict between attending to either their child’s present or their future needs. This is a very different perspective on mothers’ non-adherence to physician sleep recommendations than is provided in current models, which tend to attribute mother’s inconsistent limit setting to a lack of knowledge, skills or to maternal mental health concerns (see Bordeleau, Bernier & Carrier, 2012). These models portray mothers as not good enough. In contrast, my findings and the model presented herein reveal the far more complex situation of mothers attempts to perform their preferred version of mothering.

5.2. Powerful enough

This is one of the first studies to document health-care user’s experiences of accessing paediatric sleep-care. The present study is consistent with previous research showing that the British Columbia healthcare system lacks adequate paediatric sleep care services (see Owens, 2001; Owens & Mindell, 2006; Katz, Witmans, Barrowman, Hoey, Su, Reddy, & Narang; 2014). In addition to affirming the lack of available services this study identified systemic and attitudinal barriers that inhibited mother’s power to access services.

Mothers in this study were active and discerning consumers of parenting and health information. However, they reported difficulty in finding information on children’s sleep through public health channels, and turned to the internet and social media for ideas on how to manage their child’s sleep. This finding is inconsistent with psychoeducation models of sleep management that presuppose child sleep problems are largely the result of parents’ lack of appropriate education about healthy sleep (see Lozoff et al., 1996), and highlights a gap in public health policy and programming. In British Columbia, Public Health Nurses, like Dr. Wendy Hall, are spear-heading
initiatives to raise awareness about the importance of children’s’ sleep and make information more readily available to parents. However, these efforts are slow-going and have not been broadly incorporated into policy or health literature (Hall, Wendy, April 12, 2014, personal communication).

In encounters with physicians, mothers felt that their child’s sleep issue was neglected. They believed that their physician lacked the time to adequately address their child’s sleep, or were more concerned with managing other medical issues and did not treat sleep as a priority. These concerns are consistent with research conducted by Boerner et al., 2015a (also see Ipsiroglu, McKellin, Carey, & Loock, 2013; Gruber et al., 2011) who found that healthcare providers lacked time, knowledge, and resources for attending to paediatric sleep problems. In the present study, mothers accessing healthcare services through walk-in clinics were especially affected. According to participants, walk-in physicians were unprepared to address complex sleep issues; furthermore, they lacked knowledge of the history of the problem that would have assisted with a differential diagnosis. With regard to specialists, mothers reported that they were unlikely to deal with sleep if they considered it to be outside their professional role or not within the scope of the referring problem (see Boerner et al., 2015a). Mothers’ perceptions of the difficulty accessing appropriate professionals and of physicians’ relative lack of expertise regarding paediatric sleep contributed to their feelings of powerlessness in addressing their child’s sleep issues.

Another factor that seemed to impact mothers’ feelings of power (or lack thereof) to find help for their child’s sleep problem was their perception that physicians relied on stereotypes or common beliefs rather than evidence-based information when making decisions about sleep, a factor also noted by other researchers (see Boerner et al., 2015; Bruni et al., 2004; Owens, 2001). For example, mothers described physicians’ use of gender-based stereotypes as an explanation for problematic school performance and social relationships ignoring the possibility of sleep issues being the underlying problem. This information sheds light on a potential reason for paediatric sleep problems being routinely missed (see Ipsiroglu, McKellin, Carey, & Loock, 2013). If mothers’ cannot persuade or convince physicians that a sleep problem is present, physicians won’t implement sleep screening.
It is notable that the three mothers in this study who worked in the healthcare system all reported that this role provided them with power not available to most mothers. It created opportunities and relationships that enabled mothers to consult with and access healthcare providers who were willing to help with their child’s sleep. Their specialist knowledge allowed mothers to communicate their concerns in ways that physicians could understand and accept. This finding is consistent with the work of Ipsirolgu (2016) who described the communication challenges between parents and healthcare providers and the need for a shared language. Such a shared language would contribute to mothers’ power to access the services they need.

5.3. Safe enough

This study introduced the idea that children’s sleep problems can threaten mother’s sense of psychological safety and social belonging. This relational perspective provides new insight on mothers’ decision-making processes that are not part of the current conversation. In this section, I explore how sleep problems affect mothers’ sense of psychological safety, being loved, and belonging.

Mothers spoke about how difficult it was to live with a child whose challenges were seen, at least in part, as a consequence of parenting inadequacy. Mothers in the present study described feeling envious of the types of support and understanding that were extended to parents of children with a visible disability or medical condition. They felt that sleep was a type of hidden disability, and wished that others could appreciate that they were doing their very best to manage it. Mothers felt shamed for how they managed bedtimes and blamed for their child’s challenging daytime behaviour (that were a consequence of poor sleep) by family, friends and institutions, such as the school, and this was experienced as social rejection. Mothers learned to hide their struggles with bedtime so as to avoid the shame. Blaming and shaming responses taught mothers to censor how they spoke about their experience of their child’s sleeplessness (see Brown, 2007), which had implications for a variety of relationships. For example, clinical encounters felt risky because seeking help required mothers to be transparent about their inadequacy as a mother and expose themselves to further criticism. Similar to parents of children with mental health conditions, mothers were cautious to present information that undermined their fitness as a parent (see Corkum, Lingley-Pottie, Davidson, McGrath, Chambers, Mullane,... & Weiss, 2016; Lingley-Pottie, McGrath, &
Andreou, 2013). The fear of rejection heightened mothers’ anxiety, and they selectively presented the information in ways they hoped would solicit assistance but protect them from being judged. This protective strategy has also been described by Bluden and Bails (2016), and is consistent with mental health research conducted Lingley-Pottie, McGrath, and Andreou (2013) that indicates families avoid seeking medical treatment to spare themselves anxiety caused by fear of judgement and rejection.

To maintain a sense of psychological safety, mothers in the present study reported adopting a variety of strategies. Perhaps the most counterintuitive and clinically relevant of these strategies was mothers’ desire to acquire a psychiatric label for their child. In addition to providing guidance on treatment, a label legitimized their concerns and transformed the problem from a mothering deficit to a medical issue. Diagnostic labels, like ADHD and Autism, offered mothers a culturally sanctioned means of communicating their experience (Swartz, 2013). Additionally, by appropriating a biologically-based etiology, mothers attempted to deflect social criticism and reconstitute their social identity as a Good Mother (see Watter, 2010).

One of the most novel and impactful findings of this study concerned the role of family relationships in mother’s approaches to sleep-care. There is a well-established association between the emotional environment of the family and children’s sleep (see Appendix B) however, existing intervention models focus on the mother-child dyad and give little consideration to the influence of other family relationships. To my knowledge, the present study is one of the first to use a family systems perspective to understand maternal compliance with sleep care recommendations.

A problematic mother-child attachment relationship is central to conceptualizations of infant sleep difficulties, being viewed as both a cause and consequence of those difficulties (see Bordeleau, Bernier, & Carrier, 2012; Morrell & Steele, 2003). The present study demonstrates the continued importance well beyond infancy of the mother-child attachment relationship in understanding mother’s responses to sleep-care management. Mothers reported that their responsiveness to their child was disrupted by feelings of resentment and guilt associated with the sleep problem. Challenging daytime behaviours and negative night-time situations meant that a large portion of all mother-child interactions were experienced by mothers as negative. Mothers were motivated to try and counter-act the negativity which had accumulated
throughout the day and avoid a tense bedtime. They believed that putting their child to bed in a positive and soothing way was important for their relationship with their child. Mothers were not misguided in their belief, as positive emotional climate associated with feelings of safety and security has been demonstrated by Allen, Howlett, Coulombe, and Corkum (2015) to promote children’s sleep. Admittedly, some of mothers’ decisions about limit setting were due to fatigue and exhaustion, but many were attempts to meet their child’s immediate attachment needs. As a result, mothers were reluctant to implement sleep-interventions that they expected would provoke additional relationship distress or interfere with their ability to soothe their child into sleep.

Existing research focuses almost exclusively on mothers’ relationships with their sleep-disorder child., The present study broadens this focus to include how having a child with sleep problems can impact other relationships within the family, including those between mothers and their other children. Mothers were anxious to ensure that their other child(ren)’s emotional and sleep needs were met at bedtime. Participants described trying to minimize the impact of their child’s sleep problem on sibling children, and expressed high levels of concern about how the additional stress of the sleep intervention may affect their other child(ren). With regard to sleep hygiene interventions, mothers expressed concern about how such a restricted lifestyle would limit opportunities for their other children’s socializing outside the family and compromise their social-emotional functioning (see Kvist, Nielsen, & Simonsen, 2013; Mallick Greenbert, Gloyd, Pettee, &Hong, 2001). These findings are consistent with research on parents of children with other mental health and chronic health conditions, with Bluebond-Langer (2000) reporting that parent’s reactions to treatment protocols include consideration for how sibling children may be impacted in terms of time and attention. Further investigation is required to more fully understand mothers’ perspectives however, the present study indicates that mothers’ experience significant tension trying to attend to their childrens’ competing emotional needs, which in turn affects their implementation of physician’s sleep care recommendations.

A few studies have discussed the impact of children’s sleep problems on the parental relationship. For instance, Liu, Liu, Owens and Kaplan (2005) reported that child sleep problems have a negative impact on spousal relationships because of the loss of opportunity for sexual intimacy. They suggested that the increased stress on the spousal relationship may affect adherence with behavioural sleep recommendations.
Even so, the parental relationship has remained a cursory topic in the literature, and to my knowledge has not been examined specifically as a factor in parental compliance with sleep care recommendations. In the present study, mothers certainly expressed frustration about how the sleep situation affected their sexual relationship and opportunity to spend child-free time with their spouse, however, they described feeling most distressed by the strain that the sleep problem created in their co-parenting relationship.

In the present study, mothers described how their child’s sleep problem added to their responsibility as their child’s primary caretaker, and in turn, how the stresses of this role strained their spousal relationship. Mothers described feeling overwhelmed by the practical and emotional burden of managing their child’s sleep day-to-day and interacting with the healthcare system. While mothers indicated that they would have preferred to share this role, they believed that their experiences provided them with specialized knowledge that their spouse did not have.

Mothers accepted the caretaking responsibilities as part of their Good Mother role, but felt resentful when their spouse did not support their sleep related decisions or acted in ways that they perceived to undermine their efforts. This finding is consistent with emotional patterns described by couple’s researchers, Greenberg and Johnson (1988). While additional study is required to fully understand the dynamic between parents, and its influence on adherence behaviours, this finding suggests that mothers’ reactions to sleep-care strategies are also influenced by feeling loved and supported by their spouse.

5.4. Have enough

Giallo, Rose, Cooklin, and McCormack have also used the term *survival mode* (2013, p.13), to describe the cognitive, physical and emotional conditions faced by parents of infants experiencing sleeplessness. Such infant models recognize the reciprocal relationship between infant’s sleep problems and parental functioning whereas, models for older children tend to minimize this effect. The present study helps us to appreciate what it is like for mothers to live in *chronic* survival mode. Moreover, existing research treats sleep as a specific nighttime behaviour whereas, participants in this study help us to see how the impact of child sleeplessness can stretch across time
and be seen in many contexts outside the bedtime situation. In the following section, I describe how the chronic experience of a sleepless child affects mothers’ sense of self-efficacy and capacity to implement sleep-care interventions.

In the Pre-problem phase, mothers believed that with sufficient and sustained effort they would have success (see Stajkovic & Luthans 1998). They relied on previous mothering and professional successes to manage fears and uncertainty. In doing so, mothers were expressing a strong sense of self-efficacy (see Badura, 1982), which Tse and Hall (2007) and Beresford et al. (2015) have noted is positively correlated with a child’s healthy sleep.

Over time, mothers’ experience attempting to manage their child’s sleep taught them that sustained effort did in fact not result in successful outcomes. Such repeated failures eroded mothers’ sense of self-efficacy, so by the Intervention phase mothers had developed negative beliefs about their capacity to sustain effort and overcome obstacles. Statements such as “I learned to cope” and early cessation of effort with an intervention are indicators of diminished self-efficacy. Thus far, the importance of maternal self-efficacy has only been described in infant populations (see Huack, Hall, Dhaliwal, Bennett, & Wells, 2001) however, the present study suggests that self-efficacy continues to have a central influence on mothers’ management of their child’s sleep, contributing to lack of consistency and follow through with sleep care recommendations.

This study highlights the tremendous resources that are required by mothers to pursue help for their child’s sleep problem. One specific issue was the amount of energy involved in seeking help (e.g. coordinating appointments, following-up on referrals and communicating information from one care provider to another). Similar issues have been described by the Better Nights, Better Days research team. According to their pilot data, parents reported time and travel (including financial implications and disruption to routine/work schedule) as barriers that hindered their ability to access sleep-care treatments (Corkum, Lingley-Pottie, Davidson, McGrath, Chambers, Mullane, & Weiss, 2016; also see Hillman, Murphy, Antic and Pezullo, 2006).

As early as the Questioning phase, mothers reported symptoms consistent with impaired wellbeing. Mothers’ functioning continued to reduce overtime, such that by the Intervention phase, they reported mental health and physical conditions that they
attributed to chronic sleep deprivation and high stress levels. Researchers, including Lam, Hiscock, and Wake (2003), as well as McKenna, Thoman, Anders, Sadeh, Schechtman, & Glotzbach, 1993, have noted how even short-term sleep deprivation puts mothers at higher risk for depression and anxiety (also see Zuckerman, Stevenson, & Bailey, 1987). The present study helps us to appreciate the cumulative impact of chronic sleeplessness on mothers.

By the time mothers reached the Intervention phase, each of the participants described feeling exhausted and were considering accepting their child’s sleep situation and no longer trying to change it. This response was in contrast to their high motivation and energy expenditure earlier in the process of addressing their child’s sleep problem. Such responses may appear confusing to physicians but they are well documented by health researchers like Chesney (2003). Mothers' experience of emotional exhaustion, dysfunctional coping (cynicism/disengagement) and diminished personal accomplishment is associated with the experience of burnout (Maslach 1982; Schaufeli & Buunk, 2000). Common among helping professionals and caretakers, this term refers to a state of physical, emotional, and mental exhaustion caused by long term involvement in situations that are demanding (Pines & Aronson, 1993, p. 9). According to Regehr and Mills (2007), individuals are most vulnerable when they are confronted with high role demands, contrasted with low levels of control and supports.

Conventionally, ambivalence toward sleep care interventions has been attributed to maternal depression or anxiety (see Tse and Hall, 2007; Beresford et al, 2015). A mental health model locates the problem as endemic to the mother whereas, a burnout model normalizes mothers’ non-compliant behaviours as an expected coping response to a situation which has over-taxed mothers’ time and energy resources.

With regard to enacting sleep-care recommendations, mothers believed that the recommendations would have a low return-on-investment. As a result, mothers adopted a resource-preserving strategy and decided not to implement recommendations that they perceived would exceed their capacity. This behaviour is consistent with Beresford, Stuttard, Clarke, and Madison findings that parents lacked the emotional and physical resources to persevere with new sleep strategies and routines with their infant (2015). While the sleep-care recommendations themselves were not particularly complex, family-related factors made them very complicated to implement because they required sustained and consistent application, involved recruiting buy-in and significant lifestyle
changes, and usually incurred negative side-effects for the family dynamic. Seen this way, the low adherence rates are consistent with those for more complicated health protocols (see Martin, Williams, Haskard, & DiMatteo, 2005).
Chapter 6. Conclusion

The present study provides new understanding as to why research-based sleep-care treatments for children do not consistently translate into successful clinical outcomes. Previous research attributed unfavourable results to parental non-adherence however, focused research had not been conducted to understand mothers’ perspectives. Using a grounded theory approach, I have demonstrated how mothers’ experiences prior to intervention shape their expectations of, and capacity to, implement physician’s sleep-care recommendations. I have situated mothers’ individual behaviours in relation to experiences managing their child’s sleep in the context of the family and BC healthcare system. In so doing, I have confirmed existing hypotheses about the influence of family-related factors, and expanded our understanding of how family relationships affect the management of children’s sleep. I have also demonstrated how mothers are affected by healthcare systems and access barriers, and described the role of the physician. Perhaps the most novel aspect of this study is the addition of mothers’ phenomenological interpretation of their feelings and actions vis-à-vis cultural discourses of motherhood. In conclusion, what has been previously been interpreted as non-compliance may be better understood as ambivalence resulting from mothers’ best attempts to manage competing needs and interests with scarce resources.

6.1. Study limitations

Participants in this study were selected on the basis of their interest and ability to share their experiences about a sleepless child. Their stories have helped illustrate the complex realities of living with a sleepless child. Nevertheless, readers are cautioned to consider several potentially limiting features of this study. The sample size is relatively small and participants were not asked to identify their socio-economic status (SES) or cultural background. It is the case that individual family and cultural factors are associated with children’s sleep problems, and parents’ perceptions of them (see Bates et al., 2002; Gregory et al., 2006; Owens & Wimans, 2004; Zuckerman, Stevenson, & Bailey, 1987). Further, mothers who were low functioning by virtue of intellectual, economic, mental health or cultural barriers were not included in this research. The mothers represented here had been persistent and successful in accessing sleep-care services and there is a likelihood that they shared specific qualities and resources that
enabled them to do so. Given these sample features, the present study may not be generalizable to all mothers of a sleepless child.

6.2. Clinical implications

This study has underscored the need for systemic and policy changes that increase awareness of and access to sleep-care services in British Columbia. Conversations about how to translate research-based interventions into successful clinical outcomes must continue in the literature and at the policy-level for effective and meaningful change to take place. In the meantime, individual physicians can make changes in their practice that will support families manage sleep more effectively.

6.2.1. Early and easy access to information and sleep-care services

Accessing sleep-care information and services was a significant concern for mothers in this study. This study is further evidence of the need to raise the importance of sleep as a public health issue and incorporate sleep information into public health literature and programs. Many of the issues they identified have been previously discussed in the literature from healthcare provider’s perspectives. According to mothers, delayed treatment exacerbated morbidity and ineffective management placed additional stress on the family system. As a group, they felt that early and low-barrier access to sleep-care information and services would have mitigated the impacts of the sleep problem. Based on mother’s information seeking behaviours, this information should be available through public health channels, including online resources. Public health providers may also consider collaborating with schools to incorporate information into the curriculum and distribute information through Parent Advisory Committees.

6.2.2. Increased attention to sleep in clinical encounters

Mothers reported that their primary motivator for participating in the study was to increase awareness of sleep problems. They hoped that by sharing their story healthcare providers would gain a better appreciation of the seriousness of sleep problems and be more likely to act quickly and effectively on parents’ sleep-concerns. Clinicians are encouraged to regularly include conversations about sleep as part of their routine encounters with families. These explorations should also include how mother’s
wellbeing is affected by their child’s sleep problem; any indication that the mother’s functioning is negatively impacted should be a clinical indicator that the sleep problem is significant and requires attention. Similarly, clinicians ought to consider sleep when mothers present with concerns about their child’s daytime functioning, and not wait until the child’s impairment is serious enough to be clinically problematic. This study also indicates that mothers detect signals of sleep-problems much earlier than sleep screening indicators may indicate. Healthcare providers are also encouraged to broaden their knowledge and competency around sleep so they can be attuned to symptoms and better prepared to effectively manage the issue at the primary care level.

6.2.3. The therapeutic relationship as an intervention

There is a movement in the British Columbian healthcare system toward offering sleep-care services by telehealth as a way to offer low barrier sleep services to families (see Corkum, Lingley-Pottie, Davidson, McGrath, Chambers, Mullane,... & Weiss, 2016). Mothers in this study described geographical, time and financial costs associated with travelling distances to attend specialist appointments however, more than practical barriers, they emphasized the importance of the therapeutic relationship with their healthcare provider. The positive effects of therapeutic relationship have been shown to dramatically increase compliance with health treatment regimens (see Davis, Foley, Crigger, & Brannigan, 2008). This phenomenon has also been observed sleep-care assessments and interventions (see Ipsiroglu, 2016; Graham 2016). Given the economic and practical pressures to further utilize distributed health services, this study cautions policy makers and program developers to consider the value of the therapeutic relationship and ensure that it is attended to in distributed sleep services.

This study has demonstrated that sleep-care interventions are necessary, but not sufficient without the appropriate pre-conditions. The mothers in this study described a sense of psychological unburdening from having the opportunity to tell their story and have it validated by a caring and attentive professional. Hearing myself in their stories was relieving for me personally, and helped me to recast my experience of shame and inadequacy to appreciate my resiliency in my own journey through sleeplessness. Individual healthcare providers can make an immediate impact for their families by simply listening to mother’s sleep concerns in a non-judgmental and curious way.
6.2.4. Emotion coaching to understand and overcome treatment barriers

Mothers reported being least likely to implement sleep-recommendations that would lead their child to feeling too much distress or cause disruption in family relationships. These beliefs, and accompanying negative emotions (such as anger, resentment, hopelessness and helplessness) were barriers to treatment. Emotional blocks are common for families dealing with mental health, and may prevent parents from feeling secure and hopeful about their role as change-agent. A relatively new form of family-based therapy, called Emotion Focused Family Therapy (EFFT), has been shown to significantly improve parental self-efficacy and compliance with healthcare interventions. The Canadian model, developed by LaFrance Robinson and Dolhanty (2013), was originally designed to treat eating disorders, but is showing great promise for other mental health conditions. Feminist critics have complimented EFFT’s attachment-based formulation of problematic interactions as healthy and normal attempts to reach out and seek connection (Vatcher & Bogo, 2001). The approach is also an empirically validated interpersonal-treatment for maternal anxiety and depression (see Piteo, et al., 2013; Pascual-Leone & Greenbert, 2007; Watson, Gordon, Stermac, Steckley, & Kalogerakos, Cisler, Feldner, & Forsyth, 2010).

Mothers in this study spoke about how their own emotional distress was a barrier to treatment. They identified how non-adherence was connected to feelings of guilt about not being a Good Mother. Clinicians can prepare mothers to be more effective by validating and empathizing with their own therapy interfering emotions. Such conversations can help mothers normalize their experience, soften feelings of blame, and identify emotional patterns that may be barriers to treatment.

6.2.5. Helpful responses to requests for diagnostic labelling

Mothers in the present study described how it was a relief when their child received a diagnostic label. This seemed to help them externalize their experience and provided them with a potential community of support, and access to practical interventions. Physicians are generally cautious in assigning psychiatric labels, preferring to adopt a wait-and-see approach, especially in young paediatric patients (given ethical, developmental and psycho-social implications of diagnosis). Given the
experiences of mothers presented here, healthcare providers are encouraged to consider the meaning that a label may hold for mothers. It may provide mothers with a framework to apprehend a very challenging experience and mechanism to externalize the problem from their mothering. A label may also serve as a social currency that transforms mothers from a blaming position, where they were seen as responsible for their child’s sleep related challenging behaviours, to a mother deserving support and compassion. Insofar, clinicians are invited to consider the potential usefulness of a diagnostic label in relation to the family system and current healthcare context.

6.2.6. Sleep intervention planning

Mothers selected interventions based on their perception of available resources, the likelihood of immediate results against the potential impact on the family system and, the perceived impacts of the intervention on their preferred style of mothering. Prior to making recommendations, healthcare providers are encouraged to talk to mothers about their preferred mothering style, readiness for change, and priorities, and then assess mothers’ capacity and interest in implementing specific interventions. This may include an assessment of family system dynamics and available supports and resources, as well as a conversation about how specific interventions interact with other behavioural management plans. Healthcare providers are cautioned to implement behavioural recommendations if there are indications that the attachment relationship between mother and child is compromised. For these interventions to be successful, the healthcare provider may consider ways to strengthen the mother’s sense of self-efficacy and promote secure attachment, which may include a referral to counselling or community support services.
References


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## Appendix A.

### Study mentorship and consultation team

<table>
<thead>
<tr>
<th>Name</th>
<th>Institution/Affiliation</th>
<th>Area of Expertise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Osman S. Ispiroglu, MD [FRCPC] MAS MBA PhD [Venia legendi, Medical University of Vienna] PhD [University of British Columbia]</td>
<td>Adjunct Professor, Thompson Rivers University, Kamloops Clinical Associate Professor, University of British Columbia, Vancouver Sleep/Wake-Behaviour Clinic &amp; Research Lab [Sunny Hill Health Center for Children] BC Children's Hospital, Dept. of Pediatrics, Faculty of Medicine Children's Sleep Network</td>
<td>Developmental paediatrician specializing in the recognition and treatment of sleep disorders in children with neuro-developmental conditions</td>
</tr>
<tr>
<td>Mr. Les Matthews, RT, MA;</td>
<td>Associate Professor, Thompson River University, Respiratory Therapy Program Kamloops Paediatric Sleep Clinic</td>
<td>Respiratory Therapy; public health education</td>
</tr>
<tr>
<td>Dr. Allyson Davey</td>
<td>Kamloops Paediatric Sleep Clinic; Pediatrician</td>
<td></td>
</tr>
<tr>
<td>Dr. Manisha Witmans</td>
<td>Better Nights, Better Days</td>
<td>Board certified sleep specialist; respirologian</td>
</tr>
<tr>
<td>Dr. Wendy Hall</td>
<td>Better Nights, Better Days</td>
<td>Nursing</td>
</tr>
<tr>
<td>Ms. Jennifer Gardener</td>
<td>Children's Sleep Network</td>
<td>Occupational Therapist specializing in paediatric sleep problems</td>
</tr>
<tr>
<td>Ms. Stephanie Stevenson</td>
<td>BC Paediatric Society</td>
<td></td>
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</tbody>
</table>
Appendix B.

Study Protocol

Running head: PARRENT'S PERCEPTIONS OF MANAGING PEDIATRIC SLEEP -CARE
SFU STUDY # 2016S0267

STUDY PROTOCOL

PROJECT TITLE
“Parent’s Perceptions of the Barriers to, and Facilitators of Managing Paediatric Sleep-Care”

This study is not supported by any granting agency.

STUDY TEAM

Kirsten Graham, BA
Principal Investigator
MA Student, Counselling Psychology
Department of Education
Simon Fraser University

Dr. Lucy LeMare, PhD.
Senior Faculty Supervisor
Department of Education
Simon Fraser University

COLLABORATORS

This study is being independently conducted however, the Kamloops Pediatric Sleep Clinic, will support recruitment. The clinic is a collaborative project between the Centre for Respiratory Health and Sleep Science, Thompson Rivers University, and a local pediatrician, Dr. Allyson Davey. Respiratory therapy students from the clinic will share about the study, and collect and maintain Informed Consent documents. Students participating in this service are governed by Thompson Rivers University ethics, with direct oversight from the Centre Director, Mr. Les Matthews.

L. R. Matthews RRT (A) MA
Associate Professor of Respiratory Therapy
Anaesthesia Assistant Program Coordinator
Director, Centre for Respiratory Health and Sleep Science
Thompson Rivers University

Dr. Allyson Davey
Medical Director
Kamloops Pediatric Sleep Clinic
BACKGROUND

Pediatric sleep problems are pervasive and affect optimal child and family development. Conservative estimates suggest that up to 30% of typically developing children, and 80% of children with a neurodevelopmental condition may be affected by a sleep problem (Mindell & Owens, 2015). Pediatric sleep problems aggravate already existing health and behavioural challenges, but they also consume emotional resources, and cause increased and inappropriate use of various health services and medication driven treatments. In other words, missed sleep problems lead to unnecessary suffering. Based on my personal experience as the mother of a child with a sleep problem, and parent advocate for the Children’s Sleep Network, it has become clear to me that the current healthcare system does not adequately support families manage this health concern. With the availability of highly efficacious evidence-based treatments for sleep problems, how is this situation possible, and what can be done?

Disparity Between Research and Clinical Outcomes

The Sleep/-Wake Behaviours Clinic, operating out of Sunny Hill Children’s Health Center (an annex of BC Children’s Hospital), is the only tertiary level care center for children’s sleep in the province, and also functions as an internationally leading pediatric sleep research lab. In the fall/winter of 2013 clinicians became concerned that patients sleep did not appear to be improving, and wanted to understand the breakdown between evidence-based recommendations, and clinical outcomes. The clinic was already trialing a new assessment protocol, called “Functional Sleep/-Wake Assessment,” and decided to include the outcome evaluation with the project. In March 2013, 20 children (between the ages of 4 and 17) with suspected sleep problems were referred by community partner agencies and family doctors for assessment by a pediatric sleep specialist in their home community of Kamloops, BC. By delivering expert care in the patient’s community, the outreach clinic model attempted to overcome known barriers of access, assessment and practitioners’ skills/knowledge gaps. Based on the clinical research models, the team expected that the majority of the children would show significant improvements in their sleep (see Jan et al., 2008). One-year post-assessment, in March of 2014, I interviewed 16 of these families about their experiences of care and the usefulness of the recommended treatment plan in managing their child’s sleep problems (Graham, 2015).

All families interviewed felt that the assessment had been positive and informative. However, 80% reported no significant improvement in their child’s sleep situation; and, none of the families had fully complied with the clinical recommendations. This discrepancy between satisfaction and efficacy; and, motivation and action, provides important insights into the family’s experience of managing their child’s sleep problems, and the factors that inform ‘parental non-compliance.’ The results also problematize resource based models that conceptualize barriers as discrete entities without mutual interactions. Based on this information, existing models of sleep-care management do not adequately explain family’s experience of managing their child’s sleep problem. Why are parents non-compliant with physician’s recommendations for sleep care?
PARENT’S PERCEPTIONS OF MANAGING PEDIATRIC SLEEP-CARE
SFU STUDY # 2016S0267

Literature Review: Barriers to Pediatric Sleep-Care

Knowledge translation is a common problem in healthcare (see Green & Seifert, 2005). While clinical research has produced a variety of validated sleep-care interventions, individual outcomes remain very poor (see Boerner, Coulombe, & Corkum, 2015b; Mindell & Owens, 2015). Comparatively little attention has been given to why interventions fail to become effectively adopted in practice however, “parental non-compliance” is routinely used to explain “treatment failures” (see Mindell & Owens, 2003; Owens, 2001). Conventionally this behaviour is treated as symptomatic of the parent’s ineffectual limit setting (Mindell & Owens, 2015). However, as early as 1990, Durand and Mindell suggested that further research was required to understand the processes underlying ‘non-compliance,’ hypothesizing that poor limit setting may be influenced by factors such as maternal depression and marital stress, but as of yet, researchers have not formally explored this relationship.

A cross-disciplinary review of the literature (using CINHAL, PsychInfo and Medline), supports the need to go-beyond the clinical setting, to appreciate the complex and interacting contextual variables that may influence parent’s compliance with sleep-care interventions. A handful of studies have specifically asked parents what blocked or facilitated their ability to manage their child’s sleep problem (see Speth, Coulombe, Markovich, Chambers, Godbout, Gruber, … & Witmans, 2015). These studies offer an artificial and narrow view of the issue since they are limited to usability of a specific clinical intervention, and thus do not reflect a typical parent’s experience. This represents a critical gap given the ample evidence that associates pediatric sleep problems with contextual factors (see Table 1). Moreover, Canadian researchers have specifically identified individual and systemic factors as playing an instrumental role in the healthcare provider’s readiness and willingness to implement sleep-care treatment guidelines (Boerner, Coulombe, & Corkum, 2015a).

Table 1 Contextual Variables Associated with Pediatric Sleep Problems

<table>
<thead>
<tr>
<th>Family System</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent-Child Relationship</td>
<td>Bordeleau, Bernier, &amp; Carrier, 2012; Gregory, Rijsdijk, Dahl, McGuffin, &amp; Eley, 2006; Morrell &amp; Steele, 2003;</td>
</tr>
<tr>
<td>Parental Functioning</td>
<td>Adam, &amp; Snell, 2007; Spilsbury, Storfer-Isser, Drotar, Rosen, Kirchner, &amp; Redline, 2005; Bates, Viken, Alexander, Beyers, &amp; Stockton, 2002; Bernier, Belanger, Bordeleau, &amp; Carrier, 2013; Bordeleau, Bernier, &amp; Carrier, 2012; Byars, Yeomans-Maldonado, &amp; Noll, 2011; Hall, Zubrick, Silburn, Parsons, &amp; Kurinczuk, 2007; Minde, Popiel, Leos, Falkner, Parker, &amp; Handley-Derry, 1993; Reid, Hong, &amp; Wade, 2009; Martin, Barajas, Brooks-Gunn, &amp; Hale, 2011; Rhoades, Leve, Harold, Manning, Neiderhiser, &amp; Shaw, 2012</td>
</tr>
</tbody>
</table>
PARENT’S PERCEPTIONS OF MANAGING PEDIATRIC SLEEP-CARE  
SFU STUDY # 2016S0267  

| Family Relationships | El-Sheikh, Kelly, Bagley, & Wetter, 2012;  
| El-Sheikh, Buckhalt, Keller, Cummings, & Acebo, 2007;  
| El-Sheikh, Buckhalt, Mize, & Acebo, 2006;  
| Liu, Liu, Owens, & Kaplan, 2005  
| Lundahl, Nelson, Van Dyk, West, 2013;  
| Keller, & El-Sheikh, 2011;  
| Kelly, & El-Sheikh, 2011;  
| Reid, Hong, & Wade, 2009;  
| Rhoades, Leve, Harold, Mannering, & Neiderhiser, Shaw et al., 2012;  
| Sadeh, Raviv, & Gruber, 2000;  
| Simard, Bernier, Belanger, Carrier, 2013;  
| Scher, 2001  
| Warren, Howe, & Simmens, 2006  

| Workplace Safety and Job Performance | Hillman, Murphy, Antic, & Pezzullo, 2006  

| Healthcare System  
| Lack of Healthcare Practitioner Knowledge and Skills | Boerner et al., 2015a;  
| Boerner, Coulombe, & Corkum, 2015b  
| Limited Access to Services | Vriend, & Corkum, 2011  
| Inappropriate Pharmaceutical treatment | Jan et al., 2010  
| Inadequate Screening Measures | Spruyt & Gozal, 2011  

STUDY PURPOSE  
There is a significant disparity between clinical research and family’s lived experience of managing pediatric sleep problems that cannot be explained with existing models. Further research is required to understand the phenomenon of parent’s non-compliance with physician’s recommendations for pediatric sleep-care. Therefore, the purpose of this study is to explore parent’s perceived barriers to and facilitators of implementing sleep-care recommendations within the family, and within the current healthcare system.  

AIMS  
Using a grounded theory approach, I will seek to describe: a) the contextual factors affecting pediatric sleep problems; b) parent’s experience of implementing physician’s sleep-care recommendations; and, c) identify the resources that support the family in implementing sleep-care recommendations. At the individual level, understanding the meaning of sleep problems for
the family, and the effects they have on treatment may help inform care planning, and increase intervention success rates. Developing a better understanding of how parents experience and manage sleep problems will also help guide health policy and program development.

LOCATION OF RESEARCH

Participants will be recruited from the Kamloops Pediatric Sleep clinic, located at:

Thompson Rivers University
900 McGill Road
Kamloops, BC V2C 0C8

Participants will be given the option of choosing a time and location for their individual interview. Depending on the availability of the researcher, and the participant’s preference, this may be conducted in-person, in a private location (such as the participant’s home or physician’s office), or by telephone.

PROSPECTIVE PARTICIPANT INFORMATION

Inclusion Criteria

Participants for this study will include “Parents of children (0-18 years) with a self-reported sleep problem who are seeking support for their child’s sleep from the Kamloops Pediatric Sleep Clinic.”

Parents

The decision to limit the sample to “parents” was carefully considered, as older youth and adolescents may be able to offer important insights about their own experience. From a theoretical perspective, sleep is a learned behaviour that is co-regulated within the parent-child relationship. Regardless of the age, all evidence-based sleep-care recommendations involve some parental involvement and oversight to be successful. For the purposes of this study, the term “parent” will understood broadly as referring to a child’s primary caregiver. Additionally, based on observations made about families attending the Sleep/Wake Behaviours Clinic, it would seem that a disproportionate percentage of children with sleep problems may be living in non-traditional family arrangement (e.g. with grandparents). So as not to overlook these family’s experiences, I will include non-biological “parents.”

Parent-Reported Sleep Problem

The concept of “parent-reported sleep problems” captures clinical and sub-clinical cases, and overcomes diagnostic barriers (see Allen et al., 2003; Mindell & Owens, 2015). Furthermore, cross cultural analysis of sleep problems has shown significant differences in what is considered problematic, and normative management strategies (e.g. co-sleeping) (Sadeh, Mindell, & Rivera, 2011). To accommodate these challenges, many clinicians prefer to regard sleep problems as clinically significant when the issue is affecting the family’s wellbeing to the point where they have sought medical advice from a healthcare provider (Sadeh et al., 2011). Therefore, for the purposes of this study, I will also adopt this broad definition, and consider “parent-reported sleep problems.”
Limiting the sample to parents seeking help from the healthcare system contextualizes the problem within the healthcare system, and links parents experience directly to other known barriers. By situating the data within one shared experience—contact with the physician—common patterns may be easier to locate. For example, by understanding what the prompting event was to contact the physician, and the family’s relative level of distress at that point, we may be able to tailor interventions better to family’s resources and needs and/or intervene earlier in the health journey. Finally, Sadeh et al. (2011) have suggested that using help seeking behaviours as a measure of perceived distress may overcome differences in cultural perceptions of sleep problems.

**Medical Status**

I carefully considered limiting participants according to diagnosis and medication use. There is considerable controversy in the literature about the relationship between neurodevelopmental disabilities and sleep, and debate about whether missed/undiagnosed sleep problems may be frequently mistaken and treated as psychiatric conditions (Ipsiroglu, 2008). To manage this controversy, most studies exclude children with neurodevelopmental disabilities and/or who are taking psychotropic medications (e.g. CIHR’s Better Days, Better Nights). However, the purpose of this study is not to differentiate between diagnostic categories or investigate the effects of medication on sleep. As a grounded theorist, I am concerned with describing a central phenomenon in a way that brings awareness and support for a greater public good. I believe this is best accomplished by identifying common experiences and needs.

**Aboriginals and First Nations**

Aboriginal and First Nations populations are not a focus of this study.

**Organizations**

Approval has been sought from The Kamloops Pediatric Sleep Clinic and Thompson Rivers University. A copy of this letter is included in the application.

**Exclusion Criteria**

For practical reasons, inclusion in the study will be limited to families receiving care from the Kamloops Sleep Clinic. This service is open to all families in the Interior Health Region, with a referral from their family physician or pediatrician, limiting the sample to families covered by BC MSP healthcare.

**Number of Participants**

I anticipate enlisting between 20 and 30 parents for in-depth interviews. Guided by the concept of saturation (Glaser & Strauss, 1967), this sample size is expected to be large enough that most or all perceptions of importance will be uncovered, but not so large that data collection will become redundant.
PARENT’S PERCEPTIONS OF MANAGING PEDIATRIC SLEEP-CARE
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DETAILED RESEARCH PROCEDURES

Third-Party Recruitment Procedure

The Kamloops Pediatric Sleep Clinic will facilitate recruitment for this study. As an MSP healthcare service and university program, the Clinic is required to maintain strict confidentiality of its patients. I will only have access to the names of consenting participants. Participants will be recruited by telephone and in-person.

Telephone recruitment. Clinic staff (TRU Respiratory Therapy students) will contact parents of existing patients by telephone to invite them to participate in the study, and request verbal consent to be contacted by the researcher. Parents will be given a brief overview of the study (see “Telephone Introduction Script”). If the parent agrees to be contacted with further study details, the clinic staff will email a copy of the study package (portfolio, parent invitation letter, and consent form). The parent’s verbal consent to be contacted will be documented on the consent form (pg. 4/4), and a copy of the consent will be emailed to the researcher. The researcher will contact the parent by telephone, and provide details of the study and answer any questions. If the parent is interested, the PI will refer the participant to the consent document (received by email) and read the "Telephone consent script" to obtain verbal consent. The researcher will document verbal consent on the hard copy of the consent form.

In-person recruitment. Each family attending the Kamloops Pediatric Sleep Clinic participates in an intake interview conducted by the TRU Respiratory Therapy students. During this meeting, families are familiarized with the clinic, asked to provide a detailed history of the presenting problem, and depending on the issue, complete a set of self-assessment questionnaires. During this intake process, parents will be invited to participate in the proposed study.

The Clinic team will assure parents that participants in the study is completely voluntary, and that all families will receive the same level of care regardless of whether they choose to participate. The Informed Consent document reiterates this message, and notifies prospective participants of their rights as a participant, specifically that they have the right to refuse and/or withdraw their consent at any time without explanation or fear of repercussion.

The Clinic’s team will provide families with a letter of invitation, informed consent document, a Vancouver Sun Newspaper article about my family’s experience with pediatric sleep problems, and my related advocacy work. I hope that personalizing the invitation will make families feel more connected to the study and comfortable with me as a researcher. A copy of the recruitment materials is included in the application. Parents are free to consent/decline, or request that I call them directly to discuss the project in greater detail.

Interview Procedure

Participants will be invited to sit down for a one-hour interview in which I will ask open-ended questions about their experience managing their child’s sleep problem. I have provided an Interview Protocol in the application outlining the types of questions I will ask participants. The protocol was developed through: a series of pilot interviews, a review of guides to conducting grounded theory research (e.g. Charmaz, 1990; Cobrin & Strauss, 2006; Creswell, 2007; Glaser
PARENT’S PERCEPTIONS OF MANAGING PEDIATRIC SLEEP-CARE
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& Strauss, 1967), discussions with my senior research supervisor, as well as through the initial
review of the literature.

Following the interview, I will share a copy of the transcript with the participant for their
review and approval. The same procedure will be followed with the final draft.

Reimbursements and Payments

Participants will not be renumerated. Based on my previous experience working with this
population, I expect that they will be intrinsically motivated to participate.

Secondary Data/Tissue Analysis

Secondary data and tissue analysis will not be used in this study.

Deception/Partial Disclosure

Deception will not be used in this study, and participants will be fully briefed on all
aspects.

Video/Audio Recording

In-person and telephone interviews will be digitally audio recorded using my personal
password protected iPhone. In-person interviews will be recorded using the voice memo app and
external microphone, and phone interviews will be recorded using the Call Recorder App
developed by Component Studios. Participants are informed that all interviews will be recorded
in the Informed Consent document.

Instrumentation

No instrumentation will be used in this study.

Online Surveys

Online surveys will not be used in this study.

Obtaining Consent

Participants will review and sign the Informed Consent document. Contact information
for the study team is included in the document, and participants are invited to contact the
researcher for more information about the study prior to making their decision. The Kamloops
Pediatric Sleep Clinic team will email me a password protected electronic copy of the Informed
Consent document. I will collect these documents at the end of the study.

Once I have received the Informed Consent, I will contact participants by phone, and
answer any questions they may have. If they are agreeable, we will schedule an interview.

Competency and Capacity

This study seeks to understand parents’ experience, and will not involve minor children. However, to avoid unfairly excluding participants, parents over the age of 14-years, who
PARENT'S PERCEPTIONS OF MANAGING PEDIATRIC SLEEP-CARE
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understand the significance of the study, and appreciate the risks and benefits to participating
will be considered mature minors, and eligible for the study.

Participants will be selected on the basis of their interest in and ability to share their experiences. By making these decisions, I recognize that significant perspectives may not be included. Parents with low functioning (by virtue of intellectual, mental health or other challenges) may be excluded. This represents an important population given the connection between mental health, drug and alcohol addiction, and paediatric sleep problems. As a result, families with children in foster care, and indigenous and marginalized groups (including new immigrants) may not be adequately represented.

Consent for Individuals Who Lack the Capacity to Consent for Themselves

I will use my clinical judgment and training in psychological assessment to determine whether a participant is capable of providing informed consent.

POTENTIAL BENEFITS

Improved Quality of Care and Services

The Kamloops Pediatric Sleep Clinic will use information from this study to improve care and services for their families. This information may result in improved healthcare outcomes and quality of life for the families who participate in the study.

The community of Kamloops has demonstrated a commitment to supporting families managing sleep problems. The Kamloops Pediatric Sleep Clinic was developed in response to a similar study. Community support agencies and healthcare practitioners have endorsed this project, and intend to use the information from the study to develop local resources and services that will support participant-families.

Psychological Relief

As a parent who has dealt with her own child’s sleep problems, I understand the impact that this issue can have on the individual parent and family, and hope that participating in the study will give parents an opportunity to share their experience, and opportunity to explore the challenges they are facing. Some parents may find this psychologically unburdening, and a useful way to reflect on how their family is coping with the issue.

POTENTIAL RISKS

There is no foreseeable risk associated with this study for individual participants, organizations, or the community.

Psychological Harm

The interview is an opportunity for participants to reflect on how the issue has affected different aspects of the family’s life. In many cases, speaking about the experience may be
relieving however, it may bring up issues that could be distressing. As a Counselling Psychology student, I feel prepared to safely manage these reactions, and can support self-referral for additional care if required. I have also provided a contact number for the Kamloops Crisis Line in the informed consent document.

Risks to Principal Investigator or Research Staff

The research will be conducted inside Canada, and there are no know risks to the Principal or research team.

DESIGNATION OF THE STUDY AS MINIMAL OR NON-MINIMAL RISK.

This study carries minimal risk. Participants will already be engaged in conversations about their experience of their child’s sleep problem with the healthcare team, and as such the study does not introduce any additional element of stress or risk compared to their daily life.

MAINTENANCE OF CONFIDENTIALITY

The psychological wellbeing of participants is of upmost importance, and the research team will make every effort to protect participant’s anonymity and confidentiality.

Anonymity

A pseudonym will be assigned to each participant when the data is reported. One key sheet will be made containing the pseudonym and real name of each participant, along with contact information.

Confidentiality

Because this study uses electronic communication and audio recording, the Informed Consent document notifies participants that telephone and email are not secure methods of communication, and therefore absolute confidentiality cannot be guaranteed. Participants are encouraged to conduct the interview in a private location where they will not be interrupted or overheard. As the researcher, I commit to doing the same. All communication via email will password protected so only the participant can open them.

Because this study asks parents to speak about their family’s experience, the Informed Consent document advises participants of the legal limitations of confidentiality as they relate to child abuse and neglect, and my duty to report.

Access to the Data—Investigators and Staff

Only the research team, Kirsten Graham and Dr. Lucy LeMare, will have access to the raw data. This is outlined in the Informed Consent Document.

DATA ANALYSIS PLAN

The selection of a grounded theory approach was informed by my observations and previous experience speaking with families and clinicians suggesting that a) the constructs previously explored are too limited and do not appreciate the full dimension of the family’s experience; and, b) quantitative methodologies do not capture the systems and relationships.
influencing sleep problems and their management. Researching a novel perspective previously owned by quantitative research presents several methodological challenges.

Grounded theory is a rigorous qualitative approach (Glaser & Strauss, 1967). Because the approach uses a larger number of participants, and employs more structured procedures for data analysis, it is generally seen as the qualitative approach that allows for the greatest degree of generalization or “transferability” to other contexts (Cullingworth, 2014, p. 30; also see Charmaz, 1990; Lincoln & Guba, 1985).

Coding

I come to this project with my own personal experience and a priori theories from my previous research. Indeed, one might suggest that I have focused my research questions and participants around nascent categories. Based on this awareness, I align myself with Charmaz (1990), and see the knowledge acquired through this research as being co-constructed between myself and the participants. Thus, I will constantly ask myself “what seems to be going on here?” and create thematic codes or “categories” that represent a shared experience. (Strauss & Corbin, 1998, p. 148; see also Corbin & Strauss, 2008; Glaser & Strauss, 1967).

Data Organization

Interview data will be transcribed verbatim and uploaded into the qualitative analysis software, NVivo 10, a computer software used by researchers to create an efficient means to store, organize, and work with qualitative data. The system also facilitates credibility, making my decisions as a researcher more transparent and documented for future consumers.

Validity and Credibility

To ensure that the theory is emerging from the participants, and not being forced into my own ideas, I will engage in methodical coding, theoretical sampling, constant comparison and memoing (Charmaz, 1990; Cullingworth, 2014, p. 31). Credibility will come from making my steps clear: through generating the interview protocol, into selecting an appropriate site for study, and to selective sampling. In coding, I will make an attempt to illustrate participant’s views using their own words as possible in order to keep the theory truly grounded in the data. I will also employ validation procedures such as constant comparison, flip-flop techniques and negative case analysis to test my emergent theory.

RETENTION AND DESTRUCTION OF DATA

Informed Consent Documents

Original copies of the Informed Consent documents will be stored in a locked cabinet at the Kamloops Pediatric Sleep Clinic. Only the Clinic’s team will have access to this cabinet. The researcher will collect the documents at the end of the study.

Participant Key
PARENT’S PERCEPTIONS OF MANAGING PEDIATRIC SLEEP-CARE
SFU STUDY # 2016S0267

I will maintain one copy of the participant key, including names, pseudonyms and contact information. I will keep this document locked in a cabinet in my home during the research period.

Digitally Recorded Audio and Electronic Communication

Digital audio recordings will be immediately uploaded from my personal, password protected iPhone onto a personal, password protected laptop for the period of transcription and analysis. The audio recording will be immediately deleted my phone. Copies of emails sent between the myself and the participants will also be stored on the same laptop. These files will also be backed up on an external drive, which will be stored in the same locked cabinet as the participant key in my home.

Post-Study Storage and Destruction Plan

Once the analysis is complete, the external hard drive will be transferred to the research lab of Dr. Lucy LeMare, in SFU’s Education Building, room 7505, where it will be stored in the same locked cabinet as the key sheet for participant identities and Informed Consent documents. In compliance with SFU policy, after two years, both the hard drive, participant key, and Informed Consent documents will be destroyed.

DISSEMINATION OF RESULTS

All participants will receive a copy of the final report by email. The report will also be shared with the Kamloops Pediatric Sleep Clinic. Contact information for the study team is also included in the Informed Consent document.
References


PARENT’S PERCEPTIONS OF MANAGING PEDIATRIC SLEEP-CARE
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PARENT’S PERCEPTIONS OF MANAGING PEDIATRIC SLEEP-CARE
SFU STUDY # 2016S0267


Barriers and facilitators of evidence-based practice perceived by behavioral science health

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PARENT'S PERCEPTIONS OF MANAGING PEDIATRIC SLEEP-CARE
SFU STUDY # 2016S0267


Appendix C.

Participant invitation portfolio

Dear Parent,

My name is Kirsten Graham. I am the researcher conducting the “Parent’s Perceptions of the Barriers to and Facilitators of Managing Paediatric Sleep-Care” study. I’m also the mother of a child with a sleep problem.

Between the time she was born and Kindergarten, our daughter missed 2007 nights of sleep. Her brain suffered. Her body suffered. Our family suffered. Over five years, she was assessed by seven healthcare professionals, including three pediatric specialists. Along the way she received four different mental health diagnoses and, experienced a severe adverse drug reaction to pharmaceutical treatment. Professionals prepared us for a dark future, where unknown mental health and addiction dangers loomed. Worse yet, without sufficient explanations, my mothering was framed as the problem, and the fact that our daughter continued not to sleep got lost. I left my job, and with it financial security and my identity, to find help for our daughter. My husband and I were terrified, and through the gruelling sleepless nights and endless days, it became difficult to find support and comfort in each other. I felt ashamed, inadequate and helpless.

Based on our family’s experience, I have returned to school to become a family counsellor, and work alongside healthcare providers and families to advocate for better support for children’s sleep problems. I hope that you might be willing to share your story so healthcare providers can understand how to best help families manage their child’s sleep problem.

Regards,

Kirsten Graham
Sleep disorders go unnoticed as children suffer, parents say

ERIN ELLIS, VANCOUVER SUN 12.27.2012 |

Emmy Graham, front, sleeps better than she used to and the whole family is much happier. Dad Rob holds Emmy’s younger siblings Rachel and Derek while mom Kirsten looks on in their Burnaby home. WAYNE LEIDENFROST / VANCOUVER SUN
Even in the womb, Emmy Graham was different.

“We called her squirmy from the moment I felt her move,” says her mother, Kirsten.

“She was always moving, constantly, even in utero,” her father adds.

During a recent conversation in their toy-filled Burnaby home, Rob and Kirsten Graham, now in their early 30s, say they want to tell other parents about their five-year odyssey to find an answer for Emmy’s problems in the hope others won’t have to repeat their years of frustration, isolation and angst.

As an infant, Emmy would sleep only eight hours a day — in fits and starts, never in a stretch. There were no naps after the age of one and maybe six or eight hours of restless sleep a day. Toddlers are supposed to spend about half of every 24 hours asleep.

Without that much-needed rest, Emmy threw daily tantrums and screaming fits. Her development stalled; even at age five she couldn’t hold a pencil. She was diagnosed with a developmental co-ordination disorder, attention deficit hyperactivity disorder (ADHD), attachment disorder and anxiety.

“Her brain wasn’t sleeping enough to lay down the motor pathways for co-ordination,” says Kirsten. “None of the pieces can come together for kids if they’re not sleeping.

“So it’s not just a matter that this is a family problem where you have a tired, crazed kid that’s flying off the handle all the time. There’s a very real disability component.”

Finally, a year ago, Osman Ipsioglu, a Vancouver pediatrician with expertise in sleep problems, diagnosed Emmy with restless leg syndrome, a common condition for adults, but rarely recognized in children.

Instead, it and other under-recognized sleep disorders are lumped into the growing number of ADHD cases in B.C., he say, adding that pediatricians and child psychologists should rule out sleep disorders before making an ADHD diagnosis.

“We believe that there is a tremendous overlap with ADHD ... If you don’t sleep well, you will have some behavioural issues the next day. You will be grumpy, you will less tolerant, possibly, and this is what happens with the
kids. If they have chronic sleep deprivation, they may have an ADHD-like presentation.”

A misdiagnosis isn’t benign. If typical stimulant medications for ADHD are prescribed, the itching, crawling, creeping feelings of restless leg syndrome are amplified.

Untangling the difference between run-of-the-mill ‘I don’t want to go to bed’ pushback from a three-year-old and a child with a serious medical issue is not easy, Ipsiroglu admits.

He suggests an individualized approach to each child, something that’s effectively impossible right now in B.C. because there aren’t enough health professionals who know what they’re looking for.

“There simply isn’t the training at the medical level to recognize it,” says Kirsten. “We started to think: Maybe we are crazy. Maybe it is our fault.”

After their second child was born, it was evident that Emmy’s co-ordination and patience, at three, was about the same as her one-year-old sister. Although the family initially sought medical help for Emmy’s lack of sleep, the focus quickly moved to her worsening daytime outbursts.

Once that happened, their search for the answer to ‘Why can’t our daughter sleep?’ was forgotten. Instead, child psychiatrists told Kirsten that her lack of attachment to her child was the problem.

“I remember time and time again in the psychologist’s office saying, ‘but she came this way.’

“I won’t discount that there was a problem in our relationship, but it starts to grow out of having a child that won’t look at you, won’t touch you, (whom) you can’t comfort … I was desperate as a mother that I couldn’t care for her,” Kirsten says.

“In hindsight, it’s obvious that a child that won’t look at you and won’t be comforted is in physical distress,” says Rob.

But no one before Ipsiroglu put the puzzle together.

Research over the past decade suggests that one- to five-per cent of people have restless leg syndrome, now called Willis Ekbom disease in recognition of the doctors who documented it in the 17th and 20th centuries. It’s a
neurological disorder and may be related to levels of the neurotransmitter dopamine in the brain and iron in the blood. (See factbox.)

It’s a highly inheritable condition: both Rob and Kirsten have it — Rob more severely — but they weren’t diagnosed with it until Emmy responded to neuropathic pain medication, in her case Gabapentin, which is also used to control pain in extremities caused by diabetes.

“We’re seeing remarkable gains in Emmy now and we’re very hopeful that she’ll be able to catch up, but the truth is we don’t know what the long-term outcome is for her.”

Kirsten hopes concerned parents and professionals are able to create a proposed Children’s Sleep Network to spread information among health workers and establish a hotline for parents.

“We want people not to feel alone.”

Wendy Hall, a professor in the University of B.C.’s school of nursing, has conducted sleep studies and is currently writing up her findings following more B.C.-based research.

“It’s an overlooked public health issue,” she says. “We’re trying to work out how to raise sleep higher on the agenda for health-care professionals.”

Sleep dysfunction is not covered in the curricula for training doctors and nurses, she adds, so parents often end up seeking out ‘sleep consultants’ who have no governing body checking their credentials. “Less than one percent (of families) get evidence-based help with sleep issues.”

Part of the problem may be found in changes within society, she says, with both parents working longer hours and pushing back bedtimes in order to spend more time with their children. Studies show a trend over time of both parents and children getting fewer hours of sleep as society seems to value it less. To make it worse, today’s electronic distractions, such as TV, websurfing and video games, make people want to stay awake later.

eellis@vancouversun.com (mailto:eellis@vancouversun.com)

Appendix D.

Verbal invitation and consent procedure

VERBAL CONSENT PROCEDURE AND SCRIPT

Parent’s Perceptions of the Barriers and Facilitators of Managing Pediatric Sleep Recommendations

This document outlines the protocol and verbal consent script for contacting parents of existing patients.

STUDY INTRODUCTION: TELEPHONE PROCEDURES AND SCRIPT

1. clinic staff (TRU respiratory therapy students) will contact parents of existing patients by telephone to invite them to participate in the study.

2. Parents will be given a brief overview of the study using the following introduction script.

TELEPHONE INTRODUCTION SCRIPT

“Hello (parent name), this is (clinic staff’s name) calling from the TRU Respiratory Therapy clinic. I am calling to invite you to participate in a study about parent’s experience of managing their child’s sleep problem.

The study is being conducted by Kirsten Graham from Simon Fraser University as part of a counselling psychology thesis project. Kirsten is also the parent of a child with a sleep problem. Many families report difficulties implementing recommendations, and Kirsten is studying what helps families and some of the difficulties they face. By participating in the study, you’ll help our clinic improve the quality of care and services we offer.

Your participation in the study is completely voluntary, and will not affect the care you receive. If you choose to participate, Kirsten will schedule an interview over the phone that will take approximately 45 min. Would you be open to Kirsten contacting you? (No) Thank you for your time, we look forward to seeing you and your child at your next appointment. (Yes) Thank you. I will send you a package about the study by email, and Kirsten will be in touch within the week to schedule a call.”

1. If the parent agrees to be contacted with further study details, the clinic staff will email a copy of the participant package (portfolio, parent invitation letter, and consent form). Families regularly communicate with the clinic by email, and all potential participants have active emails. The parent’s verbal consent to be contacted will be documented on the consent form (pg. 4/4). See sample below:
Appendix E.

Participant consent form

OFFICE OF RESEARCH ETHICS
SFU Study #2016S0267

CONSENT FORM

Parent’s Perceptions of the Barriers and Facilitators of Managing Pediatric Sleep Recommendations

STUDY TEAM

Who is conducting the study?

Kirsten Graham, BA
Principal Investigator
MA Student, Counselling Psychology
Department of Education
Simon Fraser University

Dr. Lucy LeMare, PhD.
Senior Faculty Supervisor
Department of Education
Simon Fraser University

This study is being conducted as part of a graduate thesis in Counselling Psychology.

INVITATION AND STUDY PURPOSE

Why are we doing this study? Children’s sleep problems are common, and although there are proven treatments available, some families have reported difficulties implementing them. We know very little about parent’s experiences of carrying-out their physician’s recommendations for their child’s sleep, and would like to learn more about what helps families, and the barriers they may face.

VOLUNTARY PARTICIPATION

Do I need to participate to receive care from the Kamloops Pediatric Sleep Clinic? Participation in this study is completely voluntary. Your family will receive the same level of care from the Kamloops Pediatric Sleep Clinic regardless of whether you choose to participate.

STUDY PROCEDURES

What happens if you say, “Yes, I want to be in the study?” If you chose to participate, the Kamloops Pediatric Sleep Clinic team will provide the researcher, Kirsten Graham, with your contact information. Kirsten will call you, and arrange a time for an interview. This interview may take place in-person, or by phone, depending on your preference and mutual availability. The interview will last approximately one-hour, and Kirsten will ask you open-ended questions about what it has been like to manage your child’s sleep problem. The interviews will be audio recorded. After the interview, Kirsten will send you a copy of the interview transcript (record) in case you’d like to read it over. Later, Kirsten will also send all participants a draft of her findings to get their feedback, but, again, you don’t have to provide her with feedback if you don’t want to.
POTENTIAL BENEFITS

Why should I participate? By participating in this study, you will offer your healthcare team with a better understanding of what it’s like to manage your child’s sleep problem. The Kamloops Pediatric Sleep Clinic will use this information to improve care and services.

The Kamloops Pediatric Sleep Clinic came about because of parent’s feedback, and community partners and physicians may use the information you share to develop local solutions and services. More broadly, findings from this study to direct policy and program changes, or formulate future research.

As a parent who has dealt with her own child’s sleep problems, Kirsten understands how difficult it can be, and hopes that participating in the study will give you a chance to share your experience with someone who understands, and an opportunity to explore the challenges you are facing. Some parents may find sharing unburdening, and a useful way to reflect on how their family is coping with the issue.

More broadly, this information may be used as part of healthcare practitioner training, and shape how pediatric sleep problems are viewed and managed in the healthcare system.

POTENTIAL RISKS

What are the downsides to being in this study? There is minimal risk to participating in the study. Your child will receive the same level of care from the Kamloops Pediatric Sleep Clinic, regardless of whether you choose to participate.

This conversation may be an opportunity for you to reflect on how the issue has affected different aspects of your family’s life. In many cases, speaking about the experience may be relieving however, it may bring up issues that could be distressing. Should you require support please speak with your healthcare professional, or in case of emergency contact the Canadian Mental Health Service Crisis Line through:

Kamloops Crisis line number: 1-888-353-CARE (2273)

CONFIDENTIALITY

I will be sharing information about our family. How will my identity and privacy be protected?
The research team will make every effort to protect your identity and privacy.

If you decide to participate, we will take every step possible to ensure your anonymity and confidentiality. Information that discloses your identity will be not released without your consent unless required by law (such as in the case of known or suspected child abuse or neglect).

A pseudonym (fake name) will be used instead of your name when the data are reported. One key sheet will be made containing the pseudonym and real name of each participant, along with contact information. This key will be kept in a locked cabinet in the research lab of Dr. Lucy LeMare, in SFU’s Education Building, room 7505.

Participants reminded that telephone and email are not secure methods of communication, and therefore absolute confidentiality cannot be guaranteed. Participants are encouraged to conduct
the interview in a private location where they will not be interrupted or overheard. Kirsten will
do the same. Following the interview, Kirsten may communicate with participants through email.
To protect your privacy, all documents shared by email will password protected so only you can
open them.

All interviews will be digitally audio recorded on Kirsten’s personal, password protected iPhone.
Kirsten will transcribe the sessions herself. Having this record helps Kirsten to review the data
more thoroughly and come back to it if necessary. These transcriptions will not be shared with
anyone outside the Study Team. The transcriptions will be stored on Kirsten’s personal,
password protected laptop, during the period of analysis. Any audio recordings will be
immediately deleted after transcription is completed. Copies of emails sent between Kirsten and
participants will also be stored on the same laptop, and all these files will also be backed up on
an external hard drive, which will be stored in a locked cabinet in Kirsten’s home. Once the
analysis is complete, the external hard drive will be transferred to the research lab of Dr. Lucy
LeMare, in SFU’s Education Building, room, 7505, where it will be stored in the same locked
cabinet as the key sheet for participant identities. After two years, both the hard drive and key
sheet will be destroyed.

WITHDRAWAL AND COMPLAINTS

What if I decide to withdraw my consent to participate? You can withdraw your participation at
any time without giving reasons, and without any effect on the care you receive from the
Kamloops Pediatric Sleep Clinic. If you choose to withdraw, please notify the Principal
Investigator, Kirsten Graham, by email at [email protected] so your data can be removed
from the study.

ORGANIZATIONAL PERMISSIONS

Permission to conduct this research study has from Thompson Rivers University and the
Kamloops Pediatric Sleep Clinic has been obtained.

STUDY RESULTS

The results of this study will be reported in Counselling Psychology graduate thesis and may also
be published in journal articles and books. All participants will receive a copy of the final thesis
by email.

CONTACT INFORMATION ABOUT THE STUDY

I have more questions, who can I contact? Should you wish to obtain information about this
study, please contact Kirsten Graham, [email protected] or Lucy LeMare at
[email protected]

CONTACT FOR COMPLAINTS

Who can I contact if I have complaints or concerns about the study? If you have any concerns
about your rights as a research participant and/or your experiences while participating in this
study, you may contact Dr. Jeffrey Toward, Director, Office of Research Ethics [email protected]
or [email protected].
FUTURE USE OF PARTICIPANT DATA

I am interested in understanding patterns of behaviour, not describing the experience of specific individuals. As such, my findings will describe a shared experience, and individual data will be destroyed.

FUTURE CONTACT

Are you willing to be contacted in the future for follow-up or other studies related to your child’s sleep problems?

☐ Yes, I consent to being contacted in the future.

PARTICIPANT CONSENT

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on the care you receive for your child’s sleep problem.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature below indicates that you consent to participate in the study.
- Your signature indicates that you consent to Kirsten digitally audio recording the interview.
- You do not waive any of your legal rights by participating in this study.

<table>
<thead>
<tr>
<th>Participant’s Name</th>
<th>last name</th>
<th>first name</th>
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<tbody>
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<td>Participant’s Phone</td>
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<td>Participant’s Email</td>
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<td>Participant’s Signature</td>
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<tr>
<td>Date (YYYY/MM/DD)</td>
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</tbody>
</table>
Appendix F.

Sample Interview Questions

Tell me about your child’s sleep issues

   When did it start?
   How is it manifested?

What impact has it had on your family/marriage/work/relationships with child/child’s schooling/peer relationships?

What help have you sought for the sleep problem? Please explain.

Describe what your physician recommended?

   How helpful has it been?
   How much faith do you have in these recommendations?

   What made following the doctor’s recommendations hard.
   What made following the doctor’s recommendations easy.

   How much support have you had in following the recommendations?
   What support do you feel you need to follow the recommendations?

   How realistic are these recommendations?
   Have you followed all the recommendations or just some?

   Why some and not others?

How do your individual family members respond to these recommendations?

   The kid who can’t sleep?
   Siblings?
   Spouse?