"*I don't think there's anything typical about it.*" Exploring Sleep in Families with a Child with Autism Spectrum Disorder

by

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An oral defense of this thesis took place on April 13, 2023 in front of the following examining committee:

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Chair of Examining Committee	Dr. Nicholas La Delfa
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The above committee determined that the thesis is acceptable in form and content and that a satisfactory knowledge of the field covered by the thesis was demonstrated by the candidate during an oral examination. A signed copy of the Certificate of Approval is available from the School of Graduate and Postdoctoral Studies.

ABSTRACT

Purpose: Sleep is an important mechanism for everyday functioning and childhood development. Children with autism spectrum disorder (ASD) tend to have high rates of sleep problems. This interpretive phenomenology-informed study aims to fill the gaps on the experiences of family sleep with a child with ASD.

Methods: Purposive sampling was used to recruit parents of at least one child with ASD. Fifteen in-depth, semi-structured interviews were conducted with parents.

Findings: Themes included (1) environmental factors contributing to sleep, (2) individual and family consequences of sleep loss, (3) parental internalization of emotions and conflicts surrounding sleep, (4) mitigation strategies used to improve sleep; and (5) the knowledge and beliefs that parents have about sleep.

Discussion: Findings suggest that parents understand what it takes to achieve sleep in their homes and carry mental and emotional burdens related to sleep, focused on making sure their child(ren) get enough sleep.

Keywords: Sleep; Autism Spectrum Disorder; Family; Qualitative Methodology

AUTHOR'S DECLARATION

I hereby declare that this thesis consists of original work of which I have authored. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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The research work in this thesis was performed in compliance with the regulations of Research Ethics Board/Animal Care Committee under **REB Certificate number 15788.**

Emma Grant

STATEMENT OF CONTRIBUTIONS

The work described in Chapter 4 has been submitted to the *Journal of Child and Family Studies* and is currently under review:

Grant, E., Mior, S., Cancelliere, C., & Papaconstantinou, E. (2023). *"I don't think there's anything typical about it.*" Exploring Sleep in Families with a Child with Autism Spectrum Disorder.

This work has also been accepted as a poster presentation at the 2023 Canadian Sleep Society National Conference in Ottawa, Ontario, Canada (April 26-30, 2023).

I hereby certify that I am the primary author of this thesis and that no part of this thesis has been published yet. I have used standard referencing practices to acknowledge ideas, research techniques, or other materials that belong to others. Furthermore, I hereby certify that I am the sole source of the creative works and/or inventive knowledge described in this thesis.

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LIST OF ABBREVIATIONS AND SYMBOLS

ASD	Autism Spectrum Disorders
APA	American Psychological Association
CDC	Centers for Disease Control and Prevention
COREQ	Consolidated Criteria for Reporting Qualitative Research
NTD	Neuro-typically Developing
PHAC	Public Health Agency of Canada

Chapter 1. Thesis Introduction

1.1 Thesis Introduction

My thesis consists of a qualitative study designed to explore the experiences and perceptions of sleep in families with a child with Autism Spectrum Disorder (ASD). This research was undertaken to further our understanding of factors influencing sleep with participants recruited in partnership with Grandview Children's Center.

ASD is a group of neurodevelopmental disorders with a complex combination of symptoms that can impact communication, behaviours, and even sleep (APA, 2013; Benson et al., 2019; Petrou et al., 2018). Sleep is an important function in both daily functioning and, especially for children, development (Karthikeyan et al., 2020). Children with ASD experience sleep difficulties much more frequently than neuro-typically developing (NTD) children and are more likely to have disruptive sleep behaviours including bedtime resistance, nightmares, and early morning awakenings (Carmassi et al., 2019; Kirkpatrick et al., 2019; Richdale & Schrek, 2009). These problematic sleeping behaviours have the potential to impact the sleep of the entire family, beyond the child with ASD, due to burdens of nighttime care, disruptions, and stress (Karthikeyan et al., 2020; Chou et al., 2012). The family perspective of sleep, as well as how families navigate and mitigate sleep problems has remained understudied.

1.2 Contributions

I have outlined my contributions to this thesis below:

1. Conducted the review of the literature;
2. Designed the study and study protocols;

3. Contributed to the writing of the research ethics application to the University of Ontario Institute of Technology;
4. Consulted with Grandview Children's hospital on feasibility and recruitment for the qualitative study;
5. Developed and piloted the semi-structured interview guide;
6. Conducted the semi-structured interviews;
7. Conducted the qualitative analysis;
8. Primary author on the paper presented in this thesis.

1.3 Background

The purpose of this section is to:

1. Describe the complex symptomology of autism spectrum disorders (ASD);
2. Introduce the importance of sleep and sleep behaviours;
3. Identify existing literature on sleep in families with a child with ASD; and
4. Identify knowledge gaps.

1.3.1 ASD

Autism spectrum disorders (ASD) are a group of neurodevelopmental disorders characterized by a complex combination of symptoms that can impact many parts of daily functioning; especially communication, behaviour, and social skills (American Psychology Association (APA), 2013; Benson et al., 2019). The prevalence of ASD in Canada has increased in recent years with 1 in 66 children being diagnosed with ASD (Public Health Agency of Canada (PHAC), 2018). ASD is characterized by a core set of symptoms, but there is wide presentation in severity. Children with ASD may have behaviour regulation difficulties presenting as non-compliance and severe tantrums, as

well as co-existing conditions including emotional regulation disorders, and sleeping problems (Matson, 2009; Summers et al., 2017; Petrou et al., 2018).

1.3.2 Sleep

Sleep is a developmental mechanism important in physical, mental, and emotional development. Sleep is controlled, and effected, by a combination of biochemical processes and environmental signals. These environmental signals, such as light, meals, and stress, are what make up daily routines and reinforce the release of hormones that regulate the sleep cycle (Karthikeyan et al., 2020; Carmassi et al., 2019). In children, sleeping less than seven hours per night can result in negative changes in social and communication skills, and persistent sleep restriction can cause cognitive development to be altered (Carmassi et al., 2019; Karthikeyan et al., 2020).

1.3.3 Sleep in Children with ASD

Many children with ASD experience some type of sleep problem, most commonly reported are issues with falling and staying asleep (Carmassi et al., 2019; Kirkpatrick et al., 2019; Richdale & Schrek, 2009). There is rarely a singular cause for these sleeping problems which can make them difficult to address. Anxiety and sensory over-responsiveness can both lead to bedtime resistance and sleep loss and are common among children with ASD (Mazurek et al., 2014). For children, and especially children with ASD, there is a feedback between symptom presentation and sleep. A lack of sleep is associated with an increase in symptom presentation, often presenting as aggression, defiance, and communication difficulties (Schwichtenberg et al., 2013; Carmassi et al., 2019; Karthikeyan et al., 2020).

1.3.4 Family Sleep

Parents of children with ASD often experience sleep loss due to nighttime care needs, but also related to the stress that they carry (Karthikeyan et al., 2020). Neuro-typically developing (NTD) siblings' sleep may also be impacted. The disturbances caused by bedtime resistance and nighttime awakenings of the child with ASD can impact siblings, especially if they co-share a room or sleep in rooms near each other (Chou et al., 2012). NTD siblings experience more nightmares and insomnias than NTD children in families without a child with ASD, and while it is not fully understood why this happens, there is a connection between nightmares and stress and anxiety (Chou et al., 2012; Coulombe et al., 2010).

1.4 Research Gaps

Current research has focused on the sleep by isolating each individual family member and lacked a family centric approach. Sleep, and the sleep environment is highly affected by the family (Chou et al., 2012; Pavlopoulou & Dimitriou, 2019). Sleep reporting is often highly quantitative, using actigraphy and sleep scales to measure the level of sleeping problems that may exist (Carmassi et al., 2019). These measures are important, but do not tell the whole story of why this may be happening and how parents perceive these sleep problems.

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Chapter 2. Literature Review

The following section is a review of the literature. This review was conducted by doing keyword searches in several databases including CINAHL, Medline, and Proquest. It begins with a discussion about ASD and its symptomology followed by the importance of sleep and its physiology. A discussion into how sleep problems are manifested in children with ASD and how the family and home environment can influence sleep behaviours. Finally, existing interventions promoting sleep behaviours in children with ASD will be discussed.

2.1 Autism Spectrum Disorders

Autism spectrum disorders (ASD) are a group of neurodevelopmental disorders characterized by complex symptomology and challenges with behavioural, communication and social skills (American Psychology Association (APA), 2013). ASD can impact every part of daily functioning such as challenges with social communication and interactions as well as reduced regulation, restricted and repetitive behaviours and interests, and increased outbursts (Benson et al., 2019; APA, 2013).These restrictive and repetitive behaviours can result in children with ASD being more resistant to unexcepted stimuli and unexpected changes in routines (APA, 2013; O'Nions et al., 2018). Because of this, families often use routines to help create smooth transitions between daily activities and to provide structure (Schaaf et al., 2011; O'Nions et al., 2018). ASD is often accompanied with co-occurring intellectual deficits and difficulties with verbal and nonverbal communication (Karthikeyan et al., 2020; APA, 2013; Center for Disease Control (CDC); 2020).

In Canada, the prevalence of ASD has increased significantly in the last few decades. According to the Public Health Agency of Canada, 1 in 66 children are diagnosed with ASD, with males being four times more likely to be affected than females (Public Health Agency of Canada (PHAC), 2018). While individuals with ASD are characterized by a core set of symptoms, there is wide heterogeneity in the severity of the disorder. Children with ASD may have associated problems with aberrant behaviour including severe tantrums, non-compliance, destructiveness, and self injury (Matson, 2009; Summers et al., 2017). ASD is often accompanied by co-existing conditions such as feeding problems, emotional regulation disorders, anxiety, depression, and sleeping problems (Petrou et al., 2018).

2.2 Sleep

Sleep is an important developmental mechanism. Sleep is essential for physical, mental, and emotional development. Sleep helps regulate mood and is an important function of learning and memory (Karthikeyan et al., 2020). Sleep is controlled, and effected, by a variety of biochemical processes and environmental exposures through the circadian rhythm (Karthikeyan et al., 2020). Our bodies take cues from the environment, the main cues include: natural light, meals, social activities and stress, and use these cues to regulate the sleep cycle in association with the pattern of daily life and assist with the release of hormones such as melatonin and serotonin that further regulate the sleep cycle (Karthikeyan et al., 2020; Carmassi et al., 2019). This makes routines important in the chemical signalling of sleep. Consistency in routines is especially important in children as their sleep cycle is developing (Karthikeyan et al., 2020; Carmassi et al., 2019). In children, a single night of reduced sleep can impact cognition, processing, and

verbalization. Continued disturbed sleep may indicate a disturbed circadian rhythm, which can negatively impact mood and alertness (Karthikeyan et al., 2020). It has been noted that sleep restricted (<7 hours of sleep per night) neuro-typically developing (NTD) children displayed more severe impairment in social and communication difficulties when compared to children with ASD that slept 10-11 hours per night (Carmassi et al., 2019). Prolonged sleep related difficulties can result in alterations to brain and neural pathway development and overall functioning as the child develops, particularly in cognition, attention, and psychiatric health (Karthikeyan et al., 2020; Carmassi et al., 2019). This represents a significant concern if children are experiencing long term sleep challenges.

2.3 Sleep in Children with ASD

Children with ASD tend to experience sleep related problems at a higher prevalence than NTD children; 64-93% of children with ASD have sleep problems and 40-80% have insomnia, compared to 25% of NTD children that have sleep problems (Carmassi et al., 2019; Bellesheim et al., 2018; Schwichtenberg et al., 2013). The most cited sleep issues in children with ASD include difficulty falling asleep, restless and disturbed sleep, night and early morning awakenings, decreased sleep time, nightmares, bedtime resistance, and difficulties with sleep associations (Carmassi et al., 2019; Kirkpatrick et al., 2019; Richdale & Schrek, 2009).

Children with ASD are also more likely to experience mental health concerns, especially anxiety and depression, both known to interfere with the sleep cycle (Karthikeyan et al., 2020). Anxiety and sensory over-responsiveness, a common issue in children with ASD, are both associated with bedtime resistance, sleep-onset delays, sleep

loss, and night-time awakenings (Mazurek et al., 2014). There is also an increasing awareness of circadian abnormalities. Children with ASD are less likely to experience many of the key circadian exposures, such as less exposure to natural light, and less consistency in social interactions and daily stress levels, which could reduce the ability of the circadian rhythm to synchronize (Karthikeyan et al., 2020). This, coupled with reports of higher serotonin and lower melatonin, could desynchronize the circadian rhythm and lead to poor quality and mistimed sleep (Carmassi et al., 2019; Karthikeyan et al., 2020). However, children with ASD often have a dependency on predictable routines. Strong consistency to routines provides structure that many children with ASD need and act to fill gaps that may be missing key circadian cues (Larson, 2006). Routines are important in the regulation of the sleep-wake cycle and circadian rhythm and become even more important in families with a child with ASD to manage bedtime behaviours and provide a smoother transition to sleep (Karthikeyan et al., 2020, Larson, 2006, Kirkpatrick et al., 2019).

Sleep is also highly related to symptom expression and a lack of sleep is often associated with increased ASD symptom presentation, increased physical aggression, defiance, and communication and socializing difficulties (Schwichtenberg et al., 2013; Carmassi et al., 2019; Karthikeyan et al., 2020). Daytime behavioural problems as well as bed-time resistance and night-time awakenings can do more than just negatively impact the child with ASD. The consequences may include alterations in daytime behaviour, memory and learning, and significant stress in caretakers. Sleep disturbances in children with ASD not only impact their own quality of life and their daytime functioning but can also impact the entire family. Sleep disturbances have a pervasive effect on the family in

the disturbances at bedtime, behavioural problems during the day and interruptions during the night that could have a profound impact on sleep and daily life for all family members.

2.4 Familial Influence on Sleep

The parents of children with ASD are at risk for sleep loss due to often having the role of primary caregiver. The care and demands of their child, especially during nighttime, can impact their sleep, but so can the stress associated with the challenges of supporting a child with ASD (Karthikeyan et al., 2020). Parents of children with ASD report higher levels of anxiety and depression, more isolation and financial difficulties, and overall lower well-being compared to parents with NTD children (Petrou et al., 2018). It has been suggested that the desire to get a child to sleep creates a child-driven family pattern that extends beyond the physiological ASD-related sleep issues into the structure of the family itself, requiring much more than a treatment to correct the sleep in the child with ASD (Karthikeyan et al., 2020). Parents of children with neurodevelopmental disorders, including ASD, have reported significantly reduced sleep quantity and quality, as well as increased fatigue due to the obligations of care and nighttime needs of their child (Micsinszki et al., 2018). The impact of having a child with ASD does not remain with the parents but extends to the entire family unit. Lower overall wellbeing and health-related quality of life has been reported in families with a child with ASD (Petrou et al., 2018). Therefore, understanding family function and dynamics is essential.

It is estimated that as many as 85% of families with a child with ASD have more than one child (Dillenburger et al., 2010). Sleep problems in children with ASD are

known to affect family functioning (Malow et al., 2014). A current gap in the literature is how sleep behaviours of children with autism impacts their NTD sibling. These siblings represent an important population that has thus far often been overlooked in research. The sleep of siblings can be impacted in a variety of ways. The disturbances of resistance at bedtime, nightmares, and nighttime awakenings of the child with ASD can impact siblings, especially if they co-share a room or have rooms in close proximity (Chou et al., 2012). NTD siblings of children with ASD are often exposed to more outbursts, violence, and disruptive behaviours that lead to anxiety, depression, and feeling isolated (Benderix & Sivberg, 2007; Ross & Cuskelly, 2006). NTD siblings of children with ASD experience more parasomnias, such as nightmares and sleep talking, and sleep onset insomnia compared to NTD children in families without ASD, and even compared to their siblings with ASD (Chou et al., 2012; Coulombe et al., 2010). Parasomnias can be an extra source of disturbance in the home, especially intense nightmares that may disturb the household or require comforting from the parents. Stress and anxiety have been associated with poor and reduced sleep, as well as parasomnias (Chou et al., 2012).

NTD siblings of children with ASD have reported poor sleep quality because of either room sharing, or night-waking by their autistic sibling, and attending to their autistic sibling's nighttime needs (Pavlopoulou & Dimitriou, 2019). Night-wakings and similar sleep disturbances experienced by a child with ASD can contribute to a sleep environment that may not be supportive of siblings achieving sufficient, good quality sleep (Chou et al., 2012; Pavlopoulou & Dimitriou, 2019). Sleep in childhood is incredibly important. If sibling sleep is being impacted this is an important population to target to prevent negative health effects. Sleep among siblings of children with ASD

remains overlooked in research despite its importance and the likelihood that they are being impacted.

Despite a growing understanding that NTD siblings may be having challenges with their sleep as a result of sharing a household with a sibling with ASD, there is a distinct lack of research that focuses on them. Most often, research uses measures of either sleep or anxiety/depression that are then related to sleep, rather than directly approaching sleep as its own variable (Chou et al., 2012). Only one study (Chou et al., 2012), compared sleep of NTD siblings to their siblings with ASD and NTD controls without a family history of ASD. While the findings were important in understanding the presence of parasomnias and sleep disturbances in NTD siblings compared to children with ASD and children with no history of ASD, it highlights the gaps in this area of research. When the sleep of children with ASD is being studied, it is often done through a combination of parent report and highly quantitative sleep measures such as actigraphy, parent questionnaires such as the Children's Sleep Habits Questionnaire (CSHQ), genetic testing, sleep diaries, and clinical diagnosis (Carmassi et al., 2019). However, sibling sleep is often reported in qualitative research methodologies that can be very specific and make comparison difficult (Pavlopoulo & Dimitriou, 2019). This discrepancy is both interesting and concerning. If sibling sleep is a concern, their sleep should be measured just as rigorously, but the perspectives of sleep should also be heard more qualitatively from the parent or caregiver. This makes it very important to approach the research in a way that can develop a better understanding of the experiences of sleep in the family, acknowledging the individuality of experiences but finding commonality as well.

2.5 Sleep interventions for Children with ASD

Interventions for sleep problems in children with ASD have mostly focused on behavioural treatments including sleep hygiene education and parent training (Abel et al., 2017). Behavioural interventions are an important first step when addressing sleep problems in children with ASD. Sleep occurs in the home and is a daily activity, so focusing on behaviour is something that parents can implement. Parent education and sleep hygiene efforts increase the cues to and create a habit around sleep that can be incredibly helpful for children with ASD that need extra, positive associations with sleep (Karthikeyan et al., 2020).

Sleep hygiene is often a primary treatment choice for children with ASD. Sleep hygiene refers to behavioural and environmental conditions that can improve both the quantity and quality of sleep (Karthikeyan et al., 2020; Abel et al., 2017). Sleep hygiene efforts are varied and can be implemented in a variety of ways, including setting a bedtime schedule, reducing activities before bedtime that may cause excitement or wakefulness, restricting or eliminating caffeine, and creating a calm, cool, dark, and soothing sleep environment (Karthikeyan et al., 2020; Ali et al., 2018). Other behavioural interventions used have included extinction, faded bedtime, sleep restriction, and scheduled awakenings. Extinction involves parents ignoring the undesirable behaviours of their child to promote self-settling (Cuomo et al., 2019). Extinction has been shown to have fast results in reducing bedtime resistance, night waking, and early morning awakening (Turner & Johnson, 2012). However, this is an incredibly difficult approach for parents to implement because of the dedication and emotional resilience it takes to ignore the cries and calls of their child during the night (Turner & Johnson, 2012). Faded

bedtime, sleep restriction, and scheduled awakenings are designed to help normalize the child's sleep patterns through structured bedtime and sleep routines and have been successful in reducing bedtime resistance, night waking, co-sleeping, sleep terrors, and sleep walking (Turns & Johnson, 2012). The role of the parent is incredibly important in all these approaches because it is the parent that must implement these strategies. While physicians may suggest treatment methods and create plans, it is the parents that must consistently and properly complete these plans, and this is no easy task.

Parental education is key to the success of behavioural interventions of sleep. Behavioural interventions are recommended changes to the daily routine, nighttime routine, and overall behaviour. For behavioural interventions to be successful, it requires significant effort by parents outside of clinical time (Ali et al., 2018, Turner & Johnson, 2012). Ensuring parents are properly trained on the importance, implementation and use of sleep interventions is key to ensuring that they understand how interventions can help and in turn, helps motivate parents to implement changes. Sleep hygiene, as well as extinction, and faded bedtime require parental commitment to care and consistency in application to be successful (Ali et al., 2018, Turner & Johnson, 2012). Proper parental education ranked the strongest across all interventions in addressing sleep problems, especially self-settling, and night waking (Cuomo et al., 2019). These represent significant sleep problems that impact the entire family unit in their disruptiveness and care requirements. By teaching parents the skills to promote sleep hygiene and implement other behavioural sleep interventions, sleep can be improved in the entire family unit.

Physical activity is another intervention used to promote sleep in children with ASD. A study by Benson et al., (2019) examined the effect of increasing physical activity

and found that it led to increased sleepiness at bedtime, led to earlier bedtimes, and shorter sleep onset latency among children with ASD. Another study using accelerometers and actigraphy found that children who were more active during the day had less difficulty falling asleep and less sleep disruption (Wachob & Lorenzi, 2015). Similarly, it was found that children with ASD that participated in a basketball skill learning program had improved sleep efficiency, reduced sleep onset latency, longer sleep duration and returned to sleep after waking faster than those that did not participate (Tse et al., 2019). These findings are significant as children with ASD have been found to participate less in physical activity due to difficulties understanding rules and engaging with other children as well as a tendency to have extra support occur during recess times (Wachob & Lorenzi, 2015). Although physical activity is beneficial for sleep in all children (NTD and ASD), the intervention was not extended to other members of the family (Benson et al., 2019). Physical activity can be a promising intervention which can easily be applied to the entire family unit.

The vast majority of sleep therapy is targeted to the child with ASD. However, ASD does not occur in isolation, so it is important to consider a family approach to any care plans, even sleep related ones. There has been some increase in family-oriented care. For example, Bellesheim et al. (2018) had families develop specific intervention goals relating to areas they wished to see improvement rather than being told by physicians. This collaborative goal setting helped increase family engagement. These goals could have included reducing bedtime resistance or having fewer nighttime awakenings. Sixty-six percent of families did meet at least one insomnia goal during the intervention (Belleshiem et al., 2018). These interventions included educational and behavioural

strategies such as creating bedtime schedules. However, interventions focused on only the child with ASD and did not include any other family members. Despite not including family targeted interventions, it was likely that reported improvements, such as the child with ASD having less night-time awakenings, less fighting to go to bed, and better independent sleeping would have positive effects on the sleep of the entire family.

Only one sibling-based intervention was found in the literature and it also took a solution focused therapy approach but from a family perspective. All family members were involved in selecting goals, setting timelines, and tracking progress (Turns et al., 2016). This study suggested encouraging a more equal treatment for all children in the family, encouraging informal conversations between children and with parents, encouraging positive interactions and creating individual and shared token systems (Turns et al., 2016). Children with ASD often have a token system to motivate them to follow their routines for small rewards like stickers. To help reduce the feelings of neglect or unfair treatment that can occur with siblings, they are encouraged to share what they want to be involved in, such as creating a token system catered toward them or even a shared one that they can both contribute to (Turns et al., 2016). While these approaches have been researched and shown success with children with ASD, there is not yet findings on the outcomes of implementing strategies, such as token systems, with the inclusion of siblings.

These sleep related interventions heavily target the child with ASD, but several could be applied to other siblings in the home. Sleep hygiene and physical activity have both been shown to improve sleep, and can be easily applied to the entire family (Karthikeyan et al., 2020; Benson et al., 2019). The more intensive sleep related

interventions such as extinction, bedtime fading, and scheduled awakenings did not include a sibling perspective. It is possible that these interventions can be as burdensome on siblings as they are on parents, especially extinction. It may also be possible that siblings can benefit from these interventions and a more structured sleep schedule. The family-based therapy approaches start to try to address this gap. A token system could be easily applied to sleep if siblings have sleep related goals they would like to reach, such as going to bed on time, waking up at a certain time, not waking others up before a certain time, etc. It is important that the sibling experience of sleep interventions are considered, but also that interventions are being applied as holistically as possible to the family unit.

2.6 Implications

ASD is a complex disorder with many challenges and can greatly impact the child's life, as well as the family providing care. The increased prevalence of ASD, as well as complexity of care, is making ASD a greater research priority to better understand how living with a child with ASD impacts both the child and family. Research is even more of a priority considering the importance of sleep in functioning and development, and the likelihood of having sleeping difficulties in every family member. It is important for the whole family to become involved in interventions, both to promote a family approach and to allow the benefits to reach everyone. Given the complexities of sleep behaviours among families with a child with ASD, sleep interventions cannot be targeted to the child with ASD in isolation. It is important to develop an understanding of how families perceive the importance of sleep and understand how sleep difficulties reflect on daily functioning and behaviours of both individual members and the family as a whole.

Sleep is a family function and can not be studied in silos. To understand sleep in families with a child with ASD, it is necessary to view sleep from a family centric perspective. Therefore, the aims of this phenomenology-informed study are to explore the sleep behaviours, challenges, perceptions, and lived experiences of families with and caring for a child(ren) with ASD.

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Chapter 3. Methods

3.1 Objectives

To explore the sleep behaviours and perceptions of sleep in families with a child with Autism Spectrum Disorder (ASD) and to develop an understanding of the lived experiences and challenges associated with sleep within the family caring for a child with ASD through the lens of their caregiver.

3.2 Research Questions

1) What is the parent/caregiver's experiences and perception of sleep in their family?
2) What is the parent/caregiver's perceived facilitators and barriers to sleep?

3.3 Methods

3.3.1 Study Design

I used a qualitative research approach to develop an understanding of the lived experiences of having a child with ASD, through the lens of caregivers. This building of the nature of reality through multiple lenses with the goal to understand the lived experiences of the phenomenon aligns itself well with ontological interpretivism, with the main methodological approach being phenomenology (Creswell & Poth, 2018). A phenomenological approach was chosen because the goal is to understand the essence of the lived experiences, the essence being those essential and invariable structures, or themes, that are consistently found (Creswell & Poth, 2018). The core of phenomenological research is to describe and understand phenomena as they are experienced by the individuals that have lived through them (Wognar & Swanson, 2007). With phenomenology informing my work, I developed a description and understanding

of the essence of sleep in families with a child with ASD through the lens of those that have experienced it, the primary caregiver.

While there is an understanding of the poor sleep children with ASD experience, and further that parents of children with ASD have poor sleep as well, there is a lack of understanding of family sleep, and the interactions related to sleep that are family functions (Karthikeyan et al., 2020). Because of this gap, I decided the best approach would be to develop an understanding of the experience of sleep in families with a child with ASD, with a focus on the role of the family. The integration of previous knowledge and the acknowledgement of the influence of factors outside the participant, such as social and cultural influences, lends itself to an interpretive phenomenological approach to my research (Lopez & Willis, 2004; Matua et al., 2015). Interpretive phenomenology was used to address the identified gaps and allow for the blending of the participant's experiences with that of the researcher and the identified theoretical framework and literature. In so doing, this allowed for a deeper understanding of sleep that acknowledges the essences of participants' experiences and how it may be shaped and influenced by social experiences and expectations (Lopez & Willis, 2004; Wojnar & Swanson, 2007). It further allowed for the co-creation of understanding of sleep through interaction and interpretation between the researcher and participants (Wojnar & Swanson, 2007). The acknowledgement of the blending of multiple contexts that can influence experiences makes the practice of bracketing, or separating the researcher from their preconceived ideas more difficult, but is mitigated by employing intensive journaling and reflexivity (Lopez & Willis, 2004; Matua et al., 2015).

This study was approved by the Ontario Tech University Research Ethics Board, REB #15788 (Appendix A). Findings are reported in line with the Consolidated criteria for Reporting Qualitative research (COREQ) (Tong et al., 2007).

3.3.2 Study Sample and Recruitment

Participants were eligible to participate if they were the parents to at least one child, under the age of 10, diagnosed with ASD and provided informed consent. This age was selected at parents are likely to still be aware of children's sleeping habits but is old enough for most children to have received a diagnosis of ASD (PHAC, 2018; Kirkpatrick et al., 2019). Purposive sampling was used for this study to select participants that met the criteria, with the aim of interviewing 10-15 participants or until thematic saturation was reached (Creswell & Poth, 2018). Sampling was from a larger homogenous sample, in that all participants were parents/caregivers with at least one child with ASD. Within this population, a maximum variation sample was drawn to try and include the lived experiences from as many different perspectives and family situations as possible (Creswell & Poth, 2018). There was an emphasis placed on recruiting families with a child with ASD and at least one neuro-typically developing child to capture greater variation of the experiences from the family's perspective. Eligibility criteria was kept broad to ensure participation rates were sufficient. The literature suggests that sleep can vary dramatically in families for any number of reasons, so for the purpose of this exploratory study, it was important to ensure diverse families were included.

Active and passive strategies were used to recruit participants in partnership with Grandview Kids. Grandview Kids is a Children's Treatment Centre in the Durham region, providing specialized programs, outpatient clinical treatment and support to

children and youth with physical, communication and developmental needs and their families (Appendix B). In addition to REB approval, this study underwent scientific review at Grandview Children's Center before recruitment efforts were initiated. Active strategies included the use of a gatekeeper, a trusted community member, who was a parent in the Grandview Children's Center group, that was able to recruit families that met the eligibility requirements and inform them of the study and their ability to participate (Creswell & Poth, 2018). I presented the study to staff of Grandview Children's Centre during a "Lunch 'n' learn" session to inform staff who could then share study information with patients. Staff at Grandview Kids posted advertisements of the study in waiting rooms, and on social media platforms, including Facebook groups and the e-newsletter. Furthermore, a peer-navigator for Grandview Kids assisted in recruitment. Peer-navigators are members of the Grandview Kids parent community and have access to closed social media pages that include only parents of children in Grandview Kids programs. This allowed them to contact families that met criteria to inform them of the study as well as to post and moderate the poster for the study. Those interested in the study expressed so via e-mail. Eligibility was confirmed via e-mail, and participants were sent an electronic consent form along with a brief questionnaire about their demographics and life circumstances (Appendix C).

3.3.3 Data Collection Tool

Interviews were conducted online in a one-on-one setting using an interview guide (Appendix D). The semi-structured interview guide was pilot tested to assess clarity and feasibility. Probes and prompts were used to elicit more information and to clarify responses (Creswell & Poth, 2018). The interview guide covered key areas,

including parents' experiences of sleep, both their own and their children's, daily routines, opinions and beliefs of sleep, and what they perceive to be facilitators and barriers to sleep.

The use of a qualitative approach in the interview setting lent a naturalistic and subjective nature to the research that has the potential to increase the knowledgebase beyond what a quantitative approach would allow (Wisdom & Creswell, 2013).

3.3.4 Study Procedures

After eligibility was confirmed, participants were sent an online, electronic consent form to review and sign prior to the interview. After consent was obtained, a brief survey was administered to collect information on demographics and to confirm eligibility criteria. The brief survey included questions regarding the family composition, demographics, and social economic status (Appendix C). Interviews were 30-60 minutes long and were conducted in March of 2022 by the first author (EG), and recorded using the zoom platform recording function (Zoom Video Communications Inc., 2021). Interviews were conducted online due to restrictions put in place during the COVID-19 pandemic. The first author (EG), kept memos and interview notes. Participants were offered a $25 e-gift card in appreciation of their time and contribution.

3.3.5 Reflexivity

Interviews were conducted by the first author (EG), a female master's student in her twenties with a degree in public health and training in qualitative methods. The interviewer did not have lived experience, however the research team included researchers with expertise in sleep research, qualitative research methodologies and lived family experience of children with ASD. No members of the research team had an

existing relationship with participants. Participants were aware that research was being conducted as a part of the first author's thesis exploring sleep in families with a child with ASD. It can be difficult to determine the number of participants needed to reach saturation, however the literature suggests for a heterogenous sample to have 10-15 participants (Creswell & Poth, 2018). For the purpose of this study, 8-10 participants were considered satisfactory to be able to achieve a heterogenous sample within the limited participant pool, however 15 interviews were conducted due to a greater than expected variation in sleep experiences and a high community interest. Interviews were conducted until data saturation was determined to have been reached as assessed by consistency of coding and theme identification by research team members where further interviews would likely not have revealed new themes (Dworkin, 2012; Guest et al., 2006).

3.3.6 Theoretical Framework

Thematic analysis was initially informed by Christensen's conceptual framework of the health-promoting family, which describes the many factors that influence the health, and health behaviours, of a family (2004). The framework conceptualizes the complexity and multi-factorial nature of health, or in the case of this research, sleep, in a family setting. The framework was used as a preliminary way to understand the complexity of societal and community influences on health behaviours, but also heavily on intra-family factors such as family health history, child health status, and family values, goals, and needs (Christensen, 2004). The interplay of all the factors that may influence family health behaviours, sleep being the one under investigation, helped to ground this work in the concept that sleep in families was going to be complex, effecting,

and being affected by, any number of internal and external confounders from inside the family, to the surrounding community and society.

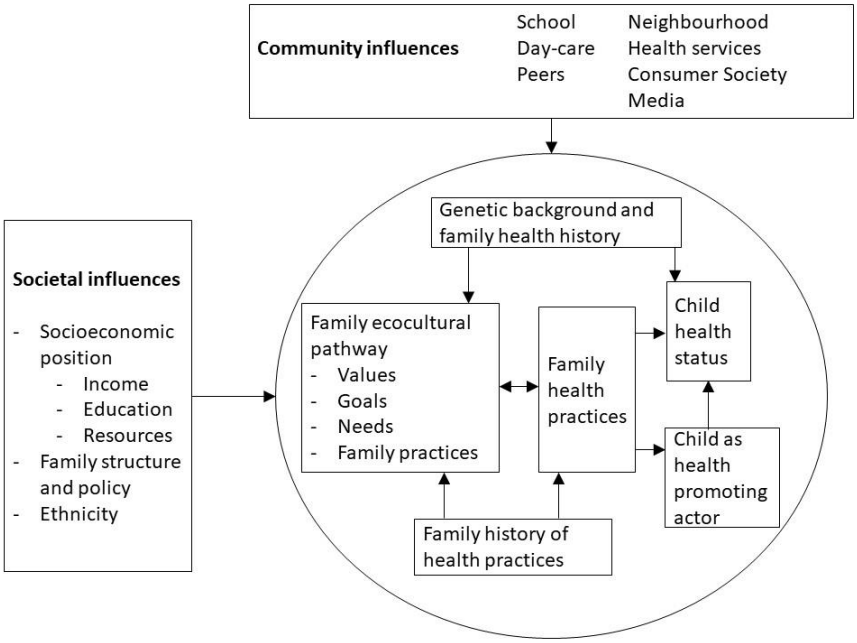

Figure 2.1: Model of the health-promoting family (Christensen, 2004)

3.3.7 Analysis

Interviews were audio-recorded using both the Zoom recording software and a back-up electronic recording device. The Zoom platform is able to record both audio and visual, however video recordings were destroyed and only audio saved (Zoom Video Communications Inc., 2021). Audio-recordings were transcribed verbatim by a transcription software and reviewed and completed for accuracy by the first author. Personal identifiers were removed, and participant names were replaced with numeric identifiers. NVivo13 (QSR International Pty Ltd. Version 13, 2020) was used to organize the interview transcripts and to assist in the thematic analysis of interview data.

Moustakas' methods of data analysis were used as a foundation for data analysis because of the inclusion of systematic steps and guidelines that can help organize the approach for a novice researcher (Creswell & Poth, 2018). An inductive approach to analysis was taken. Line-by-line coding of the transcripts resulted in lean codes. Lean codes are a tool used by novice qualitative researchers that help to provide structure and prevent over-coding by creating a few broad codes after the first transcript and revisiting and adding subthemes as coding continues (Creswell & Poth, 2018). The first and second authors independently analyzed the transcripts and discussed significant quotes with members of the research team until consensus on codes was reached. Codes and significant quotes were reviewed by the research team throughout the coding process to develop descriptive themes. Methods used to ensure methodological validity included; establishing a shared codebook, and reflexive journaling to bracket and acknowledge researcher assumptions and biases (Nowell et al., 2017: Creswell & Poth, 2018).

Following each interview, the interviewer reflected on the interview and journaled the thoughts and perceptions that arose. This reflexive journaling was used to document research activities, methodological decisions, and rationale to disclose personal reflections, interests, and insights (Nowell et al., 2017). This was then discussed with the committee members to help make sense of this data. Triangulation of multiple sources of data were included in these de-briefs with the research supervisor and committee members, consistent use of a reflexive journal and performing member-checks to ensure interpretations reflected the experiences of participants (Creswell & Poth, 2018; Nowell et al., 2017). These steps worked to challenge assumptions and ensure transparency.

Participant member checking was also conducted. Participants were sent a password protected electronic copy of their transcript. Passwords were provided at the end of the interview or in a separate email if requested. Participants were given the opportunity to review and provide feedback (including: comments, changes, or approval) within 7 days and were informed that no response would be taken as acceptance of their transcript. Not all participants responded to the member-checking email but those that did, only responded with approval. Participants were also sent a preliminary copy of the findings for feedback (including: comments or approval) within 7 days and were informed that no response would be considered an acceptance. These member checking opportunities were used to ensure that findings were an accurate representation of participant experiences (Nowell et al., 2017).

3.3.8 Reporting of Findings

Key quotes are presented to support presentation and rich description of themes. Participants are identified by participant number.

3.4 Note

The methods described in this chapter are a fulsome description of the methods and methodologies underlying this work and will be summarized as part of the methods outlined in the manuscript to follow in Chapter 4.

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Chapter 4. Manuscript; *"I don't think there's anything typical about it."*

The following has been formatted into a manuscript based on journal guidelines and was submitted to the *Journal of Child and Family Studies* on March 6, 2023 and is currently under review.

4.1 Abstract

Purpose: Sleep is an important mechanism for everyday functioning and childhood development. Children with autism spectrum disorder (ASD) tend to have higher rates of sleep problems than neuro-typically developing children (NTD). While the sleep of children with ASD has become a research and treatment priority, there is a lack of research focus into how this impacts the sleep and daily life of the entire family.

Methods: This study was informed by interpretive phenomenology. Purposive sampling was used to recruit parents of at least one child with ASD through Grandview Children's Center. Fifteen in-depth, semi-structured interviews were conducted with parents.

Results: Several critical themes emerged from interviews with parents including (1) environmental factors contributing to sleep, (2) individual and family consequences of sleep loss, (3) parental internalization of emotions and conflicts surrounding sleep, (4) mitigation strategies used to improve sleep; and (5) the knowledge and beliefs that parents have about sleep.

Conclusion: This research suggests that achieving sufficient sleep is difficult in families with a child with ASD and that the impact of lack of sleep is felt by every member of the family. Findings suggest that parents carry mental and emotional burdens that they associate with sleep and getting enough sleep. Additional research needs to be conducted

to understand how different family members perceive sleep. This work can shape future research directions and inform important programs to support families with a child with ASD and to shed light on the importance of understanding sleep from a family-centric perspective.

Keywords: Qualitative research; Sleep; Autism Spectrum Disorder (ASD); Family

4.2 Introduction

Autism spectrum disorders (ASD) are a group of neurodevelopmental disorders characterized by complex symptomology and challenges with behavioural, communication and social skills (American Psychology Association (APA), 2013). ASD can impact every part of daily functioning including challenges with social communication and interactions, reduced behavioural and emotional regulation, restricted and repetitive behaviours and interests, and increased outbursts (Benson et al., 2019; APA, 2013). In Canada, the prevalence of ASD has significantly increased in the last few decades, with 1 in 66 children being diagnosed with ASD, and males being four times more likely to be diagnosed than females (Public Health Agency of Canada (PHAC), 2018). While individuals with ASD are characterized by a core set of symptoms, there is wide heterogeneity in the severity of the disorder. ASD is often accompanied by co-existing conditions such as feeding problems, emotional regulation disorders, anxiety, depression, and sleeping problems (Petrou et al., 2018).

Sleep is essential for physical, mental, and emotional development. Sleep helps regulate mood and is an important function of learning and memory (Karthikeyan et al., 2020). Sleep is controlled, and regulated, by a variety of biochemical processes and environmental exposures, such as light, meals, social activity, and stress, through the

circadian rhythm, or sleep architecture (Karthikeyan et al., 2020: Carmassi et al., 2019). Prolonged sleep related difficulties can result in alterations to brain and neural pathway development and overall functioning as the child develops, particularly in cognition, attention, and psychiatric health (Karthikeyan et al., 2020; Carmassi et al., 2019). Children with ASD tend to experience sleep related problems at a much higher rate than neuro-typically developing (NTD) children; 64-93% of children with ASD have sleep problems and 40-80% have insomnia, compared to 25% of NTD children that have sleep problems (Carmassi et al., 2019; Bellesheim et al., 2018; Schwichtenberg et al., 2013). Sleep and behaviour are highly related, a NTD child with under 7 hours of sleep can display more severe impairments in socializing and communication than children with ASD that had sufficient sleep (10-11 hours) (Carmassi et al., 2019). Sleep is also highly related to symptom expression and a lack of sleep is often associated with increased ASD symptom presentation, increased physical aggression, defiance, and communication, and socializing difficulties (Schwichtenberg et al., 2013; Carmassi et al., 2019; Karthikeyan et al., 2020).

Sleep disturbances do not just impact the child with ASD but have a pervasive effect on the entire family. For parents, the care and demands of their child, especially during nighttime can impact their sleep, but so can the stress of raising a child with ASD (Karthikeyan et al., 2020). Parents of children with neurodevelopmental disorders, including ASD, have reported significantly reduced sleep quantity and quality, as well as increased fatigue due to the obligations of care and nighttime needs of their child (Micsinszki et al., 2018). Siblings can also be strongly impacted by sleep disturbances of a sibling with ASD. Bedtime resistance, nightmares, and nighttime awakenings of the

child with ASD can impact siblings, especially if they co-share a room or have rooms in close proximity (Chou et al., 2012). NTD siblings of children with ASD are often exposed to more outbursts, violence, and disruptive behaviours that lead to anxiety, depression, and feelings of isolation; which can contribute to sleep problems (Benderix & Sivberg, 2007; Ross & Cuskelly, 2006).

Sleep is a family function and can not be studied in silos. Current research has focused on the sleep in each individual family member and lacked a family centric approach. Sleep, and the sleep environment is highly affected by the family (Chou et al., 2012; Pavlopoulou & Dimitriou, 2019). Sleep reporting is often highly quantitative, using actigraphy and sleep scales to measure the degree of sleeping problems that may exist (Carmassi et al., 2019). These measures are important, but do not tell the whole story of why this may be happening and how parents perceive these sleep problems. To understand sleep in families with a child with ASD, it is necessary to view sleep from a family centric perspective. Therefore, the aims of this phenomenology-informed study are to explore the challenges, perceptions, and lived experiences around sleep of families with and caring for a child(ren) with ASD.

4.3 Methods

4.3.1 *Study Design*

We used a qualitative study (approved by the Ontario Tech University [Ontario Tech U] Research Ethics Board, REB# 15788) designed to acquire narratives of the parental reported experiences of sleep in families with a child with ASD. Findings are reported in line with the Consolidated criteria for Reporting Qualitative research (COREQ) (Tong et al., 2007). We used phenomenology to describe and understand the experiences of

individuals who have lived through the phenomenon of interest, namely, the family experiences of sleep (Creswell & Poth, 2018; Wognar & Swanson, 2007). Phenomenology aims to build understanding through finding the core "essences" or themes of lived experiences, which lends itself well to our research (Creswell & Poth, 2018). Specifically, an interpretive phenomenology lens was taken to acknowledge both participants' experience as well as the outside influence of social and cultural expectations that shape experiences and allow for a building of the current research to fill the identified gaps (Lopez & Willis, 2004; Wojnar & Swanson, 2007).

4.3.2 *Study Sample and Recruitment*

Participants were recruited using purposive sampling (Creswell & Poth, 2018). Parents were eligible to participate if they were the parents to at least one child, under the age of 10, diagnosed with ASD and provided informed consent. For this study, 10 years was used at the cut-off age as most children with ASD will have received a diagnosis by this age and young enough for parents to be aware of sleeping problems (PHAC, 2018; Kirkpatrick et al., 2019). Active and passive strategies were used to recruit participants in partnership with Grandview Kids. Grandview Kids is a Children's Treatment Centre in the Durham region, providing specialized programs, outpatient clinical treatment and support to children and youth with physical, communication and developmental needs and their families. Staff at Grandview Kids posted advertisements of the study in waiting rooms, social media platforms such as, Facebook groups and the e-newsletter. Furthermore, a peer-navigator for Grandview Kids assisted in recruitment. Peer-navigators are members of the Grandview Kids parent community and have access to closed social media pages that include only parents of children in Grandview Kids

programs. This allowed them to contact families that met criteria to inform them of the study as well as to post and moderate the poster for the study. Those interested in the study, expressed so via e-mail. Eligibility was confirmed via e-mail, and participants were sent an electronic consent form along with a brief questionnaire about their demographics and life circumstances.

4.3.3 *Data Collection tool*

Interviews were conducted online in a one-on-one setting using an interview guide. The semi-structured interview guide was pilot-tested to assess clarity and feasibility. Probes and prompts were used to elicit more information and clarify responses (Creswell & Poth, 2018). The interview guide covered key areas, including: parents' experiences of sleep, both their own and their children's, daily routines, opinions and beliefs of sleep, and what they perceive to be facilitators to sleep and what factors hinder sleep.

4.3.4 *Study Procedures*

After eligibility was confirmed, participants were provided a link to an online consent form and demographics questionnaire, and participants provided verbal consent prior to beginning the interview. Interviews were 30-60 minutes long and were conducted in March of 2021 by the first author (EG), recorded using the Zoom platform recording function (Zoom Video Communications Inc., 2021). The first author (EG), kept memos and interview notes. We aimed to interview 10-15 participants or until thematic saturation was achieved (Creswell & Poth, 2018).

4.3.5 *Reflexivity*

Interviews were conducted by the first author (EG), a female masters student in her twenties with a degree in public health and training in qualitative methods. The interviewer did not have lived experience; however, the research team included researchers with expertise in sleep research, qualitative research methodologies and lived family experience of children with ASD. No members of the research team had an existing relationship with participants. Participants were aware that research was being conducted as a part of the first author's thesis exploring sleep in families with a child with ASD. Interviews were conducted until data saturation was determined to have been reached as assessed by consistency of coding and theme identification by research team members, and where further interviews would likely not have revealed new themes (Dworkin, 2012; Guest et al., 2006).

4.3.6 *Theoretical Framework*

Thematic analysis was initially informed by Christensen's conceptual framework of the health-promoting family, which describes the many factors that influence the health, and health behaviours, of a family (2004) (Fig 2.1). The framework conceptualizes the complexity and multi-factorial nature of health, or in the case of this research, sleep, in a family setting. The framework conceptualises health behaviours as a factor of societal and community influences, but also heavily on intra-family factors such as family health history, child health status, and family values, goals, and needs (Christensen, 2004). This theoretical framework provided a preliminary view of how parents might describe the multi-factorial nature of sleep in their families, and what they might describe as being the most significant influences on sleep.

4.3.7 *Analysis*

Interviews were audio-recorded and transcribed verbatim. The Zoom platform is able to record both audio and visual, however video recordings were destroyed and only audio saved (Zoom Video Communications Inc., 2021). The first author reviewed all transcripts to the original audio recording to ensure accuracy. Where necessary, corrections to improve punctuation and grammar were made. All personal identifiers were removed and participant names replaced by numeric identifiers. NVivo13 (QSR International Pty Ltd. Version 13, 2020) was used to organize the interview transcripts and to assist in the thematic analysis of interview data.

Transcripts were analyzed using an inductive approach where line-by-line coding resulted in lean codes, which were used as broad codes that sub themes could be developed from (Creswell & Poth, 2018). The first and second authors independently analyzed the transcripts and discussed significant quotes with members of the research team until consensus on codes was reached. Codes and significant quotes were reviewed by the research team throughout the coding process to develop descriptive themes. Methodological validity was assured by conducting member checks with participants to ensure that transcripts were accurate and that their experiences were accurately described and interpreted; establishing a shared codebook, and reflexive journaling to bracket and acknowledge researcher assumptions and biases (Nowell et al., 2017: Creswell & Poth, 2018).

4.3.8 *Reporting of Findings*

Key quotes are presented to support presentation and rich description of themes. Participants are identified by participant number.

4.4 Results

4.4.1 *Demographic Results*

Fifteen interviews were conducted with parents, five fathers and ten mothers. Five parents were aged 26-35, nine were 36-45, and only one was under 25. Fourteen participants had a post-secondary certificate, degree or diploma. Nine participants were employed full-time, 4 were stay-at-home parents, and two worked part-time. Three participant were the parent of one child, nine had two children, two had three children, and one had four children. Two families had more than one child with ASD. Most participants had children in sixth grade or lower. The demographic characteristics of the interview participants and their children are described in Table I.

4.4.2 *Thematic Findings*

Five central themes emerged from the analysis: environmental factors that contribute to poor sleep, consequences to sleep deprivation and sleep quality, internalization of emotions surrounding sleep, mitigation strategies used to promote sleep, and understanding of sleep functions and benefits.

Environmental Factors Contributing to Poor Sleep

A major factor associated with sleep behaviours was the sleep environment, or the environmental factors that affect sleep. These factors varied but often included routines and sleeping arrangements.

Participants described their routines as a significant factor in not only their sleep, but for every part of their day. Parents described the busyness of their daily routines – morning routines, to school and work to often multi-stepped and extensive evening and

bedtime routines. Routines permeated every activity many families do, and are often strictly adhered to, with consequences when varied from. Parents often discussed the rigidity of their routines, "*the routine is like overall the same every night so they know what to expect*" (P14). When describing how firm routines are, some parents perceived that as a positive *"it really kind of locked us into a place where we had to figure it out."* (P12), while others found it to be too restrictive,

> *"he has such a rigid routine that he doesn't care whether it's the weekend or it's the holiday or you're tired. If I'm awake, you have to wake up"* (P4).

Many factors influence how the routines are made, and why there may be variability. Some parents discussed their own schedules setting daily routines, *"I work extra hours on Monday so they need to stay in school… they stay up a bit late"* (P5). While others described their schedules as being led by their children*, "most times our sleep gets controlled by the kids… whenever they wake up at night we definitely have to also"* (P11). For most parents, there was a strong sense of responsibility in keeping to the routines they had in place, *"As long as we… keep ourselves in check, if we screw up, then that's on us. But it will be stressful"* (P12).

Many discussed the consequences breaking routines can result in, often resulting in behavioural outbursts.

> *"if he doesn't get that snuggle time… I've gotten phone calls at work… where [Child 1]'s upset they didn't get to see me" (P10).*

The recent COVID-19 pandemic impacted the routines of all participants' families, but sometimes in different ways. Many discussed that the pandemic and as a

result, working from home, helped to improve sleep, *"we had most jobs from home… we had time to sleep, we had time for ourselves, and we're not always worn out"* (P5). This also allowed for more flexibility in how parents were able to spend their time,

> *"there isn't pressure to go and catch a train downtown the next morning… why not get that extra thing done during the nights and sleep a bit more during the day"* (P2).

Others discussed that the pandemic caused dramatic changes in routines, for some families this was difficult because of the dependence their child with ASD had on a strict routine. *"…for a kid who needs routines, he just doesn't trust that school will always be there"* (P10). *"The moment there are changes, it's a problem"* (P4).

Parents spoke of sleeping arrangements as an important factor in the sleep environment, particularly in making sure that their child(ren) with ASD were getting enough sleep, and that siblings were not being disturbed, even if that meant disturbed sleep for themselves. Many parents discussed having to separate their children to make sure sleep was not disturbed, *"one of them is sleeping in the office because [the] other one was screaming for three hours"* (P3). When siblings were older, some parents even discussed the older siblings asking for separation,

> *"Over the years that his brother has been complaining… that has made us give him a separate room… so that he doesn't disturb his brother's sleep"* (P6).

Achieving undisturbed sleep was an incredibly difficult task for many families with a child(ren) with ASD, but protecting the sleep environment was a factor that many parents felt they needed to control, even if that meant taking dramatic steps.

"We actually had to buy another house with the infant so that she could have her own room because we realized quickly that the two children could not share a bedroom at night." (P12).

Consequences of Sleep Deprivation and Sleep Quality

Experiencing sleep difficulties and restricted sleep due to any number of environmental or behavioural factors were common amongst participants. Parental responsibilities were a common barrier to achieving enough sleep. Parents were able to describe the consequences they associated with restricted sleep, as well as the positive consequences of getting enough sleep. Consequences to sleep encompassed clear behavioural and emotional changes that impacted not only individual family members, but the family dynamic and family interactions as well.

Many parents discussed how the responsibilities of being a parent, and caring for their child(ren) with ASD caused even more loss of or lack of sleep,

"*…if they're tired, we're tired, because we've been dealing with them too."* (P12).

"*… there are times where I'll be sleeping every other day… Most of the time I'm up most of the night."* (P12).

For many parents, the role of caregiver meant the work continued during the night and affected their sleep,

"… lying awake at night, waiting for him to wake up and cry, because it was easier to stay awake… than to fall asleep and get woken up" (P10).

"I don't know… the last time I've had a good night's sleep." (P12).

Sleep played a large role in family dynamics and interactions. These interactions between parents, the siblings, and parents to siblings, were impacted by the amount of sleep the family was able to have. Often, this dynamic was most altered between parents, with increased tensions around their bedtime roles,

> *"…my husband and I try to take turns, but when we're just so exhausted as like… you get up and I was like, well why can't you get up?"* (P1).

The dynamic between parents was very strongly impacted, especially when there was one parent who reported doing the majority of nighttime care,

> *"I was doing all the night duty, like my husband was working and commuting… so he would just get his sleep. And so obviously, then I resent him."* (P3).

The dynamic between children and their parents became altered as well, when one child requires a significant amount of care and time dedication, it led to other children in the home not receiving as much attention, which became a point of conflict within the family.

> *"… most of my time is shared by him… that becomes a problem for my family members because I don't give them time*" (P4).

Depending on the age of children and how the children interacted, some families experienced a shift in who was being most impacted by sleep disturbances. When siblings shared a room or were at an age where they were able to communicate, some parents described a shift to where siblings were waking each other up rather than getting a parents attention. As one parent described, they were able to hear their children's

conversation when one woke up crying and the other was trying to comfort them, which resulted in an argument.

"if [Child 1] has been crying… I'd hear [Child 2] saying, '[Child 1], it's okay, it's okay.' And [Child 1] like 'Stop it [Child 2], leave me alone' (P10).

There were often clear symptoms when a family member had not gotten enough sleep in comparison to times when they had. Parents were able to note that these emotional and behavioural changes occurred, recognizing it in themselves as well as in their children and partners.

> *"Everyone is just grumpy when we don't have enough sleep. Like our patience with each other, our patience with the boys, the boys fight so much more when they're tired."* (P10).

When discussing their own sleep, parents often reflected on their emotional state. In themselves, parents recognized that they were negatively impacted by a lack of sleep, both emotionally and in their ability to function.

> *"I'd probably be less grumpy and more involved in like playing… if I wasn't tired… I'm just trying to like keep everybody calm and alive instead of going above and beyond like the minimum"* (P3).

The presentation of symptoms became much more dramatic when children with ASD were not able to sleep enough. It was possible for parents to recall specific behaviours and signs that became more apparent when their child(ren) with ASD is sleep deprived, even if the child is not able to describe it themselves.

"he gets very cranky, and his behaviours skyrocket… he's definitely more likely to have a meltdown" (P12).

"he's basically nonverbal but we can just tell that he's tired… he gets the bags under the eyes and he's just not quite himself… more cranky, whiny" (P1).

Internalization

For many parents, the long-term nature of sleep problems in their family created a sense of internalization and internal conflict that they carried with them throughout their day. Parents described strong emotional responses to sleep and bedtime related to the struggles that their family had achieving sufficient sleep. In order to create a balance between sleep and their own internalized expectations of what should be done in a day, they often felt they had to make trade-offs knowing that any decision they made would have consequences.

During the interviews, parents expressed very strong emotions about sleep and their experiences with sleep in their family. These emotions often centered around anxieties towards making sure their children had enough sleep, and feelings of guilt when they were not able to reach their expectations. Many parents expressed feelings of reciprocity between sleep and their wellbeing,

> *"If they have a good night's sleep, it tends to impact me positively. I feel good about that. And if they don't have a good night's sleep, I get worried about that"* (P13).

Many expressed feelings of fear for their children's well-being when they were not able to sleep properly, especially because these sleep problems were often long-term and they felt they could not do anything to help,

"it scares me sometimes to find my child having difficulties sleeping.. it really bothers me… it's something that you can't force on someone… if he doesn't feel like sleeping you can't manipulate it." (P14).

After facing long-term sleep problems, many parents discussed strong feelings towards bedtime and bedtime rituals, with the anticipation of struggling with bedtime and sleep beginning long before bed-time routines even start.

"I start dreading bedtime on my drive home" (P10),

"*I almost feel like- I don't want to say the word traumatized…"* (P3).

These negative emotions and thoughts often led to feelings of guilt that parents were not able to ensure a peaceful bedtime or good night's sleep. This led to feelings of inadequacy, where parents could not achieve a level of success in regards to sleep that they felt they should be able to "*almost a measure of what a successful mother is by how easily bedtime goes*" (P10). Parents also described guilt because the time they dedicated towards care of their child(ren) with ASD often lead to decreased time spent with their other children,

"I have like extra guilt because he wants to like hug and cuddle and play and I just have no energy" (P1).

Feelings of guilt and inadequacy often manifested into parents choosing to do something they considered more productive than sleeping. In recognizing these trade-

offs, parents expressed understanding that they knew there were consequences of either choice, but that with limited time, it was more important to complete their work and household tasks rather than sleep.

> *"I always feel if I don't do this thing, who is going to do it right? I have to do something other than sleeping" (*P9).

The number of roles a parent plays throughout the day resulted in many feeling the need to push back sleep time as the only option they had in creating time for themselves to relax.

> *"…during the day, I'm for everybody else… I'm an employee, I'm a mom and a wife… But when the kids finally go to sleep, that's when I can have my alone time."* (P1).

Mitigation strategies

To mitigate sleep problems and help to promote sleep, parents described strategies they used. Behavioural and pharmacological strategies were common, with many families using a combination of both that they found worked to promote sleep. While there was overlap in the strategies being used, each participant described unique combinations of strategies that they discovered through extensive trial and error.

Behavioural mitigation strategies were used extensively by parents, the techniques often resulting in multi-step bedtime routines that included a unique combination of common strategies. These bedtime routines were felt to have a significant impact on sleep and ensuring that not only the child with ASD, but the family could take some enjoyment from bedtime.

"I think that things… that helped regulate his sleep… is having that lead time to sleep. And incorporating and figuring out a number of strategies in terms of what [Child] and we as a family enjoy." (P2).

Pharmacological strategies were also used to help promote sleep, often in combination with behavioural strategies. Most commonly, parents discussed the use of melatonin to help regulate sleepiness and sleep.

"[Child 1] takes melatonin otherwise she will never fall asleep, or it'll take her like three hours but with the melatonin she's good and stays asleep now the majority of nights." (P3).

Regardless of which approaches parents described as using to support and promote sleep, they all discussed the process they had to go through to find what worked for them, and this was often through a series of experiments. Parents spoke with enthusiasm about the combination of strategies they used, and often expressed an unwillingness to change from what they found to have worked.

"As long as they're sleeping, I'm not gonna mess with it (laughs). We've tried every possible combination, like no screen, screens, this, that, everything and nothing worked back then" (P3).

The process of trial and error could become a significant source of frustration as parents explored all the options and were not able to find something that worked for them, as described by this parent,

"we become really frustrated because we've done almost everything we could, we have explored all other options, which we know it hasn't really yielded enough results"

(P6). However, once parents found what did work, they expressed how significant this was to their sleep, "*its so hard to give it to him… or to find the right amount. But it's, it's literally been life chang[ing]ed"* (P10).

Understanding of sleep

An understanding of sleep as a physiological function, as well as the importance of sleep behaviours and sleep environment was relatively developed among participants. Many parents expressed a strong understanding of sleep, and its importance in daily functioning. Parents were highly aware of how daily behaviour was impacted by sleep as well as what constitutes healthy sleep environment and behaviours.

The ease of daily routines could be heavily impacted by sleep, especially the sleep of the child with ASD considering the aggravation of symptom presentation that can occur during a sleep deficit,

"our mornings are the most challenging because they're also so dependent on what sleep was like the night before" (P10).

The importance of sleep in daily functioning, both for parents and children, was well understood amongst parents, *"if you're not well rested, then you're not gonna be able to learn at school or get things done during the day" (P15).*

Sometimes, parents were aware that the strategies they used to promote sleep might be against what is generally recommended as a so-called healthy sleep behaviour to help children sleep. Despite an awareness of recommended sleep hygiene techniques, many parents recognized that having less than perfect sleep hygiene is preferable to their children not getting enough sleep.

"they watch some TV after dinner.. even though like everybody says they're not supposed to have TV before they go to sleep… we've tried not doing it and it's like, a disaster. So we just do it. It's working" (P3).

4.5 Discussion

4.5.1 *Key Findings*

Our findings suggest that in this sample of families with a child with ASD, sleep is a family activity, the daily and nighttime routines, the ability to get enough sleep and the results of insufficient or sufficient sleep is impacted, and felt, by the entire family. In trying to understand what makes a typical night's sleep, the reality was that typical does not exist for many families. When asked if they could describe a typical night's sleep, one parent said, " *No. And that's because I don't think there's anything typical about it."* (P12).

Importance of routines in sleep

Routines are important to establish healthy sleep/wake cycles in children to promote good sleep and support development (Karthikeyan et al., 2020; Camassi et al., 2019). Established and consistent routines become even more important when raising a child with ASD. Children with ASD rely on routines for consistency and predictability, something that parents constantly aim for, and become very dependant upon (McAuliffe et al., 2019; Larson, 2006). Consistent with our findings, bedtime routines play an especially important role in helping to provide the cues to sleep and promote relaxation (Kirkpatrick et al., 2019; Schaaf et al., 2011). We also found that despite parents' best efforts, children with ASD still often experience difficulties with sleep, particularly with sleep timing, where many children with ASD were up later than, and woke up before, the

remainder of the family (Kirkpatrick et al., 2019). This can cause significant disruptions to both parents and siblings' sleep. The literature often discusses how difficult morning routines can be because of time constraints and stimulations that often occur during the mornings (Schaaf et al., 2011). This was reflected when parents discussed the lengthy routines they created to maintain order in the mornings.

Routines are very important to create consistency, but the dependence can make it even more detrimental when routines are inevitably disturbed, resulting in behavioural outbursts from the child with ASD that makes parents reluctant to ever vary from their routines (Larson, 2006). This was seen even when changes would be considered "typical" developmental changes – for example, sleeping in your own bed. Parents preferred to stay "as is" in order to protect sleep.

The COVID-19 pandemic was a discussion point for many parents, and had varied impacts on sleep. While some parents enjoyed the slower pace and found more time for sleep and to explore more routines enjoyed by their children, there was underlying concerns about finances, health, and ensuring children's educational needs were being met that compounded the stress many parents already felt (Neece et al., 2020; Meral, 2021). The literature results are mixed when determining how the changes during the pandemic impacted sleep, with strong consideration for how stress and anxiety levels could be compounding existing problems (Kalb et al., 2021). The COVID-19 pandemic was an important contextual piece to the paper, as routines had been changed since the beginning of the pandemic to when the study occurred.

The sleep environment, and especially where family members slept in the home, played a significant role in sleep disturbance (Chou et al., 2012). The tendency of

children with ASD to make noise at bedtime, during the night, or early in the morning was most often the reason siblings' sleep was disturbed.

Consequences of sleep quality and quantity

Children with ASD often suffer from a variety of sleep related difficulties, such as difficulty falling asleep, restless and disturbed sleep, night and early morning awakenings, decreased sleep time, bedtime resistance and difficulties with sleep associations (Carmassi et al., 2019; Kirkpatrick et al., 2019; Richdale & Schreck, 2009). Our study supports existing literature that such difficulties are not only detrimental to the sleep of the children experiencing these difficulties, but also impact the sleep of parents who care for their children at bedtime and during the night, and the siblings who share the home environment and are exposed to this (Kirkpatrick et al., 2019). Parents reported changes in behaviours from not only their child with ASD, but also their NTD children and themselves when comparing nights they had gotten enough sleep to nights they had not.

However, these consequences could be further compounded by the ongoing nature of sleep problems. Conflict and tension between parents could occur when parents perceived the burden of care as being unequal or when they disagreed with how dealing with sleep problems is being handled (Kirkpatrick et al., 2019). The persistent and ongoing nature of sleep problems can create deep family dysfunction and strong emotional responses, especially when comparing parental nighttime roles.

Emotional connections to sleep and bedtime

Further, when discussing sleep, emotions were strongly tied to the entire conversation. Strong emotions from parents when discussing sleep has not been uncommon, and parents tended to choose very strong words to describe how severe the experiences are such as “hell” or as one parent in this study used, “traumatic” (Larson, 2006). Parental feelings of guilt are common in the literature, as parents feel they need to spend more time caring for the child with ASD and ultimately do not have as much time for their other children (Schaaf et al., 2011). Parental guilt was reflected when discussing the lack of energy to interact with other children.

Mitigation

Family attempts to improve sleep were evident throughout our interviews, with many parents describing extensive trials of mitigation strategies. Many of the strategies centered around behavioural interventions such as sleep hygiene, which in the literature is often the first targeted sleep intervention (Karthikeyan et al., 2020; Abel et al., 2017). Throughout parental discussion of mitigation strategies, there was a strong sense of experimentation, where parents had tried many different routines and variations of routines, changed the length and timing of activities, and added in extra factors such as melatonin or weighted blankets. This may suggest that this parent population is educated on basic sleep hygiene; parent education is considered to be key to successfully implementing behavioural interventions to ensure that interventions are being applied consistently (Ali et al., 2018, Turner & Johnson, 2012).

4.5.2 *Significance*

Our findings support the literature and suggest that sleep needs to be considered from a family-centric lens. Our findings can be used to support the need for further

research into family centric sleep and sleep practices. It is important to develop a more fulsome understanding of the interactions of the family around bedtime and sleep to ensure that sleep research acknowledges the role of the family and home environment on sleep.

4.5.3 *Strengths and Limitations*

This study has both strengths and limitations, a major strength being that parents from different family structures and with different experiences of ASD were able to be interviewed. Pilot-testing the semi-structured interview guide helped to develop probes and create a conversational flow in the interviews while also developing interviewing skills. Strong member-checking and inter-coder reliability testing ensured that there was rigor in the methodologies and findings were valid. Reflexivity was discussed at team meetings as each team member provided their own perspectives and interpretations.

It should be noted that the study's aim was to investigate the experiences of sleep in parents with a child with ASD, and that our sample was drawn from parents in contact with Grandview Kids, thus the findings may not be generalizable to families from other care organizations due to potential differences in available resources. Further research could explore how these perspectives could change in different regions with different approaches to care. This sample of parents spoke to the use of pharmaceutical agents to promote sleep only in the context of melatonin, this may suggest that sleep problems are not as severe in this population as they have the potential to be, as some families require stronger medications to help children sleep. Future research should attempt to recruit families that have experiences at this end of the spectrum to ensure their experiences are shared. Additionally, only one member of the family was involved in the study. Future

research can investigate more on the differences in perspectives of family members, particularly how mothers, fathers, and siblings in one family may perceive sleep differently and include families with children of different ages to explore how interactions around sleep may change with age.

4.6 Conclusions and Next Steps

Sleep in families with a child with ASD, should be considered a family function that impacts, and is impacted by, daily activities and interactions. The routines that guide daily activities and promote sleep are adhered to strictly by most family members. When sleep is disturbed, it is often disturbed for more than just the child with ASD, and usually results in impacting at least one parent and potentially the siblings as well. When sleep has been disturbed, this has pervasive effects on the mood, behaviour and productivity of every family member, as well as in family interactions. Our findings suggest that sleep research should consider the effect of family and home environment on sleep. We suggest that future research into treatments and interventions to support sleep should include not only the child with ASD, but the entire family unit as well. With an increasing understanding of the importance of sleep physiologically, emotionally, and mentally, there is a clear need to address gaps in sleep research, especially involving the sleep of children.

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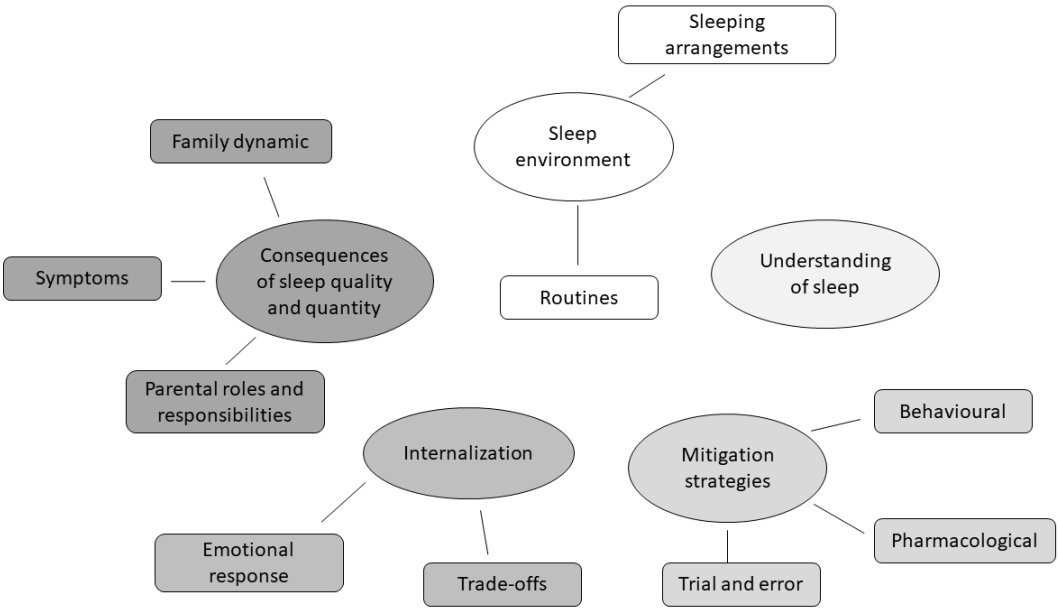
Table 1. Demographic Characteristics of Interview Participants

Characteristics		*n*
Gender	Male	5
	Female	10
Ages	18-25	1
	26-35	5
	36-45	9
Marital status	Married	14
	Separated	1
Education	Some Post-secondary	1
	Post- secondary certificate, degree or diploma	14
Occupation	Full-time	9
	Part-time	2
	Homemakers	4
Household income	< 20 000	1
	20-49 000	3
	50 - 79 000	1
	> 80 000	9
	Prefer not to disclose	1
# of children	1	3
	2	9
	3	2
	4	1
# of children with ASD	1	13
	2	2
Age of children	Pre K	7
	Kindergarten	5
	Grade 1-3	7
	Grade 4-6	4
	Grade 7-8	1
	Grade 9-12	2
	Beyond Highschool	2
Age of ASD diagnosis	Grade 1	5
	Grade 2	5
	Grade 3	3
	Grade 4	2
	Grade 5	2
Time of diagnosis	Within the year	2
	2-3 years ago	11

	4-5 years ago	2
	6+ years ago	2
Gender of child with ASD	Female	5
	Male	12
Ethnicity of child with ASD	Caucasian	8
	Black	6
	South Asian	1
	Middle Eastern	1
Required level of support for child with ASD	Requires support to: switch between activities, initiate social interactions, respond to social cues of others. Often speaks in full sentences and engages in interaction but struggles with conversation and has difficulty attempting to make friends.	10
	Requires substantial support to: change focus, cope with change, initiate and respond to social interactions. Often speaks in simple sentences, limits interactions to special interests, and has odd nonverbal communication.	3
	Requiring very substantial support to: cope with change, change focus or action, perform social interactions, respond to social cues. Often has few words, rarely initiated interaction, responds only to direct social approaches.	4
Family awareness of diagnosis	Yes	13
	No	1
	Prefer not to disclose	1

Figure 1. Schematic Diagram of Themes



Legend:

Oval text boxes represent main themes.

Square textboxes represent subthemes.

Lines connect the subthemes to main themes.

Chapter 5. Discussion and Conclusion

The following chapter will provide a summary of the thesis work, a discussion on key themes, discuss the implications, strengths and limitations of the study, and finally will conclude with next steps.

5.1 Thesis Summary

ASD is a group of neurodevelopmental disorders with a complex combination of symptoms that can impact communication, behaviours, and even sleep (APA, 2013; Benson et al., 2019; Petrou et al., 2018). Sleep is an important function in both daily functioning and, especially for children, development (Karthikeyan et al., 2020). Children with ASD experience sleep difficulties much more than NTD children and are more likely to have disruptive sleep behaviours including bedtime resistance, nightmares, and early morning awakenings (Carmassi et al., 2019; Kirkpatrick et al., 2019; Richdale & Schrek, 2009). This has the potential to impact the sleep of the entire family, beyond the child with ASD, due to burdens of nighttime care, disruptions, and stress (Karthikeyan et al., 2020; Chou et al., 2012). The family perspective of sleep, as well as how families navigate and mitigate sleep problems has remained understudied.

The purpose of this interpretive phenomenology informed study was to explore the lived experiences of sleep in families with a child with ASD, from a parent's perspective. The study was guided by two questions: what are the experiences and perceptions of sleep in these families, and what are the perceived facilitators and barriers to sleep. Parents' rich descriptions of their experiences and beliefs were obtained through fifteen semi-structured in-depth interviews. Each parent described a unique family situation and perspective about sleep, but also described commonalities that spoke to the

essence of the experience of families, and family functioning, around sleep. The inclusion of families of different structures and ages of children added diversity and richness to the discussion. The descriptions and experiences shared by parents can be separated into five themes that revolved around both sleep behaviours and perceptions of sleep; environmental factors that contributed to sleep, consequences to sleep deprivation and sleep quality, internal conflict surrounding sleep, mitigation strategies used to promote sleep and understanding of sleep functions and benefits.

5.2 Environmental Factors Contributing to Sleep

Participants described a high dependence and prioritization on controlling the environmental factors associated with sleep, particularly through the use of routines and sleeping arrangements.

5.2.1 Routines

Routines are incredibly important to establish healthy sleep/wake patterns in children to promote good quality sleep and support development (Karthikeyan et al., 2020; Carmassi et al., 2019). Established and consistent routines become even more important when raising a child with ASD. Children with ASD rely on routines for consistency and predictability, something that parents constantly work for, and become very dependant upon (McAuliffe et al., 2019; Larson, 2006). Bedtime routines play an especially important role, as was further supported by this study, in helping to provide the cues to sleep and promote relaxation (Kirkpatrick et al., 2019; Schaaf et al., 2011). Despite parents' best efforts, children with ASD still often experience difficulties with sleep, particularly, as this study found, with sleep timing, where many children with ASD were up later than, and woke up before, other family members (Kirkpatrick et al., 2019).

This can cause significant disruptions to both parents and siblings' sleep. The literature often discusses how difficult morning routines can be because of time constraints and stimulations that often occur in mornings (Schaaf et al., 2011). This was reflected in this study as parents discussed the lengthy routines they created to maintain order during the mornings, especially with their child(ren) with ASD and the impacts to the rest of the day when these routines became disturbed.

Routines are very important to create consistency, but the dependence can make it even more detrimental when routines are inevitably disturbed, resulting in behavioural outbursts from the child with ASD that makes parents reluctant to ever vary from their routines (Larson, 2006). This was seen even when changes would be considered "typical" developmental changes – for example, sleeping independently in their own bed. Parents preferred to stay "as is" in order to protect sleep.

The COVID-19 pandemic was a discussion point for many parents and had varied impacts on sleep. While some parents enjoyed the slower pace and found more time for sleep and to explore more routines enjoyed by their children, there was underlying concerns about finances, health, and ensuring children's educational needs were being met that compounded the stress many parents already felt (Neece et al., 2020; Meral, 2021). The literature results are mixed when determining how the changes during the pandemic impacted sleep, with strong consideration for how stress and anxiety levels could be compounding existing problems (Kalb et al., 2021). This was reflected during interviews as some parents discussed the extra time they had to sleep, while others felt all the changes just added to stress and ruined routines they had established.

Reliance and adherence to routines was common in families, not only at bedtime but throughout the day, and parents noted any sudden changes to routines could cause a cascading effect that ultimately made bedtime and sleep more difficult to achieve. Children with ASD are often reliant on routines and strictly adhere to them, finding it difficult to cope with changes (McAuliffe et al., 2019; APA, 2013). Parents were able to recognize when routine disturbances resulted in sleep disturbances, even when the change occurred early in the morning. Routines are incredibly important to families with a child with ASD, and this is likely related to the insistence on sameness and inflexibility when adhering to routines that is a common expression of ASD (APA, 2013).

5.2.2 Sleep Environment

The sleep environment, especially where family members sleep, played a significant role in the likelihood of experiencing sleep disturbances, a finding reflected in the literature as well (Chou et al., 2012). While parents' sleep was often disturbed as a result of their role as caretaker, sibling sleep was more often impacted when they shared a room with a child with ASD, or had rooms close together. The tendency of children with ASD to make noise at bedtime, during the night, or early in the morning was most often the reason siblings' sleep was disturbed.

5.3 Consequences of Poor Sleep Quality and Quantity

Parents often discussed the consequences for the amount of sleep they as a family, and individually, were able to obtain. The experiences were often positive when they were able to get "enough" sleep, and negative consequences where described when sleep was poor. These perceived consequences were pervasive, causing significant burden to

parents or caretakers, effecting family interactions and the family dynamic, and were accompanied by obvious behavioural and emotional changes.

Children with ASD often suffer from a variety of sleep related difficulties, such as difficulty falling asleep, restless and disturbed sleep, night and early morning awakenings, decreased sleep time, bedtime resistance and difficulties with sleep associations (Carmassi et al., 2019; Kirkpatrick et al., 2019; Richdale & Schreck, 2009). My study supports existing literature that this is not only detrimental to the sleep of the children experiencing these difficulties, but also impacts the sleep of parents who care for their children at bedtime and during the night, and the siblings who share the home environment and are exposed to thisParents reported changes in behaviours from not only their child with ASD, but also their NTD children and themselves, when comparing nights they had gotten adequate sleep to nights they had not.

5.4 Emotional Connections to Sleep and Bedtime

The behavioural consequences of sleep loss could be further compounded by the ongoing nature of sleep problems. Conflict and tension between parents could occur when parents perceived the burden of care as being unequal or when disagreements arose with how sleep problems were being handled (Kirkpatrick et al., 2019). The persistent and ongoing nature of sleep problems can create deep family dysfunction and strong emotional responses, especially when comparing parental nighttime roles.

Strong emotions from parents when discussing sleep is not uncommon (Karthikeyan et al., 2020; Jajodia & Roy, 2022). In the current study, parents used very strong language to describe the severity of the experience such as “hell” or as one parent in current study used, “traumatic” indicating the severe negative association with sleep

disturbances. Feelings of guilt by the parent are also common in the literature (Schaaf et al., 2011; Jajodia & Roy, 2022). Parents often feel they need to spend more time caring for the child with ASD and ultimately do not have as much time to spend with their other children (Schaaf et al., 2011). Parental guilt was reflected when discussing the lack of energy to interact with NTD children. This has been reflected in disability literature as NTD siblings feel a sense of neglect in comparison to their sibling receiving more care and attention (Jajodia & Roy, 2022). n alignment with the literature, parents in this study were aware that their NTD children may be feeling neglected and left out and felt a sense of guilt in that they had no way to change it (Jajodia & Roy, 2022). These feelings of guilt were significant to parents who already carried emotional burdens.

Parents shared that they often dealt with significant internal conflict when considering their family's sleep. Many parents expressed significant emotional responses to sleep, feelings of guilt knowing their children were not obtaining sufficient sleep, and in some cases significant emotional reactions when even thinking about bedtime. The concept of trade-offs emerged as parents felt they did not have enough time in the day to be parents and employees, spouses and individuals.

5.5 Mitigation Strategies to Promote Sleep

Parents were able to describe in-depth strategies their family used to help improve sleep, often a complex mix of behavioural and pharmacological strategies that they found to work through extensive trial and error. Throughout the interviews, parents often expressed an understanding of sleep built through their experiences, as well as recommendations from therapists and their own research. This building of understanding allowed parents to balance what professionals have found to be important to developing

good sleep habits with what works in their family, even though that might have been contradicting. It is important to note that while parents discussed the idea of pharmaceutical strategies to promote sleep, only melatonin was mentioned. Melatonin was discussed as an important tool to help children fall asleep and does have a history of successful use in children with ASD to promote regulation of the sleep cycle (Carmassi et al., 2019).

Family attempts to improve sleep were evident throughout the interviews, with many parents describing extensive trials with mitigation strategies. Many strategies centered around behavioural interventions such as sleep hygiene, which in the literature is often the first targeted sleep intervention (Karthikeyan et al., 2020; Abel et al., 2017). Throughout parental discussion of mitigation strategies, there was a strong sense of experimentation, where parents had tried many different routines and variations of routines, changed the length and timing of activities, and added in extra factors such as melatonin or weighted blankets. These strategies extended beyond nighttime routines, parents considered the timing they needed to dedicate to breakfast after a bad night's sleep and changed homework and dinner timing to alter when bedtime routines could start in attempts to mitigate poor sleep and help ease the transition into bedtime. The strategies used may suggest that this parent population is educated on basic sleep hygiene, and parent education is considered to be key to successfully implementing behavioural interventions (Karthikeyan et al., 2020).

5.6 Significance

The results are meaningful, in part due to the use of rigorous qualitative methodologies. Existing literature on sleep from a family perspective is limited, therefore

the research questions were designed to be broad to facilitate an exploratory understanding of this topic. Studies have identified sleep concerns in individual family members in families with a child with ASD, but lack a family perspective despite that the sleep behaviours in a home is influenced by all its members (Chou et al., 2012). In-depth interviewing revealed how pervasive a concern sleep, and trying to achieve sleep, is in the entire family unit.

The timing of this study draws further significance as interviews were conducted during the Spring of 2022 when many families were still facing impacted routines and reflecting upon the changes brought about during the COVID-19 pandemic. Adapting to a "new normal" has been something everyone has had to deal with for two years, the COVID-19 pandemic was an important contextual piece to my research, as routines had been changed since the beginning of the pandemic to when the study occurred. Existing literature is mixed when discussing if the COVID-19 pandemic has positively or negatively impacted sleep, and that is likely because it has done both. Disturbed routines and higher stress could be detrimental to sleep, but having more time at home could allow for more flexibility in getting to sleep (Neece et al., 2020; Meral, 2021; Kalb et al., 2021).

The use of a qualitative approach to this research provided a rich contextual understanding of family sleep, allowing for exploration into participants unique experiences while still being able to draw out themes that reflected the shared experiences and perceptions. The use of a phenomenological approach to this research was important to ensure that the consistent themes of lived experiences were being captured (Creswell & Poth, 2018; Wognar & Swanson, 2007).

This research was conducted to add new perspectives and awareness to fill an important gap in the literature; findings from this study can enrich the understanding of how sleep in families with a child with ASD is family centric and can create pervasive effects on family functioning. Sleep in families with a child with ASD is dependent on more than just bedtime and can especially be affected by changes to routines at any point during the day. For these families, bedtime started in the morning, with parents having to consider what throughout their child's day might impact their sleep, and therefore the whole family's sleep. Family routines are important to help manage sensory related behaviours in children with ASD, and parents acknowledged that changes to these routines during any part of the day could result in more challenges at bedtime (Schaaf et al., 2011). This study revealed that in families with a child with ASD it is important to control daily activities and stimuli through the use of routines to improve the bedtime experience and sleep overall.

This insight made it important to revisit the original theoretical framework by Christensen (2004). This study provides insight into potential ways this framework may need to be updated. In considering the role of the child, it became clear that child health status plays a much more central role in behaviours and is a contributing factor to behaviours rather than simply an outcome. The current model of the health promoting family by Christensen (2004), provides a more one-directional view of factors that influence health practices, and this study found it to be much more complex, involving an interplay between health, practices, and pathways that feed into and influence each other. Figure 5.1 shows the model of the health promoting-family (Christensen, 2004), with proposed changes represented by the dashed arrows. These arrows show a two directional

influence between child health status, family ecocultural pathways, health practices and the child's role as a health promoting agent rather than the one-directional arrows that originally represented child health status as only an output and not an influencing factor.

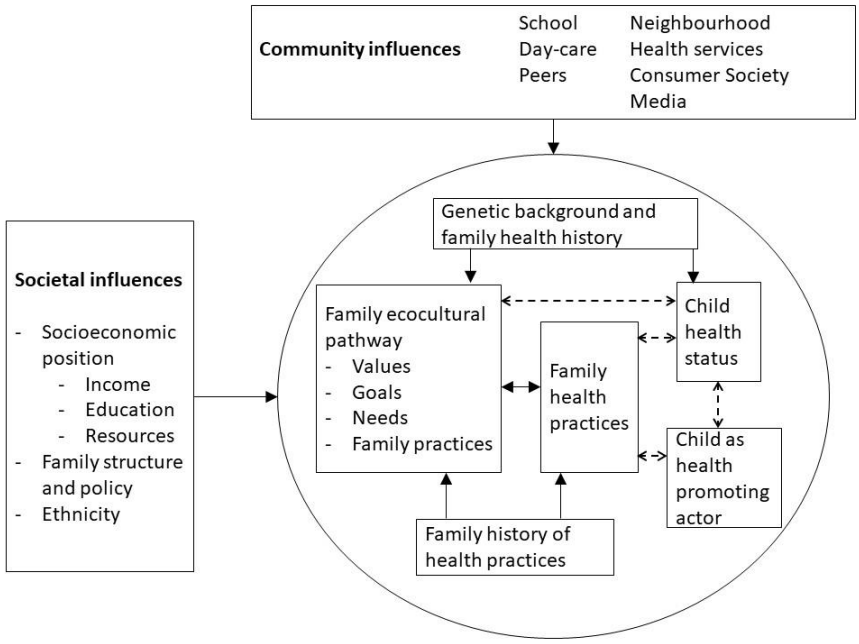


Figure 5.1: Proposed Changes to *The Model of the health-promoting family (*Christensen, 2004)

Future research should continue to revisit this framework to consider increasing the feedback between family factors influencing health practices to move from a one directional flow to better address how family health practices, child health, and the child(ren) as the health promoting factor all influence each other bidirectionally.

The findings suggest that more work needs to be done to understand how each family member may be impacted and to explore the cyclical nature of sleep and family functioning. It would also be impactful to have further variation in the age of children with ASD included to develop a further understanding of how sleep behaviours and caretaker roles change as a child ages. Future research in these areas could help develop a

stronger understanding of sleep and how it functions in a family so further work could be done to address sleep problems.

5.7 Strengths and Limitations

5.7.1 Strengths

This project has several strengths. Pilot-testing the semi-structured interview guide helped to develop probes and create a conversational flow in the interviews while also developing interviewing skills. Partnership with Grandview Children's Centre during the recruitment process allowed us access to a varied and motivated population. Strong member-checking and inter-coder reliability testing ensured that there was rigor in the methodologies and findings were valid. Reflexivity was discussed at team meetings as each team member provided their own perspectives and interpretations. The inclusion of a member of the research team and the peer navigator from Grandview Children's Centre with lived experience was important during the planning of this research to ensure that the methods would provide meaningful results to reflect lived experiences of these families.

5.7.2 Limitations

This thesis is not without limitations. Findings may not be transferable to, or representative of, all families with a child with ASD. Findings may differ among families who live in different geographical areas and have different experiences with sleep and sleep therapies. Due to the timing of the interviews during the COVID-19 pandemic, transferability of findings may also be impacted as this had been a time of instability for many.

5.8 Conclusions and Next Steps

Sleep is an important mechanism that is required for daily functioning, as well as long term health and wellness, especially amongst children (Karthikeyan et al., 2020, Camassi et al., 2019). Findings from this study highlight the work many families dedicate to achieving sleep through the use of intensive and strict control of the sleeping environment, especially through routines, and the dedication they had to find the methods that improved sleep for them. The ability to get enough sleep was a constant priority, one with clear consequences to both individual behaviour, and family functioning, that parents tied strongly to their own emotional wellbeing. This thesis provides important contributions to the understanding of the multifactorial nature of sleep, especially in families.

Continued investigation is needed to develop an even greater understanding of the perceptions of each family member. While this current study included the perspectives of mothers and fathers, the majority of participants were mothers, continued investigation into how perceptions differ between parents would be important. This study also interviewed one parent on family sleep, but this perspective might change when interviewing another parent or caregiver in the home, or their children. In developing a family-centric understanding of sleep, it is important to see how perspectives might vary between family members and depending on roles. Further exploration into mixed methods methodologies would provide a valuable opportunity to use sleep scales in addition to interviewing. Future research should gain support of peer groups to assist with recruitment and participation.

While the literature has an abundance of research on the sleep of children with ASD, it is often conducted in silos that reduce the ability to understand how family influences sleep, and conversely, how sleep influences family. This study provides a unique perspective of how sleep interplays throughout all family members, influencing daily behaviours and interactions with the family, and often becomes the focus of daily routines. In addition to contributions to the existing literature, it is the hope that this research helps to generate awareness of the importance of considering sleep as a family function and to encourage future research to explore family roles in sleep.

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Appendices

Appendix A. REB Approval

Date: *February 09, 2022*
To: *Dr. Efrosini Papaconstantinou*
From: *Janice Moseley, Research Ethics Officer on behalf of Dr. Paul Yielder, Interim REB Chair*
File # & Title: *15788 - Sleep Characteristics of Families with Children with ASD.*
Status: ***CHANGE REQUEST APPROVED (January 30, 2022 condition addressed)***
Current Expiry: ***February 01, 2023***
Documents Approved:

Document Type	Document Name	Version Date
Data Collection Materials	Appendix 2: Interview guide, Clean	2021/12/23
Data Collection Materials	Appendix 1: Demographics questionnaire	2021/12/14
Consent Letter	Appendix 3: Consent form, Clean	2021/12/23

Notwithstanding this approval, you are required to obtain/submit, to Ontario Tech's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The Ontario Tech Research Ethics Board (REB) has reviewed and approved the change request related to the research study named above. This request has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 2018), the Ontario Tech Research Ethics Policy and Procedures, and associated regulations. As the Principal Investigator (PI), you are required to adhere to the research protocol described in the REB application as last reviewed and approved by the REB.

Under the Tri-Council Policy Statement 2, the PI is responsible for complying with the continuing research ethics reviews requirements listed below.

Renewal Request Form: All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed 30 days post expiry date will be automatically suspended by the REB; projects not renewed 60 days post expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.

Change Request Form: If the research plan, methods, and/or recruitment methods should change, please submit a change request application to the REB for review and approval prior to implementing

the changes.

Adverse or Unexpected Events Form: Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).

Research Project Completion Form: This form must be completed when the research study is concluded.

Always quote your REB file number (**15788**) on future correspondence. We wish you success with your study.

Sincerely,

Janice Moseley
Research Ethics Officer
researchethics@ontariotechu.ca

On behalf of:

Dr. Paul Yielder
Interim REB Chair
paul.yielder@ontariotechu.ca

NOTE: If you are a student researcher, your supervisor has been copied on this message.

Appendix B. Recruitment Poster

Appendix C. Informed Consent

Informed Consent

Exploring Sleep Characteristics of Families with a child with Autism Spectrum Disorder (ASD).

Investigators:

Emma Grant Masters of Health Sciences Student, Faculty of Health Sciences Ontario Tech University 905-721-8668, ext. 3736 emma.grant2@ontariotechu.net

Principal Investigator:

Dr. Efrosini Papaconstantinou Assistant Professor, Faculty of Health Sciences Ontario Tech University 905-721-8668, ext. 3736 efrosini.papaconstantinou@uoit.ca

Introduction

You are invited to participate in a research study entitled *Exploring Sleep Characteristics in Families with a Child with Autism Spectrum Disorder (ASD).* You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on the study's procedures, risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the Principal Investigator (PI) or study team to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends and family. Participation in this study is voluntary.

This study has been reviewed by the University of Ontario Institute of Technology (Ontario Tech University) Research Ethics Board [REB #9200] on January 30, 2022.

Purpose and Procedure:

Purpose:

The purpose of this study is to explore the sleep characteristics and behaviours in families caring for a child with Autism Spectrum Disorder (ASD). You are invited to take part in an interview with a member of the research team that explores your opinions, attitudes, and beliefs about the sleep experiences within your family.

Background and Rationale:

Children with ASD experience poor sleep, most commonly related to difficulty falling asleep or staying asleep. When a child does not sleep well they may have problems with memory, learning, and it may worsen daytime behaviour. Sleep disturbances may cause stress in families of children with ASD. Many parents of children with ASD also report sleep problems. If the child is not sleeping, the parent is also likely to experience sleep problems. An area that has not received attention is the sleep problems of typically developing sibling(s) of children with ASD. Some preliminary studies suggest that typically developing siblings are also at risk for early morning awakenings, sleep disturbances, sleep-talking and nightmares compared to the typically developing children in non-autistic families. Although there have been some promising results with sleep hygiene education to improve the sleep of children with ASD, a better understanding of sleep behaviours in ASD families would be beneficial so that interventions can be developed that are targeted towards the entire family unit.

You have been invited to participate in this study because you have at least one child with ASD.

Procedures:

For this study, parents of children with ASD are invited to participate in a one-to-one interview with a member of the research team. Interviews will be held at a convenient time for the participant on campus at Ontario Tech University or through an on-line platform (e.g., Skype). Prior to the interview, a short questionnaire will be made available online through LimeSurvey to better understand your social contexts, no identifiers will be collected, and all responses will be anonymous. The interview will take between 45-60 minutes to complete. Once you have consented to participate, the interview will be audio-taped and later on transcribed by an experienced transcriber. Once it is transcribed, the original audio-tape will be destroyed. Transcripts will remain confidential and no connection between you and your responses will be made.

Participation in this study is completely voluntary, and you may withdraw consent at any time by telling the researcher you no longer wish to continue. There are no consequences should you choose not to participate. You will also be provided with a $25.00 Gift Card at the end of the study in appreciation of your time.

Potential Benefits:

You will not directly benefit from participating in this study. If you choose to participate in this study, you will have the opportunity to provide your opinions and attitudes about sleep behaviours within your family. Furthermore, you may benefit indirectly by contributing to our understanding of sleep behaviours in families of children with ASD which can help shape future interventions that target children with ASD and their families.

Potential Risk or Discomforts:

There are no known or anticipated risks to you from participating in this study. Your involvement in this study is entirely voluntary and will in no way affect the care that you and your family receive at Grandview Children's Centre or any other organization that you seek care from. There are no right or wrong answers and you are free not to answer any questions that you would rather not answer by simply saying 'pass.' You may withdraw at any time. Any risks associated with this research study are no greater than those which may be encountered by participants in everyday life.

Use and Storage of Data:

All interviews will be audio-recorded and later transcribed by an experienced transcriber. All audio-recorded files will be uploaded to the university server in a restricted Google Drive folder restricted to only research team members with password protected accounts. Once the files have been transcribed all audio-recordings will be destroyed. There will be no participant identifiers connecting individuals to their responses. Transcriptions will then be entered in a specific data-analysis software for thematic analysis. This will also be password protected and only members of the research team will have access to this data.

Confidentiality:

Your privacy shall be respected. No information about your identity or your family will be shared or published without your permission, unless required by law. Confidentiality will be respected to the fullest possible extent by law, professional practice standards, and ethical codes of conduct. Please note that confidentiality cannot be guaranteed while data is in transit over the Internet. Data collected from the interviews will be kept confidential. All audio-recordings will be stored on the university server in a restricted Google Drive that only members of the research team are able to access. Files will be password protected file. Once the audio-recordings have been transcribed, they will be destroyed. Data collected from the interviews will be entered into a specific data analysis software for thematic analysis.

Pseudonyms will be created and be used in a publication. You will not be named in any reports, publications, or presentations that may come from this study. Only references to findings from these interviews as a whole will be used when discussing the study. The information from this research study may be used for educational purposes, but no participant identifiers will be used.

Voluntary Participation:

Your participation in this study is voluntary and you may partake in only those aspects of the study in which you feel comfortable. You may also decide not to be in this study, or to be in the study now, and then change your mind later. You may leave the study at any time. This will not affect the care that you and your family receive at Grandview Children's Centre or any other organization that you seek care from. You may choose not to answer an interview question by saying, 'pass.'

Right to Withdraw:

Your participation in this study is voluntary. You have the right to refuse answering any questions you are uncomfortable responding to. You can withdraw from the study for any reason, at any time. Participants can choose not to participate by not attending the interview or by leaving the interview at any time. Once your interview is completed and

has been transcribed, your responses cannot be removed from the data because there are no associated participant identifiers.

Conflict of Interest:

There is no conflict of interest associated with this study. The researchers have an interest in completing this study but should not influence your decision to participate in this study.

Compensation, Reimbursement, Incentives:

Participation in this study is completely voluntary. You will be provided with a $25.00 E-Gift Card at the end of the study in appreciation of your time.

Debriefing and Dissemination of Results:

Should you be interested in learning about the study results you may contact Dr. Efrosini Papaconstantinou (efrosini.papaconstantinou@uoit.ca).

Participant Rights and Concerns:

Please read this consent form carefully and feel free to ask the researcher any questions that you might have about the study. If you have any questions about your rights as a participant in this study, complaints, or adverse events, please contact the Research Ethics Office at (905) 721-8668 ext. 3693 or at researchethics@uoit.ca.

If you have any questions concerning the research study or experience any discomfort related to the study, please contact the Principal Researcher Dr. Efrosini Papaconstantinou at 905-721-8668, ext. 3736 or via e-mail at efrosini.papaconstantinou@uoit.ca. Please note that communication via e-mail is not absolutely secure. Thus, please do not communicate personal sensitive information via e-mail.

By signing this form, you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

Consent to Participate:

Online Consent

1. I have read the consent form and understand the study being described; 2. I have had an opportunity to ask questions and those questions have been answered. I am free to ask questions about the study in the future.

3. I freely consent to participate in the research study, understanding that I may discontinue participation at any time without penalty. A copy of this Consent Form has been made available to me.

_____ _____ _____ Print

Study Participant's Name Signature Date

Appendix D. Demographics Questionnaire

Thank you for agreeing to participate in this study on sleep characteristics in families with a child with ASD. Demographic information is collected to be able to identify the variations in family's characteristics. No personal identifiers will be connected to this data, all data will be aggregate.

Please complete this brief questionnaire prior to the interview. If you have any questions, please contact emma.grant2@ontariotechu.net

Please answer each question below. Pick the one answer that best describes your situation

1. *Who is filling out this questionnaire?*

    a) *Father*
    b) *Mother*
    c) *Both parents*
    d) *Guardian*
    e) *Other (specify please)* _____

(If both parents is selected, questions 2,3, 4, 5, and 6 will appear twice

2. *Which gender do you identify with?*

    a) *Male*
    b) *Female*
    c) *Non-binary*
    d) *Other (please specify)*
    e) *Prefer not to specify*

3. *Which age range do you identify with?*

    a) *18-25*
    b) *26-35*
    c) *36-45*
    d) *46-55*
    e) *56 – above*

4. *What is your martial status?*

    a) *Married*
    b) *Living common law*
    c) *Never married (not living common law)*
    d) *Separated (not living common law)*
    e) *Divorced (not living common law)*

f) *Widowed (not living common law)*

5. *What is the highest level of education you have completed?*

   a) *Less than secondary (high) school graduation*
   b) *Secondary (high) school diploma or equivalent*
   c) *Some postsecondary education*
   d) *Postsecondary certificate, diploma or degree*

6. *What best describes your employment status?*

   a) *Full-time Employment*
   b) *Part-time*
   c) *Homemaker*
   d) *Temporary or Seasonal Work*
   e) *Retired*
   f) *Disability leave*
   g) *Parental leave*
   h) *Unemployed*
   i) *Other: _____*

7. *What is your households' annual combined income?*

   a) *< $20 000/year*
   b) *$20 000 – $49 000/year*
   c) *$50 000 – $79 000/year*
   d) *Above $80 000/year*
   e) *Don't know*
   f) *Prefer not to disclose*

8. *How many children do you have in your family (including adult children)?*

   ____

9. *How many children are diagnosed with Autism Spectrum Disorder?*

   _____

10. *Select the grade level that applies to each child in the family*

    a) *Prekindergarten*
    b) *Kindergarten*
    c) *Grade 1 to 3*

d) Grade 4 to 6
e) Grade 7 to 8
f) Grade 9 to 12
g) Beyond high school

(Question will repeat to correspond with number of children selected in question 8)

Background Information about the Child or Children with Autism Spectrum Disorder:

1. *At what age was your child or children diagnosed with ASD?*

   _____

(Question will repeat depending on number of children with autism identified in Q9 for questions 1, 2, 3, 4, and 5)

2. *What gender does your child with ASD identify as?*

   a) *Male*
   b) *Female*
   c) *Non-binary*
   d) *Other (please specify)* _____
   e) *Prefer not to answer*

3. *What is the ethnic background of your child with ASD?*
   a) Indigenous (First Nations, Inuit, Metis)Black
   b) Caucasian
   c) East Asian
   d) South Asian
   e) South East Asian
   f) Latin American
   g) Middle Easter
   h) Biracial
   i) Other: _____

4. *Which statement best reflects the level of support your child with ASD requires?*

   a) My child requires support to: switch between activities, initiate social interactions, respond to social cues of others. Often speaks in full sentences

and engages in interaction but struggles with conversation and has difficulty attempting to make friends.

b) My child requires substantial support to: change focus, cope with change, initiate and respond to social interactions. Often speaks in simple sentences, limits interactions to special interests, and has odd nonverbal communication.

c) My child requires very substantial support to: cope with change, change focus or action, perform social interactions, respond to social cues. Often has few words, rarely initiated interaction, responds only to direct social approaches.

5. Are all members of the family, including the child with ASD, aware of this diagnosis?

a) Just the primary caregivers (e.g. mom, dad, etc)
b) The child and the primary caregiver
c) All members of the household are aware of the diagnosis

Appendix E. Semi-Structured Interview Guide

Welcome and thank you for volunteering to participate in this interview. My name is ____, and I am a graduate student at Ontario Tech University. I am trying to understand the impact that Autism Spectrum Disorders (ASD) has on the sleeping behaviours of the family. As a parent or caregiver of a child with ASD, I am asking you to participate because I believe that your attitudes, opinions, and experiences about sleep within your family are important. The interview discussion will take no more than 1 hour of your time. When you are answering the questions, please give me as much detail as you would like so that I can really understand your perspective. Take your time and do not feel rushed. If you are having a hard time finding the words to describe your answer take a moment to think about it. There are no right or wrong answers. Participation is voluntary and you are free not to answer any questions that you would rather not answer. I will begin to audio-record the discussion to facilitate its recollection. I would like to assure you that this discussion will be confidential. The audio recording from this interview will be kept safely in the G Suite at Ontario Tech, which is an on-line secure cloud server located on site at Ontario Tech University with access restricted to members of the research team in password protected files, until it is transcribed verbatim, then it will be destroyed. All files Do you have any questions before we start? (If the response is no) Great! Let's begin. I will begin to audio-record.

Guiding Questions:

1. To start off, can you tell me about your family?

a. Who is in your family? You can use real names or pseudonyms. Please let me know which you would prefer
b. Number of children, ages

2. Can you describe to me what a typical day is like for you? From wake up to bed time.
    a. What is your morning routine?
        i. Wakeup, getting ready
    b. Do you take your children to school, does someone else take your children, or do they go by bus?
    c. Do you have to work during the day?
    d. Who picks up the children?
    e. Are your children involved in any after school programs or activities?
    f. What are some of the key challenges in your day? (Validated throughout responses above)
        i. Morning? Mealtime? Bedtime? Overnight?
        ii. Why?
3. Tell me about your family's experiences with sleep… We'll go into more detail in a second about routines but more about your overall experience.
    a. Is it something that is a struggle for your family? Why?
    b. What about bedtime?
4. Can you describe the typical bedtime routine in your home?
    a. Does he/she have a consistent bedtime routine?
        i. What are your experiences when putting your child to bed?

b. What are the sleeping arrangements in your home?
    i. Where is the most common place your child with ASD falls asleep?
    ii. If not in their own bed, do you move them back to their own bed?
    iii. Do they fall asleep during dinner, while watching TV at night, or playing with electronics?
c. Do your children share a room?
    i. With you? With other sibling(s)?
    ii. Do your children share a bed?
    iii. Are there toys or electronics in the rooms the children sleep in?
d. How do you feel these sleeping arrangements impact other members of your family?
    i. Other children
    ii. Parents
    iii. Any other family members that live in the home

5. Can you describe a typical night's sleep for ____ (child with ASD)?
    a. Does he/she have trouble falling asleep?
    b. How long does it take for him/her to fall asleep?
    c. Does he/she wake up often throughout the night? (what does he/she do? Who attends to him/her?)
    d. How many hours of sleep does he/she get a night?
    e. Does he/she complain about being tired?

6. How do you feel their (child with ASD) sleep impacts the sleep of your children without autism?
    a. Bedtime behaviours?
    b. Interruptions to sleep?
    c. Early morning awakening?
7. Can you tell me about how you know when your child has slept well?
    a. Child(ren) with ASD
    a. Child(ren) without ASD
    b. Are there differences in their behaviours, moods?
    c. Were there differences in their routines the day before?
        i. Ex) Did they exercise more the day before?
    d. What about other family members?
        ii. You
        iii. Your partner
8. How can you tell when they have not slept well?
    a. Behaviors, moods, emotions
    b. What is the "norm" for your child, do they sleep well or poorly more often?
    c. How does this effect you? The rest of the family?
9. How often does _____ (child with ASD) take a nap during the day or need a break?
    a. Does he/she choose to nap on their own?
    b. Where does he/she nap or break?

c. Do you feel like this relates to their nighttime sleep?

d. Does child without ASD need a nap?

e. Would they benefit from a nap even if they do not have one?

i. Why do they not have one?

10. How do you feel your children's sleep impacts you?

a. Do you feel well-rested?

b. Do you feel you could benefit from more sleep?

c. Is your sleep often get interrupted at night? How many times?

d. Do you find you are sleepy during the day? When does this impact you most? Do you need to use stimulants such as tea/coffee to feel more awake?

e. Physically? Emotionally? Mentally?

As you consider these various topics we've been talking about:

11. What sort of emotions does sleep and bedtime bring up for you?

a. Can you describe what the word sleep and thinking of sleep brings up for you?

b. Is it a source of stress?

12. How do you think sleep behaviours impact the daytime behaviour of your family?

a. Think about overall family functioning

i. After a good night sleep

ii. Vs bad night sleep

b. Child with ASD?

c. Other children in the house?

    d. Yourself?

13. Are there any barriers that stand out to you that impact sleep in your family?
    a. Routines or behaviours that delay sleep? Access to technology?
    b. Barriers to your sleep?
    c. Your child(rens) sleep?
14. Are there any coping or mitigation mechanisms that have helped with sleep?
    a. Any routines?
    b. Any family/ alternate caregiver supports?
    c. Your coping mechanisms?
    d. Your child(rens) coping mechanisms?
15. What do you think would help improve sleep outcomes for your family?
    a. Are there any supports that would help?
16. How have your recent sleep experiences been influenced by the COVID-19 pandemic?
    a. Consider being home and change of schedule.
    b. Stress? Are you more stressed, are they?
17. Thank you so much for your participation today, I am conscious of your time, before we wrap up is there any other comments you wanted to make or felt we didn't cover?

Thank you so much for participating in today's interview. Your opinions and experiences will be a valuable asset to this study. The interview today will be transcribed and sent back to you by a member of the research team, using and OntarioTech email account, for confirmation that everything you shared today was captured and portrayed properly. The

file you receive will be de-identified to remove any personal identifiers and will be a protected with a password verbally disclosed to you here. Your password is ____. Once data analysis is finished you will also be sent a copy to see the themes that were found and provide any feedback you wish to share. If you have any other questions, feel free to reach out to us via email at XXXX. Thank you so much for your participation.