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Analysis Of Occupational Therapy's Role to Promote Healthy Sleep Participation to Support Caregivers of Children with Autism Spectrum Disorder

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Analysis Of Occupational Therapy's Role to Promote Healthy Sleep Participation to Support Caregivers of Children with ASD

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Analysis Of Occupational Therapy's Role to Promote Healthy Sleep Participation to Support Caregivers of Children with Autism Spectrum Disorder

Background

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by deficiencies in two domains: social communication and restrictive, recurring patterns of behavior (Hyman et al., 2020). The Centers for Disease Control and Prevention (CDC) reported in 2020 that 1 in 54 children in the United States is diagnosed with an autism spectrum disorder (Autism and Developmental Disabilities Monitoring [ADDM] Network, 2020). Healthy sleep habits are essential for children with ASD and their caregivers to properly engage in their everyday lives. The occurrence of sleep with interruption among typically developing children is around 25% compared to children with ASD whose percentage from ranges from 50 to 80% (Mazzone et al., 2018). Sleep disturbance is common in children with ASD and can be associated with difficulty during daytime behavior (Hyman et al., 2020). Sleep was linked with greater internalizing and externalizing behavior complications and lesser adaptive skill growth (Malow et al., 2016). Sleep is an occupational domain that plays an essential role in health and well-being; therefore, occupational therapists should consider sleep throughout the lifespan (Tester & Foss, 2018).

Sleep quality influences neural networks which are essential factors for occupational engagement (De Havas et al., 2012). Sleep is an active process when the body revitalizes. Sufficient sleep is vital to one's health, cognitive function, immune system, learning, and memory (Judd, 2017). Sleep is a process that supports learning, memory, and emotion (Judd, 2017). However, little is known about what causes these sleep disturbances (Gunes et al.,2019). There are psychiatric factors such as depression and anxiety that can be associated with sleep problems affecting appropriate occupational engagement for children. Sleep disturbances impact

the quality and quantity of sleep an individual with ASD may experience (Moore et al., 2017). Professionals who work with this population such as occupational therapists should be aware of sleep disorders screening tools and interventions to improve sleep performance for this population (Tester & Foss, 2018).

Individuals diagnosed with ASD may have sleep disturbances that are associated with impairments and difficulties such as emotional and behavior dysregulation (Gunes et al.,2019). Increased occurrence of sleep disturbances in children with ASD may appear because of differences in melatonin metabolism, disturbance of developmental neurotransmitter systems that disturb sleep, or deficiency of social expectations (Hyman et al., 2020). Children with ASD tend to have a variety of behavioral problems that can worsen sleep complications. Mazzone et al. (2018) did a study using the Child Behavior Checklist (CBCL) and found that children with ASD sleep disturbances were more likely to be involved in aggressive behaviors compared to those without sleep problems. Reported sleep problems involve complications such as sleep commencement and maintenance, bedtime resistance, parasomnias, and early morning awakenings (Levin & Scher, 2016). Results like these suggest the negative effect sleep disturbances have on occupational engagement.

Caregivers are often involved in sleep evaluation. Data on sleep behaviors and quality for children with ASD are primarily derived from caregiver report (Al Backer et al., 2018). There is a negative correlation between caregiver stress and sleep difficulties with their children. Parents have a greater risk of sleep deprivation because of their child showing these challenging behaviors of sleep (Schoen et al., 2017). Caregivers are unable to sleep due to safety concerns of their child such as attempting to put the child back to sleep. Since the child are family are affected by a child's sleep disturbance, it is important to address the specific family needs.

Occupational therapists use family-centered approaches in which the family's priorities are respected. Therefore, this capstone project seeks to provide caregivers with a quantitative questionnaire to portray if sleep hygiene is well-defined throughout occupational therapy for their children with ASD.

Given this association between sleep disturbances and children with ASD, there is a need for effective sleep intervention programs for this population due to limited applicable treatments (Schoen et al., 2017). Sleep hygiene intervention studies in this population are currently inadequate (Van der Heijden et al., 2018). A consideration in assessing sleep includes questionnaires on daytime behavioral functioning that may impact the child's sleep and other negative behaviors such as anxiety or hyperactivity (Moore et al.,2017). Currently, common pharmacologic interventions such as iron supplementation and melatonin are included in interventions for sleep disturbances. Prescribing medications to manage insomnia is the most common for children with ASD (Blackmer & Feinstein, 2016). Current research only focuses on medical management rather than using a holistic model and sleep's impact on occupations. Sleep medications, however, have not been successful in treating sleep disturbances and were also not found advantageous with quality of life (Malow et al., 2016). There has not been medication that is presently approved by the United States Food and Drug Administration for management of insomnia in children with or without ASD (Hyman et al., 2020). Behavioral interventions are preferred by physicians compared to pharmacologic intervention and should be used methodically. Behavioral methods are time consuming, and medications continuously have the risk of side effects (Schoen et al., 2017). Recommendations are usually made such as augmenting the sleep environment, maintaining a sleep routine, implementing a calm one, and handling physiologic considerations like nighttime hunger (Blackmer & Feinstein, 2016).

Although there are some pharmacological and nonpharmacological interventions available, more research is still needed to make caregivers aware. Awareness of treatment options regarding sleep disturbances are significant for caregivers and practitioners due to the lack of attentiveness of sleep approaches in therapy (Veatch et al., 2015). Pharmacological intervention should be monitored by physicians and is prescribed on a short-term basis. Nonpharmacological sleep interventions can also include education and cognitive-behavioral treatment for insomnia (Ho & Siu, 2018). Ho and Siu performed a literature search resulting in 11 articles to research occupational therapy's practice in sleep management. Out of those eleven articles, only two studies mention the use of cognitive behavioral therapy. There were limitations including the eleven studies being the only ones identified by the review causing a lack of evidence-based studies of sleep intervention in occupational therapy (Ho & Siu, 2018). Furthermore, caregivers should be provided with the expectations of pharmacologic and nonpharmacological benefits and risks, as well as the norms of sleep across development (Blackmer & Feinstein, 2016). Children with ASD and poor sleep hygiene have impaired function and mental health resulting in poor occupational engagement (Weaver, 2015).

Sufficient sleep is fundamental to health and occupational engagement (Judd, 2017). Negative daytime behaviors may influence sleep quality, which influences neural networks which are essential factors for occupational engagement (De Havas et al., 2012). Sleep hygiene intervention studies in the autism population are currently insufficient (Blackmer & Feinstein, 2016). Insufficient evidence-based interventions suggest that children need suitable sleep routines and interventions to participate in their occupational engagement for their everyday lives. Occupational therapy practitioners use the knowledge of evidence-based practice to address sleep and evaluate these consequences including sleep preparation and sleep

participation; sleep latency, sleep duration, sleep maintenance and how these factors affect the child (Picard, 2017).

In occupational therapy theories, sleep is defined as an uplifting occupation with rest supporting one's everyday life and occupational balance (Ho & Siu, 2018). The concept of this essential occupational balance is crucial to promote function and well-being. There is a growing need for occupational therapists to provide interventions for patients with sleep difficulties (Ho & Siu, 2018). The Person-Environment-Occupation-Performance (PEOP) framework is used by occupational therapists to study how sleep is related to occupation to promote an environment advantageous to sleep, and restructure daytime occupations with an emphasis on occupational balance to promote well-being and function (Ho & Siu, 2018). These constructs are essential when addressing caregivers' perceptions of their child's sleep disturbance, if their child's sleep disturbances influence occupational engagement, and if occupational therapists have collaborated with caregivers to treat this area of occupation.

There is a need to acquire standardized sleep assessments and interventions unambiguous to the occupational therapy field (Tester & Foss, 2018). The role of sleep is not assessed enough as a routine with standardized measures for clients with neurological impairments. Interventional evidence for sleep is inadequate, but increasing, across diagnoses (Tester & Foss, 2018). The project will address this issue by exploring caregivers' perspectives on occupational therapy's role of sleep with children with ASD. In this quantitative type capstone project, caregivers are able to express if sleep is well-defined throughout occupational therapy for their children with ASD. Collecting data from caregivers regarding emphasis on healthy sleep in their child's occupational therapy setting can help to highlight the need to promote healthy occupational engagement for children with ASD.

Statement of the Problem

The problem is little is known on caregivers' perceptions of their child's sleep disturbance, these disturbances' influence on occupational engagement, and whether occupational therapists have collaborated with caregivers of children with ASD to treat this area of occupation. Therefore, this quantitative project addresses this issue by exploring the perspectives of caregivers with children with ASD. Sleep is the only occupation in the OTPF that is completed independently (Quint, 2017). Most information about sleep in children with ASD is gained from caregiver reports due to social communication insufficiencies and general developmental limitations (Moore et al., 2017). There are no known standardized occupational therapy assessments that are specific to sleep which causes a disconnect between occupational therapists and caregivers during their child's initial evaluation or treatment session (Tester & Foss, 2018). Occupational therapists are licensed to evaluate clients in areas that contribute to sleep dysfunction and focus on promoting optimal sleep performance (Picard, 2017). This will help to highlight the concern that sleep problems are not addressed during analysis of this client population.

Purpose Statement

The purpose of this quantitative research project is to establish occupational therapy's role in sleep disturbance and its impact on occupational engagement to support caregivers of children with ASD. Collecting data from caregivers by using a questionnaire can provide occupational therapy practitioners with the emphasis of healthy sleep habits to promote healthy occupational engagement for children with ASD. This quantitative research will explore the perceptions of caregivers with children with ASD to indorse healthy sleep for children with ASD by directing a Likert scale-based questionnaire. A better understanding of the perceptions of

caregivers about their children's sleep disturbance can improve understanding for healthcare providers serving this population.

There are several quantitative research questions that support this capstone and the customized questionnaire. Appendix A demonstrates the customized questionnaire for caregivers of children with ASD. The first research question supports the child's demographics asks is there a relationship between age of child and sleep disturbance? For quantitative type research, there is a null hypothesis (HO) and alternative hypothesis (HA) (Creswell & Creswell, 2018). The HO states that there is no relationship between age of child and sleep disturbance. The HA states that there is a relationship between age of child and sleep disturbance. The second and third research questions support the questionnaire's demographics concerning caregivers. The next question asks is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention? The HO states that there is no relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention. The HA states that there is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention. The third research question asks is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation? The HO states that there is a no relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation. The HA states that there is a relationship between a caregiver expressing concerns about their child's sleep problems with their

occupational therapist and receiving services to address sleep during the OT evaluation. The last research question asks is there a relationship between sleep disturbances and occupational engagement? The HO states that there is no relationship between sleep disturbances and occupational engagement. The HA states that there is a relationship between sleep disturbances and occupational engagement.

Collecting data from caregivers regarding emphasis on healthy sleep in their child's occupational therapy setting can help to highlight the need to promote healthy occupational engagement for children with ASD. Evidence-based support exists for the efficacy of parent education and behavioral interventions for children with ASD and sleep disturbances (Hyman et al., 2020). Sleep is the primary occupation of children until the age of five and usually into adulthood (Quint, 2017). It is essential to ask caregivers how their children's sleeping habits are to assess an appropriate initial evaluation and diverse interventions. Practitioners should include sleep screening questions in their assessments to fit in the initial evaluation. Occupational therapists working with this population need to address sleep complications for children with ASD and their families to help children develop healthy sleep habits. Strengthening the role of sleep within clinical practice and educating family members on what can be done in occupational therapy can be beneficial for these families.

Rationale for Proposed Project

The rationale of this quantitative type study is to analyze caregivers' perceptions of their child with ASD's sleep disturbances, how these disturbances influence occupational engagement, and how occupational therapists collaborate with caregivers to address this concern. Children with ASD have various forms of sleep problems such as behavioral problems, aggression, and self-injury which can affect their ability to participate in occupational engagement and activities

of daily living (Blackmer & Feinstein, 2016). Although rest and sleep are part of the occupational therapy practice framework, there is not enough literature to describe roles and caregivers' perceptions to determine evidence for sleep interventions in children with ASD. According to the American Occupational Therapy Association (AOTA), rest and sleep are needed to support health and active engagement. Sleep screening for this population may include a brief clinical interview and completion of a questionnaire (Moore et al., 2017). Subjective assessment approaches have advantages of cost and time efficiency but are not addressed enough for sleep disturbances (Moore et al., 2017). Caregivers use sleep hygiene routines such as sleep schedules, but the question is how effective these interventions are and is it addressed utterly in the occupational therapy evaluation or session.

This study will benefit caregivers to express their perceptions on how occupational therapy manages sleep difficulties to increase their children's occupational engagement. The benefit of having more sleep resources available for these families can also assist caregiver stresses. As previously mentioned, sleep is an activity related to achieving the appropriate rest to lead to healthy engagement in other occupations (OTPF, 2014). There are few research studies on how occupational therapists follow different theories to produce appropriate and evidence-based interventions. This study will allow caregivers to provide feedback on how occupational therapy can assist these concerns.

Project Significance

The significance of this quantitative type research project is to fill the gap in knowledge regarding how caregivers' perceptions of their child's sleep disturbance affect their collaboration with occupational therapists and how child's sleep disturbances influence occupational engagement. Few studies have investigated the association between sleep problems among

children with ASD and how parents handle this stress (Levin & Scher, 2016). The significance of this quantitative type capstone project is to collect and gather data to fill the gap in literature towards better understanding of the lack of sleep in occupational therapy's scope of practice. Parenting related factors can be associated with sleep hygiene and it is vital to understand the importance of developing good sleep hygiene in early childhood to avoid sleep problems later in life (Van der Heijden et al., 2018).

The significance of this project improves understanding to support caregivers of children with ASD establish occupational therapy's role in sleep disturbance and its impact on occupational engagement. There have been many challenges to measure the occurrence of sleep abnormalities and to determine the causes of poor sleep quality with this population. Many parent-reported surveys for poor sleep place the amount of actual sleep occurring during the night in a range from 50 to 80% (Elrod & Hood, 2015). Using the Children's Sleep Habits Questionnaire (CSHQ) as a model, a customized questionnaire will be established for caregivers of children with ASD to ask questions about occupational therapy's role in sleep. Therefore, similar clinical data can be found to determine what factors affect healthy sleep habits including a lack of communication between the occupational therapist and caregiver. Johnson, et al. (2015) describes the (CSHQ) as a widely used measure in ASD to assess sleep disturbances. Providing a parent-educational, occupational therapy designed program can improve the quality of sleep for children and their families to promote a healthy lifestyle (Wooster et al., 2015).

Occupational therapists are constantly advocating promoting the most optimal functioning for one's meaningful activities. Promoting healthy sleep habits and routines tend to be difficult for these families and the scope of occupational therapy practice can benefit this population and address the lack of research that is significantly needed. Research has

demonstrated that raising a child with ASD may instigate higher levels of parenting stress compared to typically developing children (Levin & Scher, 2016). This study can assist caregivers' needs regarding their child's sleep disturbances affecting occupational engagement.

Project Objectives

Learning Objectives

- L1: Compare and contrast sleep concerns for children with ASD as compared to the literature at site 1.
    - This objective was met by creating a weekly reflection paper demonstrating the concerns presented at Creating Bridges outpatient pediatric clinic.
- L2: Compare and contrast sleep concerns for children with ASD as compared to the literature at site 2
    - This objective was met by creating a weekly reflection paper demonstrating the concerns presented at Dade Therapy outpatient pediatric clinic.
- L3: Discuss and identify the need for sleep in occupational therapy for occupational participation
    - Met by week one-reflection paper to augment literature review
- L4: Identify the correlation between sleep concerns and children with ASD
    - Met by week thirteen-statistical findings will be explored in weekly reflection papers
- L5: Meet with mentor weekly who specializes in pediatric specialty and setting
    - Met weekly for fifteen weeks to assist with progression of capstone project

Project-based and Outcome Objectives

- PB1: Conduct a needs assessment to address sleep for children with ASD

    - Met week 1-reflection paper and identified with background to figure out problem and purpose

- PB2: Collaborate with occupational therapists (OT) that have background in ASD
    - Met every week for fifteen weeks
- PB3: Observe ~5 OT's initial evaluation and ~20 treatment sessions for children with ASD and their caregivers
    - Met every week for fifteen weeks-reflection papers to describe sessions seen and how it compares to the literature
- PB4: Deliver a customized survey questionnaire that asks appropriate questions for caregivers of children with ASD regarding sleep
    - Questionnaires were delivered weeks seven through nine
    - Reflection papers on progression and evidence of invitations sent to caregivers
- PB5: Collect and analyze data from caregivers' perspectives to disseminate to a forum of OT practitioners the importance of addressing the issue of sleep within the pediatric ASD population
    - Questionnaires were analyzed in week ten through thirteen using bar graphs and histograms. This objective was measured by gathering data from caregivers' responses to the questionnaire to analyze similarities and differences between responses.
- PB6: Edit chapters 1-3
    - Met by week six
- PB7: Write chapters 4 & 5 of the capstone paper.
    - Met by week fourteen

- PB8: Create a poster for dissemination using USAHS template.
    - Met by week fourteen
- PB9: Submit completed and approved project (Chapter 1-5 plus appendices into SOAR (Strengths Opportunities Aspirations Results))
    - Met by week fifteen

Definition of terms

- **Sleep hygiene**: habits that are beneficial to healthy sleeping (Van der Heijden et al., 2018).
- **ASD**: Autism Spectrum Disorder-a neurological and developmental disorder that can distress the aptitude to communicate and interact (Lord, 2019).
- **Occupational engagement**: active involvement and participation of occupations (Butera et al., 2019).
- **Occupational balance**: the balance between rest/sleep and daytime activity to promote well-being (Ho & Siu, 2018).
- **Insomnia**: difficulty falling asleep (Veatch, Maxwell-Horn, & Malow, 2015).
- **Bedtime resistance**: when children refuse or postpone the ability to sleep at night (Levin & Scher, 2016).
- **Neurodevelopmental condition**: disorders that affect the nervous system development that may affect varied factors such as memory and emotions (Blackmer & Feinstein, 2016).

Assumptions

An assumption that must be considered in this quantitative research study is that caregivers participating in the study might not answer the questionnaire truthfully. All caregivers

were asked before responding to the questionnaire if their child has sleep disturbances, but one caregiver responded that their child does not. Caregivers could have been biased, not willing to share information. The participants were given a flyer stating that the study is voluntary, and they may withdraw at any time. The flyer also stated that information will be kept confidential, and no information could identify caregivers to be published.

The advantages to questionnaires are that it is easy to administer, it is developed in less time, and can be managed remotely by collecting data from the outpatient clinic. The questionnaire survey is completed by key informants, the caregivers. Online surveys have the greatest potential to increase response rates since the informants can complete the surveys at their own chosen pace. Results of the questionnaire will be automatically inputted and stored into the Survey Monkey database, decreasing the possibility of data errors. My customized questionnaire was approved by the University of St. Augustine institutional review board (IRB).

Limitations

Limitations for the proposed study can vary. During the time of data collection, there was a worldwide pandemic. This altered the sample size of the capstone. It can be difficult to find families who were willing to participate, which can affect the sample size of this capstone being a small population in an urban area. This study can be time-consuming, therefore, only caregivers of children with ASD will participate. There is a lack of diversity in a small sample size by not addressing individuals of different socio-economic disparities. The questionnaire may be limited to individuals who have access to a computer or internet. Also, participants may not be able to answer questions as they would like to or understand the questions being asked (Merrian & Tisdell, 2016). Five out of six caregivers responded to the questionnaire. The

response rate was eighty-three percent. One caregiver never responded but was invited to participate after agreeing to.

Delimitations

This study only included caregivers of children with ASD that experience difficulties sleeping. The participants will only be recruited from Creating Bridges and Dade Therapy, two outpatient pediatric clinics in Miami, Florida. The questionnaire questions will only ask about demographics, sleep, occupational therapy, and occupational engagement. The proposed project only focused on answering the following questions: (1) is there a relationship between the age of child and sleep disturbance? (2) is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention? (3) is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation? (4) is there a relationship between sleep disturbances and occupational engagement?

Chapter II: Literature Review

The purpose of this literature review is to provide an overview of already existing literature related to children with autism spectrum disorder (ASD) and sleep disturbances. The problem is little is known on caregivers' perceptions of their child's sleep disturbance, these disturbances' influence on occupational engagement, and whether occupational therapists have collaborated with caregivers of children with ASD to treat this area of occupation. This chapter will further explore the common themes presented when a thorough review of the literature was conducted. The following themes are categorized into the following: definition and prevalence of autism spectrum disorder, impact of poor sleep on children with ASD, impact of poor sleep on caregivers and families, sleep as an occupational need, occupational balance, and engagement, how sleep problems are identified-pharmacological treatment, the role of occupational therapy, and the problem-why research is needed.

Definition and Prevalence of Autism Spectrum Disorder

ASD is a commonly diagnosed neurodevelopmental disorder with prevalence of 1 in 59 children in the United States (Hyman et al., 2020). ASD can occur as young as 18 months of age and is currently more diagnosed than in the past (Hyman et al., 2020). The diagnostic criteria, *Diagnostic and statistical manual of mental disorders, 5th Edition* (American Psychiatric Association, 2013) diagnostic criteria define ASD as consisting of two domains: social communication and interaction and restricted, repetitive behaviors. There are also co-occurring symptoms including medical conditions such as sleep disorders and seizures.

Impact of Poor Sleep on Children with ASD

Adequate and wholesome habits for sleep have proven to be essential for growing children and adolescents to avoid affecting behavioral and emotional concerns (Van der Heijden

et al., 2018). Poor sleep can also affect the child's memory, learning, and attention affecting everyday performance (Gunes et al.,2019). There are distinct categories of sleep problems found in children with ASD including insomnia, sleep disordered breathing, nightmares, parasomnias, and sleepwalking (Veatch et al., 2015). The presence of sleep disturbances could negatively influence intrinsic ASD characteristics such as behavior (Al Backer et al., 2018).

Sleep disturbance is correlated with exacerbation of challenging daytime behavior. The AAP reports that 50% to 80% of children with ASD have sleep problems. Caregivers of children who are later diagnosed with ASD also report to have sleep difficulties by 30 months of age. Half of adolescents with ASD continue to have sleep problems. Younger children with ASD tend to have bedtime resistance, parasomnias, and night waking while adolescents have briefer sleep duration, daytime sleepiness, and late sleep onset (Hyman et al., 2020).

The most common complaints are bedtime resistance, sleep initiation, nighttime wakening, and not enough sleep time (Elrod & Hood, 2015). Insomnia is the most common sleep difficulty reported by parents in assorted studies retaining questionnaire statistics (Veatch et al., 2015). Sleep difficulties have negative behavioral affects such as accumulating restrictive behavior that led to self-harm and violence making life difficult for families (Lord, 2019).

Children with ASD have complications transitioning from stimulating activities to sleep. Adjusting different routines and schedules are challenging for parents (Levin & Scher, 2016). Providers usually do not have the training or time to implement behavioral interventions for sleep in children with ASD (Malow et al., 2016). This increased stress has been linked to the caregivers of children with autism having poor sleep compared to other caregivers. These alterations for affected caregivers may also intensify the behavioral symptoms of autism (Elrod & Hood, 2015).

Impact of Poor Sleep on Caregivers and Families

Caregivers of children with ASD report more stress and augmented expenses compared to caregivers with typically developing children. These issues affect family members, specifically caregivers, because sleep-related problems are the most recurrently reported area of difficulty (Levin & Scher, 2016). Caregivers report that sleep-related issues are the most frequent concern for their children with ASD. These sleep difficulties have been found to be more stressful to caregivers than their child's health concerns (Levin & Scher, 2016).

There was a study in 2016 that invited caregivers to fill out different measures to express their stresses with their children's sleep difficulties for the ASD population (Levin & Scher, 2016). The measures included *Demographic form, Gilliam Autism Rating Scale-Second Edition (GARS-2), Parenting Stress Index-Short Form, Children's Sleep Habits Questionnaire (CSHQ), Maternal Cognitions about Infant Sleep Questionnaire (MCISQ),* and *Parental Interaction Bedtime Behavior Scale (PIBBS).* Like previous research, it is more stressful for caregivers to raise a child with ASD with sleep difficulties. Caregivers reported longer sleep onset delay, parasomnias, and increased daytime sleepiness. There is a chance that behavioral deficits associated with ASD may interfere with these sleep challenges (Levin & Scher, 2016). The impact from this evidence is that stress is high for caregivers of children with ASD who experience sleep difficulties affecting their everyday activities.

Sleep as an Occupational Need

Sleep is a state of changed consciousness during which the body rests and renovates itself. The American Occupational Therapy Association (AOTA, 2020) classifies sleep as an area of occupation. Sleep is an occupational domain that plays a role in wellbeing and is vital to participation (Tester & Foss, 2018). In young children with ASD, occupational therapists focus

on other aspects such as sensory processing, social-behavioral performance, self-care, and play, but do not emphasize sleep (Case-Smith & Arbesman, 2008). Sleep is recognized as equally important to work and play to maintain one's health (Tester & Foss, 2018). Sleep is an active process that the body requires to restore and regenerate. Without adequate sleep, the body negatively reacts resulting in a low quality of life (Judd, 2017).

Occupations are separated into categories of activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, education, work, play, leisure, and social participation within one's contexts. Research indicates that individuals with ASD are most likely to have difficulties in self-care, IADLs, sleep, play, social participation, and more. The role of occupational therapy is to promote optimal occupational engagement in daily activities for individuals with ASD within the context of their families and everyday participation. The framework of practice for occupational therapy of rest and sleep including preparing for sleep, developing routines that encourage sleep, and partaking and achieving restful sleep (*Scope of Occupational Therapy,* 2015). In occupational therapy theories, sleep is conceptualized as a restorative occupation with rest and good sleep as the ambition (Ho & Siu, 2018).

The Occupational Therapy Practice Framework (2020) defines rest and sleep as an activity serving to restore the body and promote healthy engagement in other occupations. Occupational therapists are qualified to provide sleep intervention which includes alteration in routine, environmental modifications, behavioral methods, and more. Rest and sleep are part of the *Occupational Therapy Practice Framework: Domain and Process*, there is not enough literature to describe roles and interventions for occupational therapy (Wooster et al., 2015).

Occupational Balance and Engagement

The concept of occupational balance emphasizes time use and that balance between rest/sleep and daytime activity is significant in supporting function and well-being (Ho & Siu, 2018). Although many health professionals may consider lack of sleep as a secondary concern, it plays a critical role in daily functioning and daytime activities (Tester & Foss, 2018). Sleep problems are known to be correlated with immune, behavior, attention, metabolic, and learning deficits (Fadini et al., 2015). Therefore, occupational balance and engagement can be promoted with the appropriate sleep environment and schedule.

Sleep hygiene correlates with parenting factors associated with children's sleep development and concerns, especially in early childhood (Van der Heijden et al., 2018). Sleep hygiene includes actions associated to the sleep environment and schedule to prepare for suitable sleep (Blackmer & Feinstein, 2016). Sleep hygiene enables appropriate sleep quality, length, and diminishes daytime sleepiness (Van der Heijden et al., 2018). If there is an inconsistency during the bedtime routine or sleep throughout the night, this may cause sleep disturbances that have a negative influence throughout everyday participation disrupting occupational balance and engagement (Van der Heijden et al., 2018). Sleep hygiene interventions in the ASD population are insufficient so far, but current findings suggest that sleep hygiene enhancement can be an effective strategy in this population (Van der Heijden et al., 2018).

Sleep hygiene must be instigated as first-line therapy (Blackmer & Feinstein, 2016). Occupational therapy practitioners are professionals who deliver and design intervention services for children with ASD and caregivers (Case-Smith & Arbesman, 2008). Diagnosis of sleep-related conditions is not within the scope of practice for occupational therapy, but occupational therapy can evaluate sleep and its influence on participation and contentment. There are no known standardized occupational therapy assessments that are specific to sleep, but there are

qualitative assessments such as *The Functional Outcomes of Sleep Questionnaire* that are useful to identify issues and intervention approaches (Tester & Foss, 2018). Although most work is done by caregivers, suitable interventions must be done to monitor and address sleep disturbances (Lord, 2019).

Sufficient sleep is vital to health and occupational engagement (Judd, 2017). Inadequate sleep aggravates the core symptoms of ASD. Sleep quality impacts neural networks such as the default mode network (DMN). The DMN is a network of brain regions that disengages in reaction to externally oriented tasks (De Havas et al., 2012). This network is essential for elements of occupational engagement such as executive and social functioning (Butera et al., 2019).

How Sleep Problems Are Identified-Pharmacological Treatment

Sleep concerns are commonly reported by caregivers and usually medications are given by physicians causing children of ASD decreased quality of life (Malow et al., 2016). Parent questionnaires are the most collected assessment for this population. General developmental screening is assessed by pediatricians at ages 9, 18, and 30 months according to the AAP (Hyman et al., 2020). Varied reasons for these sleep disturbances are reported as pharmacological interventions such as melatonin metabolism developmental interference of other neurotransmitter systems that affect sleep. No medication is currently accepted by the U.S Food and Drug Administration for the treatment of insomnia for all children (Hyman et al., 2020). Recommendations state that behavioral programs should be attempted before medications (Lord, 2019). Evidence-based research supports the effectiveness of parent education and behavioral interventions for this population and sleep disturbances such as creating a bedtime

routine. Establishing these routines may be difficult for children with ASD due to repetitive rituals or co-existing comorbidities.

There has been a finding that 46% of children aged 4-10 with sleep diagnoses take at least one sleep related medication making this a common treatment intervention. (Malow et al., 2016). There are numerous studies that confirm that melatonin increases sleep initiation and duration for children. Melatonin is a regulatory agent that promotes the normal sleep-wake cycle comprising of elevated levels at night and low levels during the day (Blackmer & Feinstein, 2016). Melatonin is principally used as a sedative at low doses given 30 minutes before bed (Veatch et al., 2015). Melatonin did not improve sleep problems for children with ASD due to disturbances in melatonin production and rhythm (Van der Heijden et al., 2018).

Medications such as fluoxetine used to treat sleep conditions tend to be stimulating and disturb sleep (Veatch et al., 2015). When melatonin and behavioral therapies are ineffective, psychotropic medications are recommended by physicians such as clonidine, mirtazapine, and gabapentin to assist with insomnia (Veatch et al., 2015). Medication has been found to lower quality of life for children with ASD because they were not successfully treating sleep disturbance affecting daytime behaviors (Malow et al., 2016).

The Role of Occupational Therapy

Occupational therapy services vary for children with ASD. Occupational therapists can assist in promoting fine motor, adaptive skills, self-care, handwriting, play, sensory-based interventions and more. Occupations are daily life activities that are essential to client's individuality including rest and sleep (*Scope of occupational therapy Service*, 2015). Two-thirds of preschool-aged children with ASD receive occupational therapy services (Hyman et al., 2020, p. 27). Caregivers who comprehend more about their child's ASD can advocate for appropriate

services (Hyman et al., 2020). The American Academy of Pediatrics (AAP) report that health, education, and social needs for these children and family members reflect areas of necessity for resources, evidence-based practice, and education (Hyman et al., 2020). Occupational therapists work to improve sleeping habits and routines.

Occupational therapists work with all the different causes of sleep problems including neurobiological, medical, and behavioral (Veatch et al., 2015). Common interventions for individuals with sleep disorders include the use of cognitive behavioral therapy (CBT), physical activity intervention, and alterations to the sleep environment. This may be incorporated into the scope of occupational therapy to promote sleep awareness. CBT can include stress, pain, sleep, diet, and apnea, as well as teach strategies to alter these factors. Combining interventions may also be incorporated. Interventional research is growing but continues to be limited within occupational therapy (Tester & Foss, 2018). The importance of sleep hygiene needs to be addressed since it tends to be overlooked in children with ASD due to difficulties in implementation and the need for frequent reassessment and adaptation (Blackmer & Feinstein, 2016).

Occupational therapy interventions need to coincide with the necessities of the child and caregivers in order to be effective. Multiple interventions for various aspects are currently being done including minimizing night waking, creating successful bedtime routines, and getting the child to sleep throughout the night (Lord, 2019). Proper sleep hygiene may compose of having a cool, dark environment for sleep as a behavioral approach (Veatch et al., 2015). Other recommendations are to preserve a consistent sleep schedule and routine and manage physiologic factors such as nighttime hunger. These nonpharmacologic interventions are preferred rather than pharmacologic interventions (Blackmer & Feinstein, 2016).

A pilot study of sleep interventions for children with ASD used by occupational therapist's state that the Integrated Listening Systems Dreampad pillow has become an alternative approach. There are no published studies with this approach, but the sleep diary measures indicated that this was useful for caregivers (Schoen et al., 2017). Sleep diaries are an additional outcome measure for those evaluating sleep difficulties (Schoen et al., 2017). Sleep diaries can be useful to occupational therapists to keep a record of the sleep disturbances of children with ASD.

Addressing daytime behavior and occupational engagement with disordered sleep may assist the other with these challenges (Hyman et al., 2020). Typically, occupational therapy addresses these concerns, however, does not address the underlying cause of poor sleep habits which affect participation. Daytime behavior problems with poor sleep cause aggression and mood instability within these children (Blackmer & Feinstein, 2016). There is evidence that increasing sleep quality positively impacts behavioral contexts (Fadini et al., 2015). Sleep hygiene interventions continue to be infrequent in the ASD population (Van der Heijden et al., 2018).

Occupational therapy interventions to address the issue of sleep may include energy conservation, rest breaks, and schedules. Although these strategies may be advantageous, they are only compensatory approaches that limit life participation. Occupational therapists should consider additional interventions for children with ASD. Considering that sleep is an occupational domain that affects daily participation, there is a need to develop standardized sleep assessments and interventions specific to occupational therapy. There needs to be mindfulness throughout different healthcare disciplines of the magnitudes of inadequate sleep and the scope of occupational therapy (Tester & Foss, 2018). Someone in healthcare needs to ask the

caregivers about sleep to make sure these difficulties are being attended to, along with follow up and monitoring (Lord, 2019).

Sleep and rest are crucial to optimal functioning in ADLs, IADLs, education, and work. When individuals with ASD can fully participate in ADLs with the assistance of occupational therapy practitioners they can accomplish higher quality of life and self-efficacy. Prevalence of sleep problems within this population are proven, but efficacy studies supporting occupational therapy interventions for sleep have not been published. Occupational therapy is a highly requested service for children with ASD, therefore, it is the profession's responsibility to increase the research on sleep interventions (Weaver, 2015).

Theoretical Framework

The PEOP framework was developed by Charles Christiansen and Carolyn Baum in 1985. It is used by occupational therapists to study how sleep relates to occupation and to promote an environment advantageous to sleep. Therapists further use the model to restructure daytime occupations with an emphasis on occupational balance and promoting well-being and function (Ho & Siu, 2018). This project will utilize the PEOP model, focusing on three levels: the person, environment, and occupation to frame the research questions. Sleep is an occupation-based activity during which these three components are involved. (Akbarfahimi et al., 2020). PEOP can include physical and mental aspects of children with ASD while using environmental modifications and getting caregivers perspectives based on the theory is based on the literature.

The occupational therapy practice framework (OTPF, 2020) explains rest and sleep as an activity relating to restoring the body to promote healthy engagement in other occupations. The questionnaire addressed the PEOP model in question number fifteen. The question asked what is your child's sleep environment like? (Check all that apply): dark room, room with nightlight,

quiet room, room with noise such as music or white noise, room with television (TV), noise from outside (IE traffic or neighbors), child sleeps with clothes on, child sleeps with no clothes on (only with diaper or underwear), child sleeps with blanket or stuffed animal, and room temperature between 68 degrees and 72 degrees. The first eight questions were related to the person by supporting demographic questions of the child and caregiver. Sleep is occupation-based that takes these three levels into consideration. (Akbarfahimi et al., 2020). The OTPF explains that meaningful activities develop health in individuals (OTPF, 2014).

The Problem - Why Research is Needed

Unfortunately, there is limited research on caregivers' perceptions of their child's sleep disturbance, these disturbances' influence on occupational engagement, and whether occupational therapists have collaborated with caregivers of children with ASD to treat this area of occupation. Providers usually do not have the training or time to implement behavioral interventions for sleep in children with ASD (Malow et al., 2016). There are inadequate supporting occupational therapy interventions for sleep or rest in individuals with ASD. Therefore, research on sleep interventions within the scope of occupational therapy is required (Weaver, 2015).

As children develop, sleep patterns alter, especially in the infant and toddler age ranges continuing into adolescence (Elrod & Hood, 2015). There is no evidence-based algorithm that exists to guide clinicians in managing sleep disturbances in children with neurodevelopmental disorders due to the cause of sleep disorders and the shortage of clinical data (Blackmer & Feinstein, 2016). Collecting data from caregivers regarding emphasis on healthy sleep in their child's occupational therapy setting can help to highlight the need to promote healthy occupational engagement for children with ASD.

Caregivers must be provided with appropriate education to gain a better understanding including effectiveness and safety inferences (Blackmer & Feinstein, 2016). Occupational therapists use family-centered approaches in which the family's priorities are valued (Case-Smith & Arbesman, 2008).

Conclusion

Evidence-based research exists for the efficacy of parent education and behavioral interventions for children with ASD and sleep disturbances (Hyman et al., 2020); however, there is a lack of evidence to support if sleep interventions are provided to caregivers of children with ASD. Occupational therapists are licensed to evaluate clients in areas that contribute to sleep dysfunction and to focus on promoting optimal sleep performance (Picard, 2017). Therefore, this project will explore the gaps between occupational therapy and caregiver's perception of their children's sleep disturbances. This will help to highlight the concern that sleep problems are not addressed during analysis of this client population. Information on the caregivers' perspective will be collected using a customized questionnaire to be completed by caregivers of children with ASD.

The purpose of this quantitative type research project is to expand the body of knowledge to provide help for those children who have difficulties sleeping. This was accomplished by analyzing information from caregivers' perceptions of their child's sleep disturbance, the impact on occupational engagement due to the sleep disturbance and learning if occupational therapists addressed the sleep disturbance. The next chapter will explain the project description.

Chapter III: Project Description

The planned project includes analyzing caregivers' perspectives on their child's sleeping concerns and occupational therapy's role with this problem. The role of occupational therapy in the treatment of children with ASD is to create interventions that will increase independence and function in daily life (Weaver, 2015). Previous studies have proposed that complications with sleep onset, maintenance, and duration are the most common sleep issues in children with ASD (Gunes et al.,2019). The rationale for this project is to learn caregiver's perspectives on occupational therapy's role regarding sleep for children with ASD who have difficulties sleeping and help occupational therapy's profession by emphasizing this gap in practice. The purpose of this quantitative research project is to establish occupational therapy's role in sleep disturbance and its impact on occupational engagement to support caregivers of children with ASD. Collecting data from caregivers by using a customized questionnaire can give more information to occupational therapists to highlight the need to promote healthy occupational engagement for these children with sleep difficulties.

Sleep and rest are vital to optimal functioning (Weaver, 2015). The significance of this quantitative capstone project is to collect and gather data to fill the gap towards better understanding of the lack of sleep in the occupational therapy scope of practice. Therefore, the collection will be from caregivers to disseminate to a forum of occupational therapy practitioners the importance of addressing healthy sleep for children with ASD by receiving adequate services during the initial evaluation and treatment process.

Research Questions

There is limited research on caregivers' perceptions of their child's sleep disturbance, these disturbances' influence on occupational engagement, and whether occupational therapists have collaborated with caregivers of children with ASD to treat this area of occupation.

The research questions are broken up to support the problem and purpose of this capstone project.

This question below supports the child's demographic questions.

1. Is there a relationship between age of child and sleep disturbance?

   HO: There is no relationship between age of child and sleep disturbance.

   HA: There is a relationship between age of child and sleep disturbance.

The second and third research questions support the caregivers' demographics.

2. Is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention?

   HO: There is no relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention.

   HA: There is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention.

3. Is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation?

HO: There is no relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation.

HA: There is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation.

The last research question asks if occupational engagement is influenced by sleep disturbances.

4. Is there a relationship between sleep disturbances and occupational engagement?

   HO: There is no relationship between sleep disturbances and occupational engagement.

   HA: There is a relationship between sleep disturbances and occupational engagement.

Process and Methods

Participants

Participants were caregivers from two outpatient pediatric clinics in Miami, Florida. Filling out the questionnaire was voluntary. Participants were given a participant information sheet along with a flyer and individuals who met inclusion criteria participated in the study. All children are currently receiving occupational therapy services. The inclusion criteria included caregivers of children with ASD who experience sleeping problems. The caregivers were between the ages of 18-65. The questionnaire should take around twenty-five minutes. Individuals who met the inclusion criteria emailed the Survey Monkey link that will lead the participants to the survey questions online. This study was considered an exempt study; therefore, participants were not required to sign an informed consent. Participants were not

compensated for participating in this research study. Any information provided was kept strictly confidential.

Recruitment Procedures

The questionnaire was answered using a Survey Monkey link that was emailed to participants, caregivers of children with ASD (Appendix D). These participants were caregivers from two outpatient pediatric clinics in Florida. The questionnaire should have taken 25 minutes; only one session was required. Questionnaire analysis was stored within an encrypted folder on the investigator's computer. The analysis will be kept for a minimum of three years before they are destroyed. No information that could potentially identify the participants will be published.

The doctoral student gained knowledge on the ASD population and occupational therapy's scope of practice regarding sleep by attending two outpatient pediatric clinics in the state of Florida to observe the occupational therapists and how they address sleep with the families of children with ASD. Common patterns were also correlated with the literature review throughout these observations while collecting data from caregivers of children with ASD. This occurred in a matter of fifteen weeks from January to April 2021 for three hundred and eighty-eight hours.

Instrumentation and Data Collection

The outcome objective was gathering data from caregivers' perspectives to disseminate to a forum of occupational therapy practitioners the importance of addressing this issue within the pediatric ASD evaluation and treatment. The doctoral student provided a 34-question customized questionnaire through Survey Monkey. The questions were asked in a Likert-type scale that are perceptual to caregivers' ranges from 1-5; 1 being very unsatisfied, 2 being unsatisfied, 3 being neutral, 4 being satisfied, and 5 being very satisfied (Sullivan & Artino, 2013). There are other Likert-type scale questions that ask the caregivers' perceptions ranging

from 1-5; 1 being strongly disagree, 2 being disagree, 3 being neutral, 4 being agree, and 5 being strongly agree. The questions also included yes/no questions and demographics. There was an open-ended text box at the end of the questionnaire for additional comments. The responses remained anonymous. Experts have stated that the median should be used as the measure of central tendency for Likert scale data (Sullivan & Artino, 2013). A survey analysis was done in excel and descriptive statistics will be described to explain the results. Due to time constraint, caregivers of children with ASD will be the only individuals participating in the questionnaire. The data analysis will potentially correlate with the research questions stated in the beginning of this chapter.

Data analysis

Appendix B will demonstrate the survey questions on a chart, but participants responded on Survey Monkey. Descriptive statistics will be used to analyze the data. Descriptive statistics give a summary about the sample. Descriptive status can be used to group and visually display results. The mode is the most used data point (Kaliyadan, & Kulkarni, 2019). The data analysis will be represented with charts to visually represent the data.

Alignment with Objectives

As previously stated, the purpose of this quantitative research project was to establish occupational therapy's role in sleep disturbance and its impact on occupational engagement to support caregivers of children with ASD. This capstone experience took place at Creating Bridges Therapy and Dade Therapy, two outpatient pediatric clinics. The objectives included collaborating with occupational therapists that treat children with ASD and observing these sessions to connect the gap that literature states. Accomplishing the learning and outcome objectives were met by the end of the fifteen weeks to address this issue to promote to a forum of

occupational therapy practitioners the importance of sleep. The project objectives below corelate with appendix A, a viable timeline to achieve the capstone project objects. The doctoral student submitted weekly reflection papers throughout the fifteen weeks to meet the progression of the capstone project.

Project Objectives

Learning Objectives

- L1: Compare and contrast sleep concerns for children with ASD as compared to the literature at site 1.
    - This objective was met by creating a weekly reflection paper demonstrating the concerns presented at Creating Bridges outpatient pediatric clinic.
- L2: Compare and contrast sleep concerns for children with ASD as compared to the literature at site 2
    - This objective was met by creating a weekly reflection paper demonstrating the concerns presented at Dade Therapy outpatient pediatric clinic.
- L3: Discuss and identify the need for sleep in occupational therapy for occupational participation
    - Met by week one-reflection paper to augment literature review
- L4: Identify the correlation between sleep concerns and children with ASD
    - Met by week thirteen-statistical findings will be explored in weekly reflection papers
- L5: Meet with mentor weekly who specializes in pediatric specialty and setting
    - Met weekly for fifteen weeks to assist with progression of capstone project

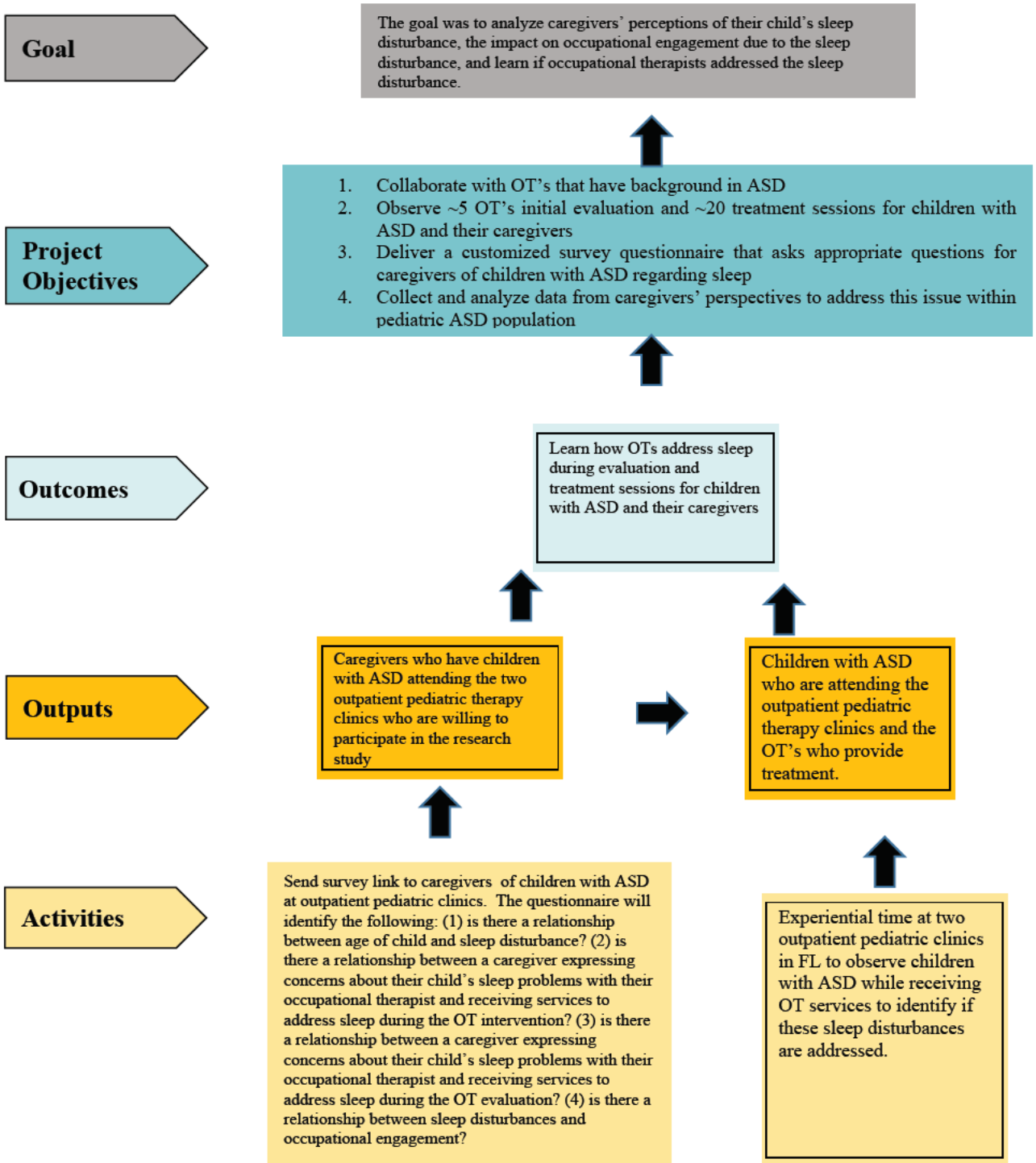
Project-based and Outcome Objectives

- PB1: Conduct a needs assessment to address sleep for children with ASD
    - Met week 1-reflection paper and identified with background to figure out problem and purpose
- PB2: Collaborate with occupational therapists (OT) that have background in ASD
    - Met every week for fifteen weeks
- PB3: Observe ~5 OT's initial evaluation and ~20 treatment sessions for children with ASD and their caregivers
    - Met every week for fifteen weeks-reflection papers to describe sessions seen and how it compares to the literature
- PB4: Deliver a customized survey questionnaire that asks appropriate questions for caregivers of children with ASD regarding sleep
    - Questionnaires were delivered weeks seven through nine
    - Reflection papers on progression and evidence of invitations sent to caregivers
- PB5: Collect and analyze data from caregivers' perspectives to disseminate to a forum of OT practitioners the importance of addressing the issue of sleep within the pediatric ASD population
    - Questionnaires were analyzed in week ten through thirteen using bar graphs and histograms. This objective was measured by gathering data from caregivers' responses to the questionnaire to analyze similarities and differences between responses.
- PB6: Edit chapters 1-3
    - Met by week six
- PB7: Write chapters 4 & 5 of the capstone paper.

- Met by week fourteen

- PB8: Create a poster for dissemination using USAHS template.
  - Met by week fourteen
- PB9: Submit completed and approved project (Chapter 1-5 plus appendices into SOAR)
  - Met by week fifteen

Conceptual Framework: Theory of Change Diagram



Timeline

The review of literature continued to be an ongoing process and meetings with mentors, site supervisor, and doctoral coordinators occurred weekly. This project was implemented over a 15-week period from January-April 2021. The doctoral student took the time to familiarize the outpatient clinic and staff to observe sessions to learn more about sleep and children with ASD. At the end of the 15 weeks, data will be analyzed to provide insight to occupational therapists to promote sleep in their initial evaluation and treatment sessions for children with ASD. Hours were split into direct hours and indirect hours to complete all learning and project-based deliverables. The doctoral student completed 388 direct hours observing treatment sessions for children with ASD and their caregivers and collaborating with two occupational therapists that have background in ASD. 112 hours were completed as indirect hours allotted to collecting research and learning the research process. Refer to appendix A for a visual chart of how the 15-week process assisted with meeting the goals of the project.

Conclusion

The purpose of this quantitative type research project was to analyze information about caregivers' perceptions of their child's sleep disturbance, the impact on occupational engagement due to the sleep disturbance and learn if occupational therapists addressed the sleep disturbance. This population focuses on children with ASD allowing caregivers to fill out a customized questionnaire. The objectives stated in chapter two's conclusion will assist the implementation of this research project and will be visually explained in appendix A, the time log. This will give a deliverable forum to occupational therapy practitioners on the emphasis of healthy sleep habits to promote healthy occupational engagement for children with ASD. This study has implications for both clinical practice and aspects of future research. The results of this research project will

inform occupational therapists who work with children with ASD and caregivers to promote sleep in their initial evaluation and treatment sessions. The next section will review the results of the questionnaires.

Chapter IV: Results and Analysis

Introduction

The purpose of this quantitative research project was to analyze information about caregivers' perceptions of their child's sleep disturbance, the impact on occupational engagement due to the sleep disturbance and learn if occupational therapists addressed the sleep disturbance. Five caregivers from two outpatient pediatric clinics voluntarily participated. There is limited research on caregivers' perceptions of their child's sleep disturbance, these disturbances' influence on occupational engagement, and whether occupational therapists have collaborated with caregivers of children with ASD to treat this area of occupation. Therefore, this quantitative project addresses this issue by exploring caregivers with children with ASD's perspectives. Within this chapter, we will discuss the data collection, objectives and deliverables, project analysis, and evidence of trustworthiness.

There are several quantitative research questions that support this capstone and the purpose of this project. Appendix A demonstrates the fifteen-week time log, appendix B demonstrates the research study flyer, appendix c demonstrates the participant information sheet, and appendix D demonstrates the customized questionnaire to caregivers of children with ASD.

For quantitative type research, there is a null hypothesis (HO) and alternative hypothesis (HA) (Creswell & Creswell, 2018). The four research questions are stated below.

1. Is there a relationship between age of child and sleep disturbance?

   HO: There is no relationship between age of child and sleep disturbance.

   HA: There is a relationship between age of child and sleep disturbance.

1. Is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention?

   HO: There is no relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention.

   HA: There is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention.

2. Is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation?

   HO: There is no relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation.

   HA: There is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation.

3. Is there a relationship between sleep disturbances and occupational engagement?

   HO: There is no relationship between sleep disturbances and occupational engagement.

   HA: There is a relationship between sleep disturbances and occupational engagement.

Data Collection

Data analysis and results consisted of collecting data from female caregivers of children with ASD. The capstone timeline occurred for fifteen weeks from January-April 2021. The data collection occurred from week eight through eleven. Participants were caregivers from two pediatric outpatient clinics. Participants were given a research study flyer and participant informant sheet which are shown below in appendices B and C. The sample of individuals who participated were similar to the caregivers of children with ASD validated in chapter two, the literature review. Out of the five caregivers who responded to the questionnaire, four said that their child sleep problems affected their quality of life by selecting extremely likely and likely. Literature states that children with ASD that experience sleep disturbances take medications as a primary intervention (Malow et al., 2016). Out of these five children, only one child takes medication and parents reports that she is very satisfied with her child's medical management and the four other caregivers reported that no sleep medications are taken.

Being in a worldwide pandemic, COVID-19, it was difficult to speak to caregivers in person because most caregivers would drop off their children at the clinics. The doctoral student spoke to six caregivers in person while handing out a flyer and participant information sheet to explain the purpose of the capstone project. Once the participants agreed to participate, the doctoral student collected their personal emails. Each caregiver received the Survey Monkey customized questionnaire to respond at their own pace and time. Participants received a reminder email two days later if they had not responded yet. All caregivers responded at home. All caregivers reported back to the doctoral student after responding to the questionnaire that it took twenty-five minutes or less to participate. There were six total invitations sent out and only five caregivers participated. There seemed to be implicit bias with some responses because all

caregivers explained to the doctoral student that their child had sleeping difficulties, but some did not justify that in the questionnaire.

Objectives and Deliverables

Learning Objectives:

- L1: Compare and contrast sleep concerns for children with ASD as compared to the literature at site 1.
    - Met by week thirteen-weekly reflection papers
    - Sleep was only mentioned twice on this site, but other activities of daily living were addressed every day. The occupational therapist at this clinic mentioned that sleep is mostly spoken about if the caregivers express their concerns. Around two caregivers mentioned that they did not that occupational therapy incorporated sleep in their interventions. Therapists have expressed that it is sometimes forgotten because there are no standardized sleep occupational therapy assessments.
- L2: Compare and contrast sleep concerns for children with ASD as compared to the literature at site 2
    - Met by week thirteen-weekly reflection papers
    - Sleep was mentioned with one child on this site because caregiver has expressed sleep difficulties since therapy began for her child. The occupational therapist at this site also mentioned that it is an occupation that is rarely brought up in the evaluation and modifications are given if caregivers request and speak about these concerns.

- L3: Discuss and identify the need for sleep in occupational therapy for occupational participation
    - Met by week one-reflection paper to augment literature review
    - Sufficient sleep is vital to health and occupational engagement (Judd, 2017). Diagnosis of sleep-related conditions is not within the scope of practice for occupational therapy, but occupational therapy has the capability to evaluate sleep and its influence on occupational engagement. Although most work is done by caregivers, suitable interventions must be done to monitor and address (Lord, 2019).
- L4: Identify the correlation between sleep concerns and children with ASD
    - Met by week thirteen-weekly reflection papers
    - Research demonstrates that children with autism have sleep disturbances and concerns (Gunes et al., 2019). This project concluded that each individual child has their own specific contexts that can affect these disturbances. Occupational therapists should evaluate each child and communicate with caregivers to narrow down how these concerns can be resolved.
- L5: Meet with mentor weekly who specializes in pediatric specialty and setting
    - Met weekly for fifteen weeks to assist with progression of capstone project

Project-based and Outcome Objectives

- PB1: Conduct a needs assessment to address sleep for children with ASD
    - Met week 1-reflection paper

    - The literature review led to gather information about this population to identify the caregivers of children with ASD and their sleep disturbances to increase occupational engagement proving that there is lack of evidence on this topic.
- PB2: Collaborate with occupational therapists (OT) that have background in ASD
    - Met every week for fifteen weeks
    - Every week, doctoral students spoke with occupational therapists about sleep concerns. Both occupational therapists said that it was one of the least occupations spoken about with caregivers, but they give modifications when needed. The doctoral student demonstrated analysis of project and promoted that caregiver should be educated on this occupation.
- PB3: Observe ~5 OT's initial evaluation and ~20 treatment sessions for children with ASD and their caregivers
    - Met every week for fifteen weeks-reflection papers to describe sessions seen and how it compares to the literature.
    - The literature and clinical observations were similar in demonstrating the lack of knowledge in sleep with caregivers of children with ASD.
- PB4: Deliver a customized survey questionnaire that asks appropriate questions for caregivers of children with ASD regarding sleep
    - Questionnaires were delivered weeks seven through nine
    - Reflection papers on progression and evidence of invitations sent to caregivers
    - The first eight questions regarded the child and caregiver demographics, questions nine through fifteen regarded sleep, sixteen through eighteen regarded interventions, and nineteen through twenty-four regarded occupational therapy,

and questions twenty-five through thirty-three regarded occupational engagement. The last question was a text box to assist the doctoral student explore more with anything related to their child's sleep.

- PB5: Collect and analyze data from caregivers' perspectives to disseminate to a forum of OT practitioners the importance of addressing the issue of sleep within the pediatric ASD population
    - Questionnaires were analyzed in week ten through thirteen
    - Both occupational therapists were shown the results and analysis from the questionnaire to portray the need to address sleep in the initial evaluation and interventions. The questionnaire results also showed that occupational engagement is affected which can affect therapy. Results will be demonstrated in detail in the data analysis below.
- PB6: Edit chapters 1-3
    - Met by week six
- PB7: Write chapters 4 & 5 of the capstone paper.
    - Met by week fourteen
- PB8: Create a poster for dissemination using USAHS template.
    - Met by week fourteen
- PB9: Submit completed and approved project (Chapter 1-5 plus appendices into SOAR)
    - Met by week fifteen

Project Analysis

Five out of six caregivers that were invited to participate responded to the questionnaire anonymously. All five were female caregivers. One caregiver was between the ages of twenty-

six and thirty-four, three caregivers were between the ages of thirty-five and forty-four, and one caregiver was between the ages of forty-five and fifty-four years old. Four caregivers have one child at home and the remaining caregiver has two children at home. Four caregivers responded yes; their child has problems sleeping. All caregivers were asked in advance if their child had difficulties sleeping to be eligible to participate, but one caregiver responded no in the questionnaire that their child does not have problems sleeping. Even though a caregiver responded no, she continued to answer the questionnaire reporting that certain occupations impact her child, therefore answers were considered. All children are diagnosed with ASD, and one caregiver responded that their child is also diagnosed with attention-deficit/hyperactivity disorder. All five children receive occupational therapy services. One child has been receiving occupational therapy services for zero to one years, three children have been receiving services for three years, and the last child has been receiving services for six or more years. In total there were thirty-four questions with a text box at the end to help the student researcher better understand their child's sleep problems.

There are four research questions that are proven or disproven from chapter one. The first one asks is there a relationship between age of child and sleep disturbance? According to the child's demographics, one child is between birth to three years old, three children are between four to seven years old, and one child is between eight to eleven years old. Three caregivers responded that they recognized sleep problems at birth to three years old and one caregiver responded that she recognized sleep problems at four to seven years old. This proves the research question that there is a relationship between age of child and sleep disturbance because currently sixty percent of the children are four to seven years old, and seventy-five percent of caregivers recognized sleep disturbances at between birth to three years old. The second research question

asks is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention? One out of five caregivers responded that they strongly disagree, and three out of five caregivers responded that they disagree on expressing their concerns with their child's occupational therapist. Only one out of the five caregivers agreed that she expresses her concerns with the occupational therapist about her child's sleep problems. Sixty percent of caregivers also responded that they disagree on receiving services addressing sleep during a treatment session. There is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention. The third research question asks if is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation? Twenty percent of caregivers responded that they disagree that the occupational therapist does not address sleep during the initial evaluation. Another twenty percent of caregivers felt neutral towards the occupational therapist addressing sleep during the initial evaluation and sixty percent agreed. This shows that there is no relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation. The last research question asks if there is a relationship between sleep disturbances and occupational engagement. There is a relationship between sleep disturbances and occupational engagement. The next section will visually display the data analysis.

Data analysis

Research question one

The first research question asks is there a relationship between age of child and sleep disturbance? This research question was proven with the alternative hypothesis, there is a relationship between age of child and sleep disturbance. The analysis of research question one was analyzed using histograms and bar graphs to display numerical values comparing the findings. As shown in Figure 1, sixty percent of children were between the ages of four and seven years old. Figure 2 shows seventy-five percent of children began their sleep disturbances from birth to three years old. The statical assumptions show that these are the most common ages for children with ASD to experience sleep difficulties.

Figure 1

Child Demographics

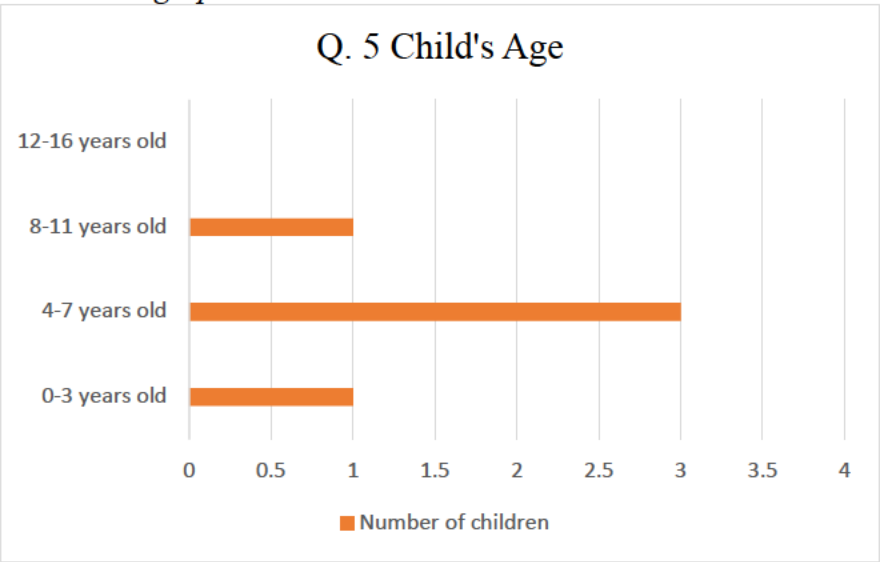
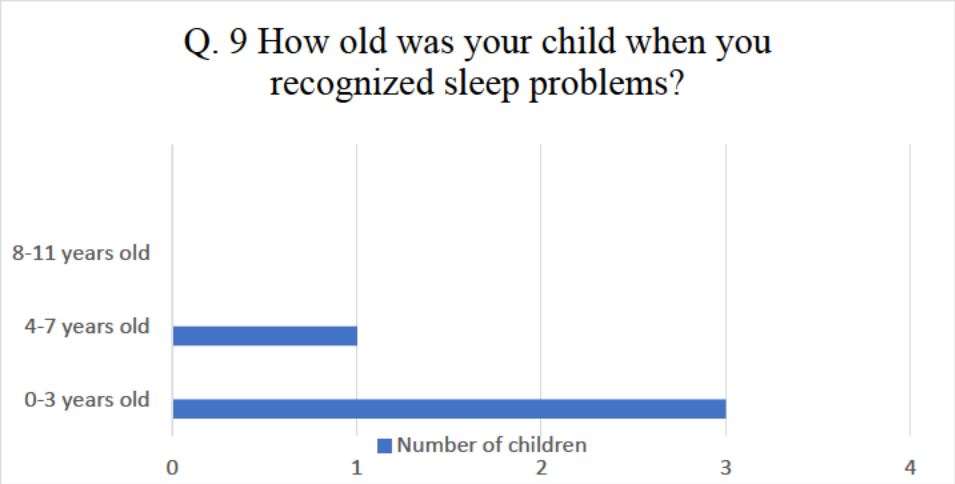


Figure 2

Child Demographics



Research question two

The second research question asks is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention? There is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention. Eighty percent of caregivers disagreed that they do not express their concerns about their child's sleep disturbances with their occupational therapist. An assumption could be made those caregivers do not know that sleep is part of occupational therapy's scope of practice, therefore, do not express their concerns about their child's sleep disturbances with their occupational therapist. This causes barriers of communication for the occupational therapist and the caregiver. In Figure 4, sixty percent of caregivers responded that they disagree, their occupational therapist does not address sleep during treatment sessions. Another assumption is that the occupational therapist will incorporate sleep during the treatment session if caregivers express their concerns. Both occupational therapists from Creating Bridges Therapy and Dade Therapy expressed these similar limitations with the occupation of sleep.

Figure 3

Occupational Therapy and Sleep

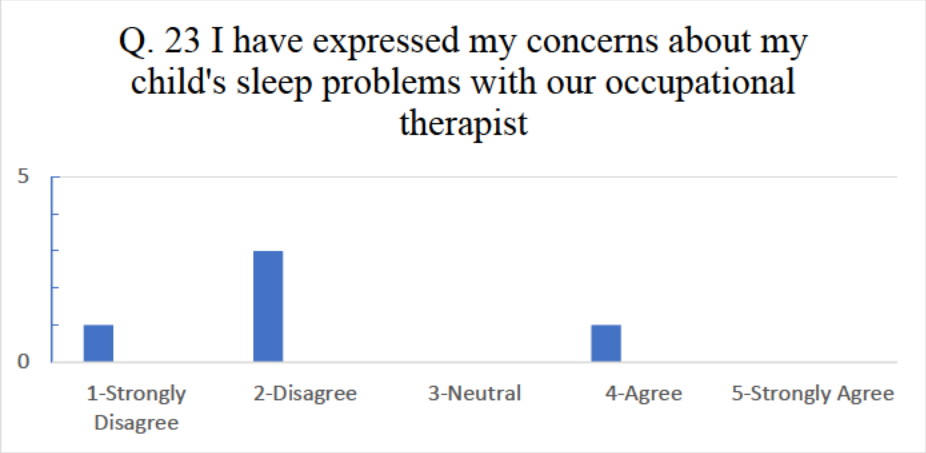
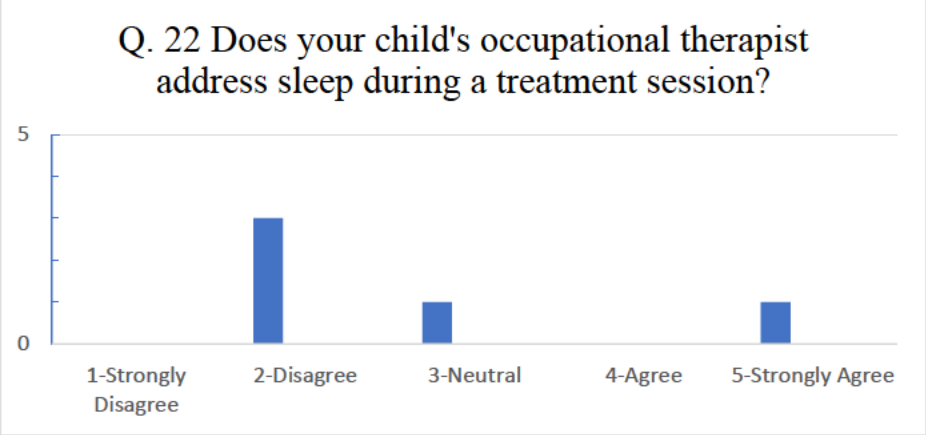


Figure 4

Occupational Therapy and Sleep



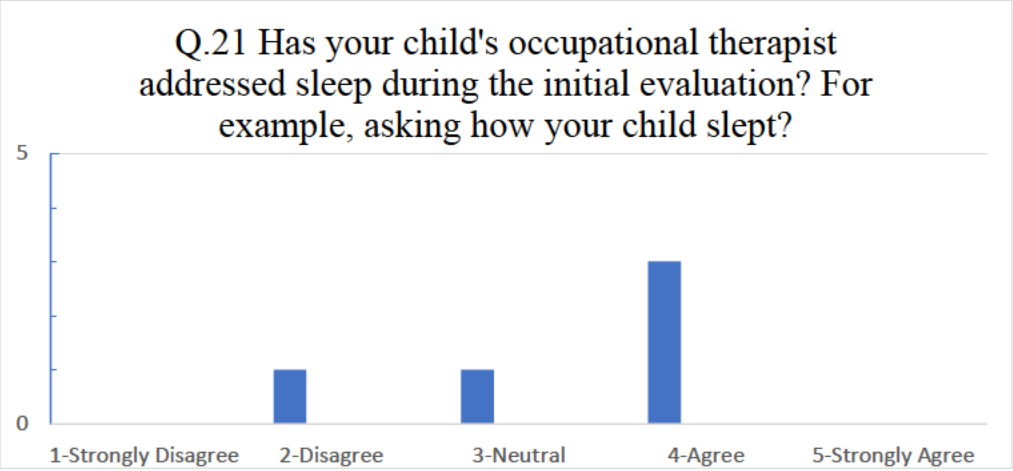
Research question three

The third research question asks is there a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation? Sleep was addressed during the evaluation, but four out five caregivers stated sleep was a problem for their children with ASD. In Figure 4, sleep interventions are not given to caregivers. There is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation. Sixty percent of caregivers agreed that the occupational

therapist addressed sleep during the initial evaluation. One out of five caregivers responded that they do not agree, their chilld's occupational therapist did not address sleep during the initial evaluation. There is an assumption that caregivers of children with ASD are not receiving proper intervention early in life as shown in Figures 1 and 2, even though the next research question answers that these difficulites are spoken about in the initial evaluation.

Figure 5

Occupational Therapy and Sleep



Research question four

The fourth research question asks, is there a relationship between sleep disturbances and occupational engagement? There were nine questions regarding sleep disturbances and occupational engagement. Caregivers had to answer with their perception using a Likert scale from one to five. The alternative hypothesis was proven that there is a relationship between sleep disturbances and occupational engagement. The doctoral student considered the occupations that were sixty percent or higher as the most impacted being the following: academic performance, feeding themselves, bathing/showering, brushing his/her teeth resulting in sixty percent of caregivers report these concerns. Two out of five caregivers strongly agree and agree that sleep

affects their child's social participation with peers or siblings. Figure 10 shows this occupation being impacted by forty percent of children. One caregiver responded the text box at the end of the questionnaire explaining that "my child sleeps throughout the night but often gets burnt out from long days and falls asleep during car rides homes. When this happens, his sleep schedule is off." This caregiver explained that his off schedule will not allow her child to sleep throughout the night resulting in being cranky the next day. Another caregiver states "we are trying to figure out what can be the reason he wakes up 1-3 times a night." This caregiver said that she is not sure if these are difficulties due to ASD, gastro problems, or something else. A caregiver at one of the clinics told the occupational therapist that she did not even know that sleep is part of occupational therapy's scope of practice.

Figure 6

Occupational Therapy and Occupational Engagement

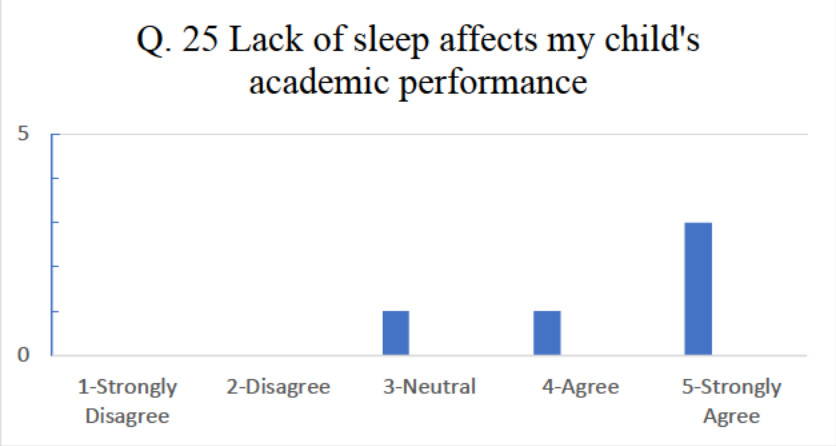


Figure 7

Occupational Therapy and Occupational Engagement

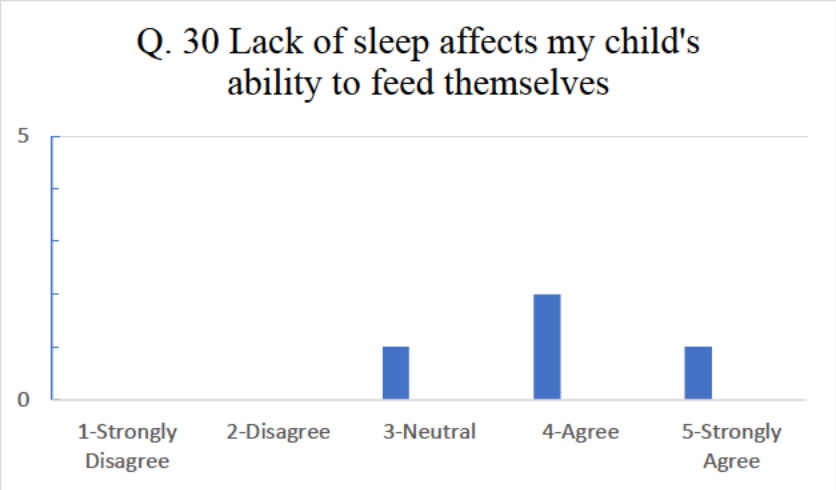


Figure 8

Occupational Therapy and Occupational Engagement

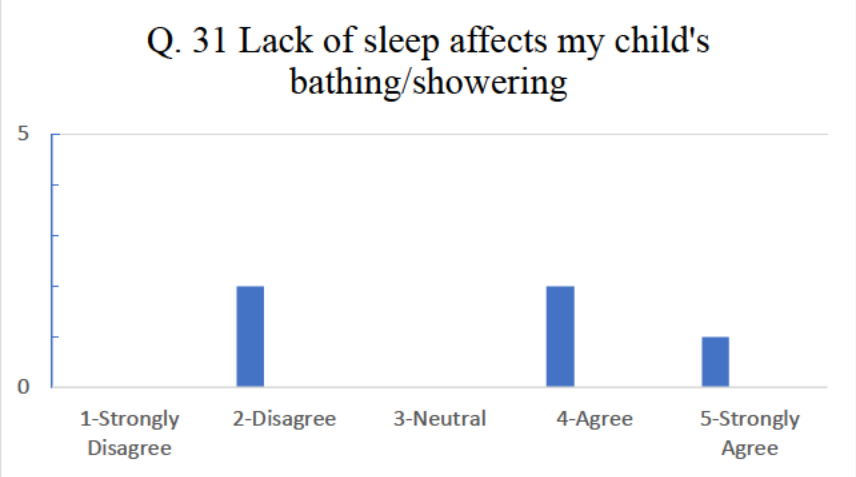


Figure 9

Occupational Therapy and Occupational Engagement

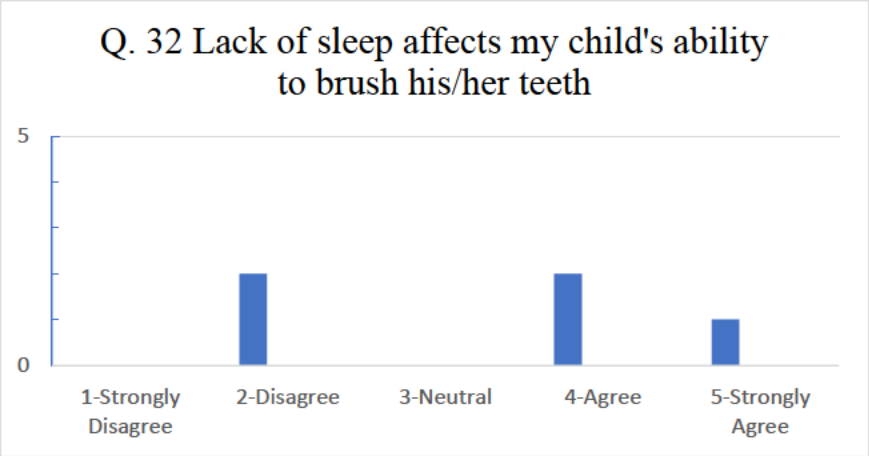
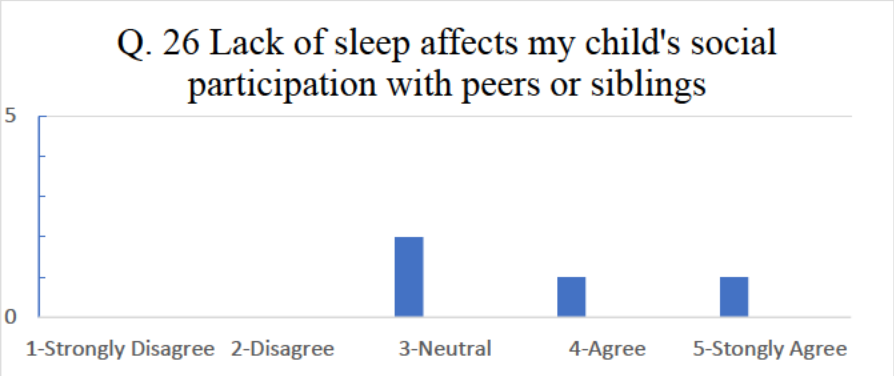


Figure 10

Occupational Therapy and Occupational Engagement



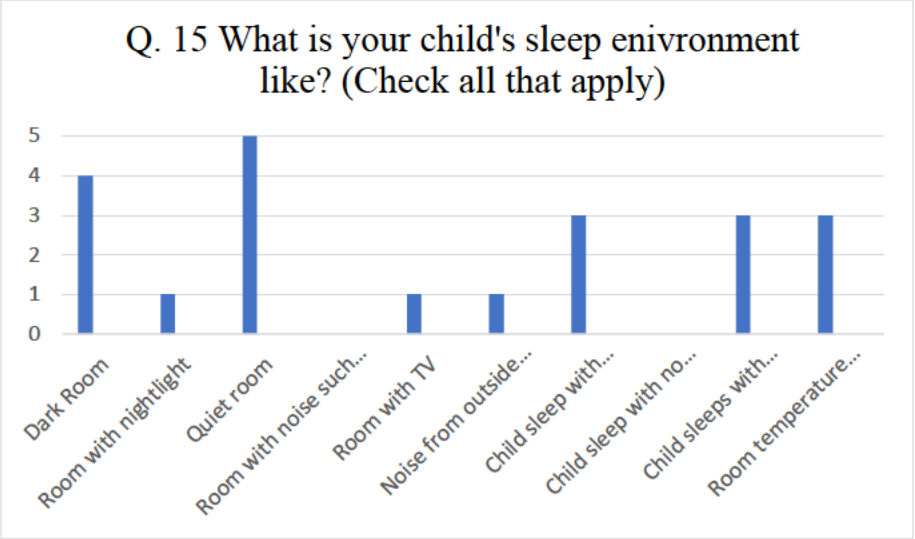
Theoretical Framework

Question number fifteen asked caregivers what is your child's sleep environment like? This question supports the PEOP framework in occupational therapy. To reiterate, the Person-Environment-Occupation-Performance (PEOP) framework is utilized by occupational therapists to analyze how sleep is related to occupation to promote an environment beneficial to sleep and reorganize daytime occupations with an emphasis on occupational balance to promote well-being and function (Ho & Siu, 2018). These results varied within the five children. Figure 11 shows that eighty percent of children sleep in a dark room, twenty percent sleep in a room with a nightlight, hundred percent sleep in a quiet room, no children sleep in a room with noise such as music or white noise, twenty percent sleep in a room with a television, twenty percent sleep with

noise from outside such as traffic or neighbors, sixty percent sleep with clothes on, no children sleep with no clothes, sixty percent sleep with blanket or stuffed animal, and sixty percent sleep with room temperature between sixty-eight degrees and seventy-two degrees. These questions are detailed and specific to each child. Occupational therapists should ask this question to see if any modifications must be made to improve their child's sleep disturbances.

Figure 11

Theoretical Framework and Sleep



Evidence of Trustworthiness

There are four components of trustworthiness for a research project which are credibility, transferability, dependability, and confirmability. There were varied factors that led to the implementation of credibility. The doctoral student reviewed and discussed data with her mentor who is a subject matter expert in pediatrics and children with ASD. Both site supervisors are also subject matter experts in pediatrics and work at outpatient pediatric clinics with this population. The doctoral coordinator reviewed capstone paper and analysis frequently and provided feedback to student throughout the process. There was interrater reliability between the doctoral student and mentor while reviewing the data analysis reaching the same conclusions.

This capstone project can be adjusted to transferability. This project can be applied to any child receiving occupational therapy services with sleep difficulties, rather than specifically choosing children with ASD. In the IRB document created by the doctoral student, the exclusion criteria included caregivers of other diagnoses with sleeping problems. External validity can be applied to this quantitative research project to make this study more generalized to others that face these difficulties.

To implement this capstone project, dependability was required to create consistent strategies. Appendix A describes the time log on how this entire project was broken down into fifteen weeks. Every week, the doctoral student reviewed the progression with her mentor to stay organized and share current information. Data analysis was obtained from Survey Monkey and the data analysis was investigated. The responses will remain anonymous and stored within an encrypted folder on the student investigator's computer and will be destroyed after three years. Information and results were also shared with site supervisors who are pediatric occupational therapists that were interested in the topic to learn more about the occupation of sleep with this population.

The data is represented accurately because all participants' responses were analyzed automatically with the Survey Monkey database. From this analysis, the doctoral student created her own charts to create a more visual way to display data for the audience. At the end of the questionnaire, there were three responses written by caregivers to assist the student investigator better understand their child's sleep problems. Above in research question four, there are quotes from a caregiver to represent confirmability that the data came from participants and not the student investigator. This whole capstone project followed quantitative study regulations.

Conclusion

The results of the capstone project were analyzed in detail by validating that each research question was met or not met. All hypotheses were proven being the following: there is a relationship between age of child and sleep disturbance, there is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention, there is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation, and there is a relationship between sleep disturbances and occupational engagement. Weekly reflection papers were submitted to the doctoral coordinator to meet learning and project-based objectives. All objectives were met on time. The next chapter will explain future implications and how the literature correlated with what was observed at the clinics.

CHAPTER V: Discussion and Conclusion

Introduction

The purpose of this quantitative capstone project is to provide an overview of already existing literature related to children with autism spectrum disorder (ASD) and sleep disturbances. There is limited research on caregivers' perceptions of their child's sleep disturbance, these disturbances' influence on occupational engagement, and whether occupational therapists have collaborated with caregivers of children with ASD to treat this area of occupation. This project was pursued to see if all research questions were answered relating to sleep, occupational therapy, and occupational engagement.

The questionnaire results suggested that there is a relationship between age of child and sleep disturbance, there is a relationship between a caregiver expressing concerns about their

child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention, there is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation, and there is a relationship between sleep disturbances and occupational engagement. The doctoral student produced many assumptions and opinions with these results such as caregivers are only educated on sleep modifications if it is mentioned the occupational therapist. Another assumption is that caregivers do not know that occupational therapy addresses sleep in their practice which is a reason to why they do not express concerns causing a lack of communication. The results of this study were presented to both occupational therapists from the two outpatient clinics to promote sleep difficulties. The next section will describe the interpretation of results and how it correlated with chapter's two, literature review.

Interpretation of Results

Research Questions

The questionnaire results suggested that there is a relationship between the age of child and sleep disturbance. Literature states that caregivers report that their children with ASD have sleep difficulties by 30 months of age and continue during their adolescence (Hyman et al., 2020). Figure 2 shows similar statistics that seventy-five percent of children began their sleep disturbances from birth to three years old.

Blackmer and Feinstein (2016) state that sleep interventions must be implemented with caregivers of children with ASD to manage negative factors affecting their sleep. The second research question was answered by proving that there is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT intervention.

There is a relationship between a caregiver expressing concerns about their child's sleep problems with their occupational therapist and receiving services to address sleep during the OT evaluation, and there is a relationship between sleep disturbances and occupational engagement. Sleep quality affects neural networks that impact elements of occupational engagement (Butera et al., 2019).

Pharmacological Treatment

Nonpharmacologic interventions are preferred by caregivers (Blackmer & Feinstein, 2016). This study also demonstrated similar evidence resulting in eighty percent of children with ASD not taking any medications. Only one child out of five is taking medications and the caregiver has noticed an improvement in sleep with sleep medications. This caregiver also rated that she was 1-very satisfied with her child's medical management for sleeping problems. The doctoral student assumes that this was the same caregiver that mentioned to the student that her child takes medication but continues to sleep with both caregivers. A question for the future would be does your child sleep alone or with caregivers? An assumption can be made that those young children are only sleeping through the night because they sleep with caregivers.

Occupational Therapy

Intervention research is expanding but continues to be inadequate within occupational therapy (Tester & Foss, 2018). Out of the ~twenty treatment sessions, sleep was only spoken about twice to caregivers of children with ASD at both pediatric clinics. Some caregivers did not even know that occupational therapy addressed sleep. The occupational therapists both stated that the topic of sleep was mostly brought up when caregivers expressed their child's concerns. Occupational therapy should provide recommendations to caregivers on a consistent sleep schedule and routine, physiologic factors, and additional suggestions to improve sleep (Blackmer

& Feinstein, 2016). The questionnaire given to the volunteered participants asked caregivers how their child's sleep environment is supporting the PEOP model. In the future, the doctoral student would ask additional questions such as contextual questions regarding each child individually to see what proper suggestions can be made. The results suggest that there is a need for more interventions to address sleep with this population and for occupational therapists.

Strengths and Limitations

There were various strengths and limitations towards this capstone project. A strength was that the questionnaires were easily sent and user friendly for participants. Caregivers reported that the questionnaire did not take long and was easy to understand. Another strength was that the doctoral student was able to attend two outpatient pediatric clinics, therefore, she was able to collect enough data for the study. Both occupational therapists from the clinics allowed the doctoral student to talk to this targeted population and observe sessions during a worldwide pandemic. Being a quantitative study, the statistics that were analyzed by the response rates determined the validity of the capstone project. The limitations were that COVID-19, a worldwide pandemic, was still occurring making it difficult to talk to all caregivers with children with ASD and the time to implement a project. An assumption was that caregivers could have been biased, not willing to share all information.

Recommendations for the Future

If there was more time for this study, the doctoral student would include all children with sleep difficulties that receive occupational therapy services. The doctoral student would individually observe and ask child's difficulties, sleeping environment, and have an in-depth conversation with caregivers. The questionnaires were asked generally but can be made specific per child to analyze deeper. If this were to be done, appropriate recommendations can be made to

caregivers. Further research could investigate the success of OT interventions and a program can be developed and analyzed. Another recommendation for the future is to keep a sleep diary per child to see progression before and after recommendations. These potential impacts can be positive changes for this population and for any child who has difficulty sleeping. Children with autism have other motor impairments that affect occupational engagement and daily participation. Therefore, there is a need for an assessment to determine whether the barriers are sleep related or not. With an assessment, an occupational therapist can determine if it is correlated with other concerns such as gastro, sensory, motor, or more. There is a need for caregiver education from occupational therapists that sleep is an occupation. There is also a need to investigate successful sleep interventions and educate occupational therapists to understand their role, within the scope of practice in addressing sleep during evaluations and interventions.

Conclusion

To conclude this capstone project, the purpose of this quantitative research project was to analyze information about caregivers' perceptions of their child's sleep disturbance, the impact on occupational engagement due to the sleep disturbance and learn if occupational therapists addressed the sleep disturbance. Both occupational therapists were present in the poster presentation to continue learning the emphasis of this problem. With all the hypotheses being proven, this project supports how occupational therapists can become more involved with the caregivers of children with ASD and their sleep difficulties. Even though these results show that sleep is brought up in the initial evaluation, there is a lack of communication and interventional sessions on this topic. The results show that even if it brought up in the initial evaluation, there are rarely treatment sessions that cover these difficulties with this population. An occupational therapy sleep assessment must be made to evaluate each child to address these complications

with caregivers. Occupational therapists use the PEOP model to analyze each child's environment physically and mentally to provide modifications for sleep to increase occupational engagement. Occupational therapists are critical members to assist society to increase negative sleep routines and schedules. There is a need to advocate for increased caregiver awareness of sleep education and interventions to eliminate barriers to increase communication between occupational therapists and families to address sleep concerns. Sleep and rest are necessary towards optimal functioning to increase higher quality of life for both caregivers and children with ASD.

References

Al Backer, N., Jaafar, M., Habibullah, H., & Bashir, S. (2018). The Relationship between Sleep and Cognitive Performance in Autism Spectrum Disorder (ASD): A pilot study. *Children*, 5(11),153. https://doi.org/10.3390/children5110153

American Occupational Therapy Association. (2020). Occupational Therapy Practice Framework: Domain and Process—Fourth Edition. *American Journal of Occupational Therapy* 2020;74(Supplement_2):7412410010. https://doi.org/10.5014/ajot.2020.74S2001

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, 5th ed. Washington, DC: American Psychiatric Association; 2013

Akbarfahimi, M., Nabavi, S. M., Kor, B., Rezaie, L., & Paschall, E. (2020). The Effectiveness of Occupational Therapy-Based Sleep Interventions on Quality of Life and Fatigue in Patients with Multiple Sclerosis: A Pilot Randomized Clinical Trial Study. *Neuropsychiatric disease and treatment*, *16*, 1369–1379. https://doi.org/10.2147/NDT.S249277

Autism and Developmental Disabilities Monitoring (ADDM) Network. (2020, March 26). Retrieved October 27, 2020, from https://www.cdc.gov/ncbddd/autism/addm.html

Blackmer, A. B., & Feinstein, J. A. (2016). Management of Sleep Disorders in Children with Neurodevelopmental Disorders: A Review. *Pharmacotherapy*, *36*(1), 84–98. https://doi.org/10.1002/phar.1686

Butera, C., Kilroy, E., Zeisler, C., Krishnan, S., Gosparini, G., Harrison, L., & Aziz-Zadeh, L. (2019). https://doi:10.5014/ajot.2019.73s1-po8039

Case-Smith, J., & Arbesman, M. (2008). Evidence-Based Review of Interventions for Autism Used in or of Relevance to Occupational Therapy. *American Journal of Occupational Therapy, 62*(4), 416-429. https://doi:10.5014/ajot.62.4.416

Creswell, J. W., & Creswell, J. D. (2018). *Research design: qualitative, quantitative, and mixed methods approaches.* Fifth edition. Los Angeles: SAGE.

De Havas, J. A., Parimal, S., Soon, C. S., & Chee, M. W. (2012). Sleep deprivation reduces default mode network connectivity and anti-correlation during rest and task performance. *NeuroImage*, *59*(2), 1745–1751. https://doi.org/10.1016/j.neuroimage.2011.08.026

Elrod, M. G., & Hood, B. S. (2015). Sleep differences among children with autism spectrum disorders and typically developing peers: a meta-analysis. *Journal of developmental and behavioral pediatrics: JDBP*, *36*(3), 166–177. https://doi.org/10.1097/DBP.0000000000000140

Fadini, C. C., Lamônica, D. A., Fett-Conte, A. C., Osório, E., Zuculo, G. M., Giacheti, C. M., & Pinato, L. (2015). Influence of sleep disorders on the behavior of individuals with autism spectrum disorder. *Frontiers in human neuroscience*, *9*, 347. https://doi.org/10.3389/fnhum.2015.00347

Gunes, S., Ekinci, O., Feyzioglu, A., Ekinci, N., & Kalinli, M. (2019). Sleep problems in children with autism spectrum disorder: clinical correlates and the impact of attention deficit hyperactivity disorder. *Neuropsychiatric disease and treatment*, *15*, 763–771. https://doi.org/10.2147/NDT.S195738

Ho, E., & Siu, A. (2018). Occupational Therapy Practice in Sleep Management: A Review of Conceptual Models and Research Evidence. *Occupational Therapy International*, *2018*, 8637498. https://doi.org/10.1155/2018/8637498

Hyman, S. L., Levy, S. E., Myers, S. M., & Council on Children with Disabilities, Section on Developmental and Behavioral Pediatrics (2020). Identification, Evaluation, and Management of Children with Autism Spectrum Disorder. *Pediatrics*, *145*(1), e20193447. https://doi.org/10.1542/peds.2019-3447

Johnson, C. R., DeMand, A., Lecavalier, L., Smith, T., Aman, M., Foldes, E., & Scahill, L. (2015, December 29). Psychometric properties of the children's sleep habits questionnaire in children with autism spectrum disorder. Retrieved from https://www.sciencedirect.com/science/article/pii/S1389945715020821

Judd S. R. (2017). Uncovering Common Sleep Disorders and Their Impacts on Occupational Performance. *Workplace Health & Safety*, *65*(5), 232. https://doi.org/10.1177/2165079917702911

Kaliyadan, F., & Kulkarni, V. (2019). Types of Variables, Descriptive Statistics, and Sample Size. *Indian Dermatology Online Journal*, *10*(1), 82–86. https://doi.org/10.4103/idoj.IDOJ_468_18

Levin, A., & Scher, A. (2016). Sleep Problems in Young Children with Autism Spectrum Disorders: A Study of Parenting Stress, Mothers' Sleep-Related Cognitions, and Bedtime Behaviors. *CNS neuroscience & therapeutics*, *22*(11), 921–927. https://doi.org/10.1111/cns.12651

Lord C. (2019). Taking Sleep Difficulties Seriously in Children with Neurodevelopmental

Disorders and ASD. *Pediatrics*, *143*(3), e20182629. https://doi.org/10.1542/peds.2018-2629

Malow, B. A., Katz, T., Reynolds, A. M., Shui, A., Carno, M., Connolly, H. V., Coury, D., & Bennett, A. E. (2016). Sleep Difficulties and Medications in Children with Autism Spectrum Disorders: A Registry Study. *Pediatrics*, *137 Suppl 2*, S98–S104. https://doi.org/10.1542/peds.2015-2851H

Mazzone, L., Postorino, V., Siracusano, M., Riccioni, A., & Curatolo, P. (2018). The Relationship between Sleep Problems, Neurobiological Alterations, Core Symptoms of Autism Spectrum Disorder, and Psychiatric Comorbidities. *Journal of Clinical Medicine*, *7*(5), 102. https://doi.org/10.3390/jcm7050102

Maxwell-Horn, A., & Malow, B. A. (2017). Sleep in Autism. *Seminars in neurology*, *37*(4), 413–418. https://doi.org/10.1055/s-0037-1604353

Moore, M., Evans, V., Hanvey, G., & Johnson, C. (2017). Assessment of Sleep in Children with Autism Spectrum Disorder. *Children (Basel, Switzerland)*, *4*(8), 72. https://doi.org/10.3390/children4080072

Picard, M. (2017). Occupational Therapy's Role in Sleep. Retrieved October 30, 2020, from https://www.aota.org/About-Occupational-Therapy/Professionals/HW/Sleep.aspx

Schoen, S. A., Man, S., & Spiro, C. (2017). A Sleep Intervention for Children with Autism Spectrum Disorder: A Pilot Study. The Open Journal of Occupational Therapy, 5(2). https://doi.org/10.15453/2168-6408.1293

Scope of Occupational Therapy Services for Individuals with Autism Spectrum Disorder Across the Life Course. (2015). *American Journal of Occupational Therapy, 69*(Supplement_3). https://doi:10.5014/ajot.2015.696s18

Sullivan, G. M., & Artino, A. R., Jr (2013). Analyzing and interpreting data from likert-type scales. *Journal of graduate medical education*, *5*(4), 541–542. https://doi.org/10.4300/JGME-5-4-18

van der Heijden, K. B., Stoffelsen, R. J., Popma, A., & Swaab, H. (2018). Sleep, chronotype, and sleep hygiene in children with attention-deficit/hyperactivity disorder, autism spectrum disorder, and controls. *European Child & Adolescent Psychiatry*, *27*(1), 99–111. https://doi.org/10.1007/s00787-017-1025-8

Veatch, O. J., Maxwell-Horn, A. C., & Malow, B. A. (2015). Sleep in Autism Spectrum Disorders. *Current Sleep Medicine Reports*, *1*(2), 131–140. https://doi.org/10.1007/s40675-015-0012-1

Weaver L. L. (2015). Effectiveness of Work, Activities of Daily Living, Education, and Sleep Interventions for People with Autism Spectrum Disorder: A Systematic Review. *The American journal of occupational therapy: Official Publication of the American Occupational Therapy Association*, *69*(5), 6905180020p1–6905180020p11. https://doi.org/10.5014/ajot.2015.017962

Wooster, D., Gwin, H., Gwin, S., Hargis, L., Papania, J., Register, J., & Rood, K. (2015). Efficacy of Sleep Education for Parents with Children with Autism Spectrum Disorder.

American Journal of Occupational Therapy, 69(Suppl. 1). doi:10.5014/ajot.2015.69s1-po3058

Appendix A

TIME LOG	*ACTIVITIES/TASKS*
Week 1: January 4-8, 2021 Objectives met: PB1, PB2, PB3, L3, L5	• Conduct a needs assessment to address sleep for children with ASD • Collaborate with occupational therapist that has background in ASD and explain questionnaire • Observe treatment sessions for children with ASD and their caregivers • Complete deliverable for learning objective 3 • Meet with mentor to discuss progress
Week 2: January 11-15, 2021 Objectives met: PB2, PB3, L5, PB6, L3, L5	• Collaborate with occupational therapist that has background in ASD and explain questionnaire • Observe treatment sessions for children with ASD and their caregivers • Meet with mentor to discuss progress • Continue editing chapters 1-3 • Complete deliverable for learning objective 3 • Meet with mentor to discuss progress
Week 3: January 18-22, 2021 Objectives met: L4, PB2, PB3, PB6, L5	• Identify the correlation between sleep concerns and children with ASD • Collaborate with two occupational therapists that have background in ASD • Observe treatment sessions for children with ASD and their caregivers • Gather list of caregivers to participate in questionnaire • Continue editing chapters 1-3 • Meet with mentor to discuss progress
Week 4: January 25-29, 2021 Objectives met: L1, L2, PB2, PB3, POB	• Compare and contrast sleep concerns for children with ASD as compared to the literature at both sites • Collaborate with two occupational therapists that have background in ASD

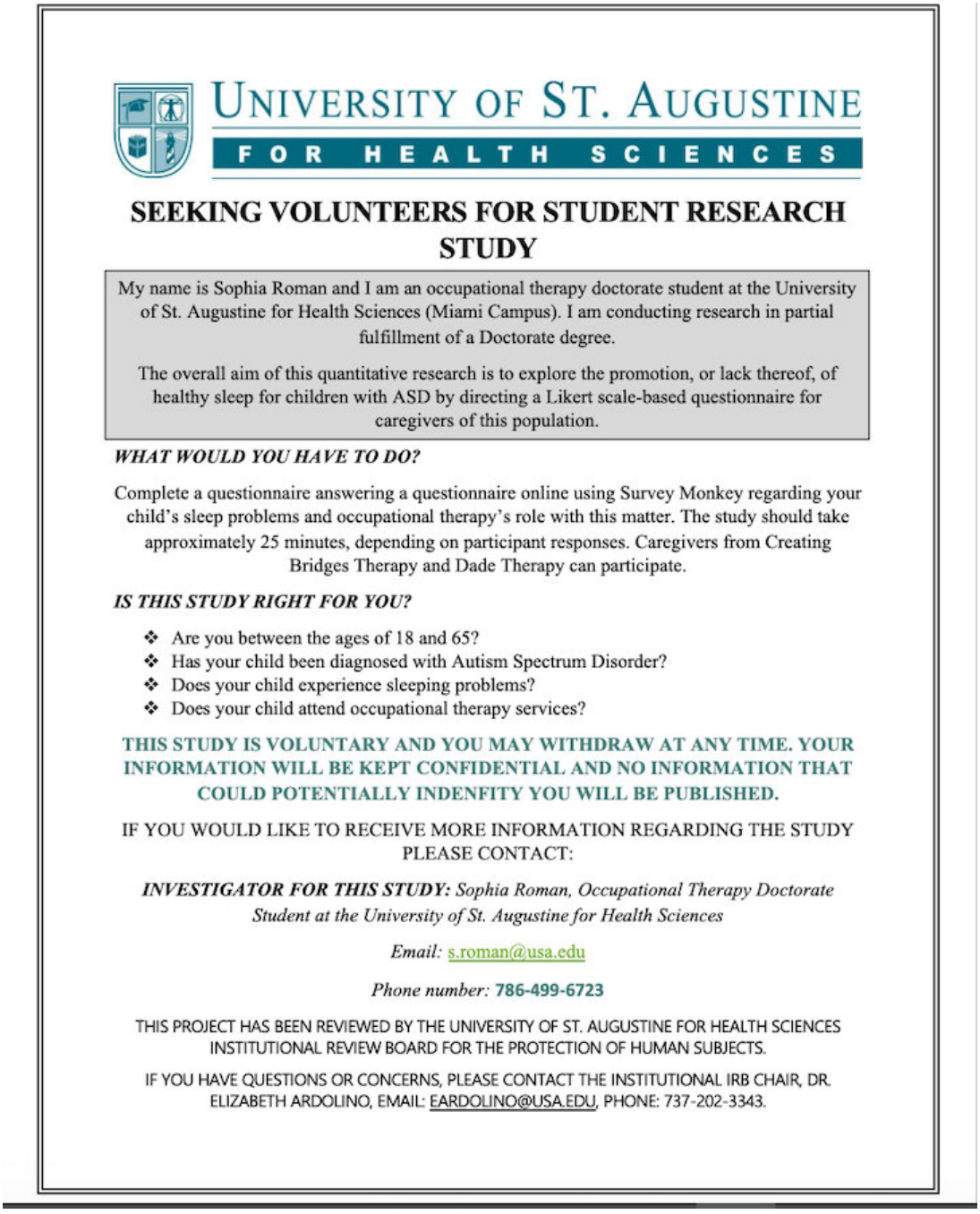
	• Continue to gain knowledge and experience observing treatment sessions for children with ASD and their caregivers • Document and reflect on session outcomes while continuing to gather list of caregivers willing to participate • Continue editing chapters
Week 5: February 1-5, 2021 Objectives met: PB2, PB3, L1, L2, L3, L4, L5, PB6	• Document and reflect on session outcomes while continuing to gather list of caregivers willing to participate • Continue to gain knowledge and experience observing treatment sessions for children with ASD and their caregivers • Collaborate with two occupational therapists that have background in ASD • Meet with mentor to discuss progress • Weekly deliverable • Final edits to chapters 1-3
Week 6: February 8-12, 2021 Objectives met: L1, L2, L3, L4, L5, PB2, PB3, PB6	• Document and reflect on session outcomes while continuing to gather list of caregivers willing to participate • Continue to gain knowledge and experience observing treatment sessions for children with ASD and their caregivers • Collaborate with two occupational therapists that have background in ASD • Meet with mentor to discuss progress • Weekly deliverable • Final edits to chapters 1-3
Week 7-9: **February 15-19, 2021** Objectives met: PB2, PB3, PB4, L1, L2, L3, L4, L5 **February 22-26, 2021**	• Collaborate with two occupational therapists that have background in ASD • Observe treatment sessions for children with ASD and their caregivers • Deliver a customized survey questionnaire for caregivers of children with ASD • Meet with mentor to discuss progress • Weekly deliverable

Objectives met: L1, L2, L3, L4, L5, PB2, PB3, PB4 **March 1-5, 2021** Objectives met: L1, L2, L3 , L4, L5, PB2, PB3, PB4	
Week 10-11: **March 8-12, 2021** Objectives met: L1, L2, L3, L4, L5, PB2, PB3, PB5 **March 15-19, 2021** Objectives met: L1, L2, L3, L4, L5, PB2, PB3, PB5	• Collaborate with two occupational therapists that have background in ASD • Continue to gain knowledge and experience observing treatment sessions for children with ASD • Gather data from caregivers' perspectives • Meet with mentor to discuss progress • Weekly deliverable • Begin analysis
Week 12: March 22-26, 2021 Objectives met: L1, L2, L3, L4, L5, PB2, PB3, PB5, PB7	• Continue to gain knowledge and experience observing treatment sessions for children with ASD • Continue analysis • Begin discussing and reflection on research/results with both site supervisors • Write chapters four and five of capstone project • Meet with mentor to discuss progress • Weekly deliverable
Week 13: March 29-April 2, 2021 Objectives met: L1, L2, L3, L4, PB2, PB3, PB5, PB7, PB8	• Continue to gain knowledge and experience observing treatment sessions for children with ASD • Continue analysis • Final discussion and reflection on research/results with both site supervisors

	• Write chapters four and five of capstone project • Meet with mentor to discuss progress • Weekly deliverable • Create a poster for dissemination using USA template
Week 14: April 5-9, 2021 Objectives met: L5, PB3, PB5, PB8	• Continue to gain knowledge and experience observing treatment sessions for children with ASD • Create a poster for dissemination using USA template • Final edits to chapters • Meet with mentor to discuss progress
Week 15: April 12-16, 2021 Objectives met: L5, PB3, PB8	• Meet with mentor to discuss progress • Final week in gaining knowledge and experience from pediatric clinics; farewells • Submit and discuss with faculty/staff on outcomes of research project
Total: **Direct hours: 388 hours** **Indirect hours: 190 hours**	

Appendix B

Research Study Flyer



UNIVERSITY OF ST. AUGUSTINE
FOR HEALTH SCIENCES

SEEKING VOLUNTEERS FOR STUDENT RESEARCH STUDY

My name is Sophia Roman and I am an occupational therapy doctorate student at the University of St. Augustine for Health Sciences (Miami Campus). I am conducting research in partial fulfillment of a Doctorate degree.

The overall aim of this quantitative research is to explore the promotion, or lack thereof, of healthy sleep for children with ASD by directing a Likert scale-based questionnaire for caregivers of this population.

WHAT WOULD YOU HAVE TO DO?

Complete a questionnaire answering a questionnaire online using Survey Monkey regarding your child's sleep problems and occupational therapy's role with this matter. The study should take approximately 25 minutes, depending on participant responses. Caregivers from Creating Bridges Therapy and Dade Therapy can participate.

IS THIS STUDY RIGHT FOR YOU?

- Are you between the ages of 18 and 65?
- Has your child been diagnosed with Autism Spectrum Disorder?
- Does your child experience sleeping problems?
- Does your child attend occupational therapy services?

THIS STUDY IS VOLUNTARY AND YOU MAY WITHDRAW AT ANY TIME. YOUR INFORMATION WILL BE KEPT CONFIDENTIAL AND NO INFORMATION THAT COULD POTENTIALLY INDENFITY YOU WILL BE PUBLISHED.

IF YOU WOULD LIKE TO RECEIVE MORE INFORMATION REGARDING THE STUDY PLEASE CONTACT:

INVESTIGATOR FOR THIS STUDY: *Sophia Roman, Occupational Therapy Doctorate Student at the University of St. Augustine for Health Sciences*

Email: s.roman@usa.edu

Phone number: **786-499-6723**

THIS PROJECT HAS BEEN REVIEWED BY THE UNIVERSITY OF ST. AUGUSTINE FOR HEALTH SCIENCES INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN SUBJECTS.

IF YOU HAVE QUESTIONS OR CONCERNS, PLEASE CONTACT THE INSTITUTIONAL IRB CHAIR, DR. ELIZABETH ARDOLINO, EMAIL: EARDOLINO@USA.EDU, PHONE: 737-202-3343.

Appendix C

Participant Information Sheet

Occupational therapy's role in promoting healthy sleep to assist caregivers of children with ASD improve occupational engagement

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and involvement you would have. Please take a moment to read the following information carefully. Ask questions if you need clarification or if you would like more information. Take time to decide whether or not you can take part in the study. You may contact me at s.roman@usa.edu with any questions.

Who am I and what this study is about?

My name is Sophia Roman and I am an occupational therapy doctorate student at the University of St. Augustine for Health Sciences (Miami Campus). I am conducting research in partial fulfillment of a Doctorate degree. The purpose for this project is to learn caregivers' perspectives on occupational therapy's role regarding sleep for children with Autism Spectrum Disorder in order to provide help for these children who have difficulties sleeping. This study also serves to aid in the profession of occupational therapy by emphasizing this gap in practice and the lack of attention to the subject of sleep. The purpose of this quantitative research is to explore the promotion, or lack thereof, of healthy sleep for children with ASD by directing a Likert scale-based questionnaire for caregivers of this population.

What will taking part involve?

Your participation in this research study will consist of answering a questionnaire concerning your child with Autism Spectrum Disorder by accessing Survey Monkey. The anticipated duration of your participation is approximately 25-minutes, which will be dependent on participant response.

Why have you been invited to take part?

You have been invited to take part in this study because your child has a diagnosis of Autism Spectrum Disorder and experiences sleep difficulties.

Do you have to take part?

It is up to you to decide whether or not to take part in the study. You can withdraw at any time and you do not have to give a reason for withdrawal. If you decide to take part you will be given this information sheet to keep and will be asked to sign a consent form.

What are the possible risks and benefits of taking part?

You will receive no personal benefits other than contributing to the body of research to assist caregivers of children with autism spectrum disorder and their sleeping problems. Contributing to the body of research may be identified as a benefit to assist occupational therapy's role regarding sleep concerns to increase occupational engagement.

Risks are no more than those encountered in everyday life. If at any point you feel uncomfortable answering a question, feel free to stop at any time. If you decide that you want to stop being in the study, we ask that you let us know.

Will taking part be confidential?

Your participation in this study will be strictly confidential. Any information that you provide that could be used to identify you will not be published.

How will information you provide be recorded, stored, and protected?

Responses will be retained within an encrypted folder on the student investigator's personal computer. No information that could potentially identify you will be published. All data will be destroyed after 2 years following the completion of the study.

Who should you contact for further information?

Sophia Roman

Occupational Therapy Doctorate Student at the University of St. Augustine for Health Sciences

Email: s.roman@usa.edu

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Appendix D

Caregiver Questionnaire

Analysis of occupational therapy's role to promote healthy sleep participation to support caregivers of children with ASD

The following questions are directed to caregivers of children with ASD and sleep difficulties.

Parent/Caregiver Demographics	
1. Parent/Caregiver Gender	• Male • Female • Other
2. Parent/Caregiver Age	• <18 years old • 19-24 years old • 26-34 years old • 35-44 years old • 45-54 years old • 55-64 years old • 65 +
3. Number of children in your home	• 1 child • 2 children • 3 children • 4 children • 5+
4. Does your child have problems sleeping?	• Yes • No If yes – continue with survey If no- Survey ends
Child Demographics – Please answer the following questions as they relate to your child that has problems sleeping.	
5. Child age	• 0-3 years old • 4-7 years old • 8- 11 years old • 12-16 years old • 17- 19 years old • 19+

6. Child Gender	• Male • Female • Other
7. Does your child with problems sleeping have any of the following diagnoses (Select all that apply):	• ASD-autism spectrum disorder • ADD/ADHD-Attention-deficit/hyperactivity disorder • PDD-Pervasive developmental disorder • NDD/Sensory Issues-Neurodevelopmental disorder
8. On a night when your child has sleep problems, how likely does their behaviors the following day affect caregivers and/or family members' quality of life?	• 1-Extremely likely • 2-Likely • 3-Neutral • 4-Unlikely • 5-Extremely unlikely
Sleep Questionnaire	
9. How old was your child when you recognized sleep problems?	• 0-3 years old • 4-7 years old • 8-11 years old • Other __
10. In a typical week, how many days does your child take a nap throughout the day?	• 1 • 2 • 3 • 4 • 5 • 6 • 7
11. On average, how many hours does your child sleep per day, including naps?	• 0-1 hour • 2-3 hours • 4-5 hours • 6-7 hours • 8-9 hours • 10-11 hours • 12+ • Other

12. In a typical week, how many days does your child seem tired during the daytime?	• 0 – my child does not seem tired during the day • 1 • 2 • 3 • 4 • 5 • 6 7
13. In a typical week, how many days does your child fall asleep while involved in activities?	• 0 – my child doesn't seem tired during the day • 1 • 2 • 3 • 4 • 5 • 6 7
14. In the typical week, how many nights does your child wake up during the night?	• 0 – my child typically sleeps through the night. • 1 • 2 • 3 • 4 • 5 • 6 • 7
15. What is your child's sleep environment look like? (check all that apply)	a.) Dark room b.) Room with nightlight c.) Quiet Room d.) Room with noise such as music, or white noise e.) Room with TV f.) Noise from outside (IE Traffic or neighbors) g.) Child sleeps with clothes on (Pajamas) h.) Child sleeps with no clothes (if only sleeps with diaper or underwear on) i.) Child sleeps with blanket or stuffed animal j.) Room temperature between 68 degrees and 72 degrees k. Other
Interventions	

16. Does your child take medications for sleep? If yes, which one? _____ If no – go to next question. 17. Have you noticed improvement in sleep with sleep medications? Yes No 18. How satisfied are you with your child's medical management for his/her sleep problems? 1- very unsatisfied 2 unsatisfied 3-neutral, 4 satisfied 5-very satisfied N/A	
Occupational Therapy	
19. Has your child ever received occupational therapy?	Yes No If yes – go to next relevant question, If no skip next 2 questions
20. How long has your child been receiving occupational therapy services? _____	• 0-1 year • 2 years • 3 years • 4 years • 5 years • 6+
21. Has your child's occupational therapist addressed sleep during the initial evaluation? For example, asking how your child slept?	1 Strongly disagree, 2 Disagree 3 Neutral 4 Agree 5 Strongly agree
22. Does your occupational therapist address sleep during a treatment session?	1 Strongly disagree, 2 Disagree 3 Neutral 4 Agree 5 Strongly agree
23. I have expressed my concerns about my child's sleep problems with our occupational therapist	1 Strongly disagree, 2 Disagree 3 Neutral 4 Agree 5 Strongly agree
24. The occupational therapist adequately addresses my child's sleep problems	1 Strongly disagree, 2 Disagree 3 Neutral 4 Agree 5 Strongly agree

Occupational Engagement	

1 Strongly disagree,
2 Disagree
3 Neutral
4 Agree
5 Strongly agree
N/A

Lack of sleep affects my child's

25. Academic Performance
26. Social participation with peers or siblings
27. Play with peers siblings
28. Play by themselves
29. Dress by themselves
30. Feed themselves
31. Bathing/showering,
32. Brush teeth
33. Complete chores

34. To help the researcher better describe problems with child's sleep, please provide any additional information about your child, their sleep problems, services they have received to improve the sleep problem, and anything that has helped your child's sleep problems.

    Insert text box – But can be left blank.

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