Arab American University

Faculty of Graduate Studies

"The relationships between sleep disturbance of children with ASD and parent quality of life: A cross sectional study."

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Thesis Approval

The relationships between sleep disturbance of children with Autism Spectrum Disorder (ASD) and parent quality of life: A cross sectional study.

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Declaration

I declare that, except where explicit reference is made to the contribution of others, this thesis is substantially my own work

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Abstract

Background: Existing literature indicates that a significant proportion of children with Autism Spectrum Disorder (ASD) experience at least one additional medical or behavioral comorbidity, Sleep disturbance is one of the most prevalent comorbidities.Sleep disturbances in children with ASD may effect on parents QoL.

Aims: The study aims to examine the relationships between sleep disturbance and parent quality of life in children with ASD from Palestine.

Objective: To examine the relationship between sleep disturbance among ASD children and parents' quality of life, and to explore and report sleep disturbances among ASD children from Palestine.

Methods:This study use a quantitative cross-sectional design through Demographic data and two assessments used an Arabic version of SF-36 v2 and an Arabic version of Children's Sleep Habits Questionnaire (CSHQ), two assessments are valid and reliable. Convenience as a sampling technique, the sample count 98 from parents of children with ASD native Arabic speakers and 98 from parents of TD children. The study conducted in the northern and central area of Palestine.

Result: The main findings of our study revealed significant differences in QOL between parents of children with ASD and parents of TD, sleep disturbances are more common in children with ASD than in TD children and sleep disturbances in children with ASD affect parental QOL.

Keywords: Autism, Sleep disturbance, Insomnia, parent quality of life, parenting.

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Chapter 1 Introduction and background

1.1 Background

Autism spectrum disorder (ASD) is a neurodevelopmental disorder linked with chronic deficits in social interactions and communication and repetitive patterns of attention, attitude, or activities (American Psychiatric Association (APA), 2013). Existing literature indicates that a significant proportion of children with Autism Spectrum Disorder (ASD) experience at least one additional medical or behavioral comorbidity (Soke et al., 2018). Sleep disturbance is one of the most prevalent comorbidities with studies estimating its prevalence to range between 40% and 90% among individuals with ASD (Tyagi et al., 2018). Sleep disturbance are conditions that disrupt normal sleep patterns, leading to insufficient or poor-quality sleep. These disorders can significantly impact physical, mental, social, and emotional functioning, affecting overall health and quality of life (QoL)(Karna et al., 2023). In addition to influencing ASD children, sleep issues may also have an adverse effect on parents' health and well-being.

Usman Baig and colleagues (2020) have reported that nearly 40% of Lahore children with ASD had sleep disturbances, with insomnia being the most reported. Moreover, according to Posar and Visconti (2020), children with ASD have sleep disturbances with a prevalence ranging from 60% to 86%. Similarly, Singh and Zimmerman (2015) have reported a prevalence of sleep disturbances in children with Autism of 50-80%, using parent-reported assessments. Furthermore, studies conducted in the Arab world, specifically in Oman, In the Arab world in Oman, the prevalence of sleep disturbances in children with ASD was high (87.4%) (Al-Farsi et al., 2018). In addition, Chen and colleagues (2021) have conducted a

cross-sectional study in which children with ASD reportedly had 67.4% sleep disturbances; this indicates a higher prevalence when compared to typically developing (TD) children of the same age.

Sleep disturbances may influence to harmful effects on psychological states and the arousal of negative behavior, aggression, hyperactivity, and decreased concentration in ASD children. Sleep disturbances are connected with higher levels of autism symptoms, stereotypic movement, social interaction, and hypersensitivity (Posar & Visconti, 2020).

Though sleep disturbances belong to the comorbidities with ASD, some factors may cause rising in their intensity. sensory hypersensitivity may lead to sleep disturbances in some autistic children and that may lead to poor permanence during the day (Mazurek et al., 2019). According to Elkhatib Smidt and colleagues (2019), there was a connection between the parents' low educational level and sleep disturbances. Besides, sleep disturbance appears if the mother doesn't know how to react to an autistic child during sleep according to (Levin & Scher, 2016).

Quality of life (QOL) has been utilized in several earlier studies to assess how ASD and other common developmental disorders affect children or their families (Alhazmi et al., 2018; He et al., 2018). The definition of quality of life according to the World Health Organization (WHO), is the individual's perception of his situation in life within the framework of value systems and culture in which he lives and concerning his expectations, hopes, interests, and goals (World Health Organization [WHO], 1995). It is a multifaceted concept that includes

a person's social connections, personal views, physical and mental health, and other areas of life (Mugno et al., 2007).

Children with ASD exhibit behavioral characteristics that negatively affect the quality of life for their families, including sleep disturbances, dietary restrictions, stereotyped behaviors, furious outbursts, and a lack of social reciprocity (Øien & Eisemann, 2015; Khanna et al., 2010). In a study by Liu and colleagues(2020), the impact of sleep issues on QoL and the quality of life of parents of children with ASD was examined. The findings suggested that sleep issues in children with ASD may have different effects on parental QOL than those in TD children and may have independent effects on the physical health of parents (Liu et al., 2020). Moreover, deficits in parental QoL could also be interpreted in light of the difficulties these parents experience; such as higher levels of stress, poor sleep, and exhaustion, which are likely to impair their mental and physical health. (Giallo et al., 2011; Seymour et al., 2012).

The study of Giallo and colleagues (2011) also indicated a significant connection between poor sleep and anxiety, lack of physical activity, stress, and poor parenting effectiveness and satisfaction. Similarly, Hodge and colleagues (2012) reported that parents face more problems with the sleep of children, weaker mental health, and higher stress. Sleep disturbance in autistic children has led to increased parents' exhaustion (Klukowski et al., 2015). Martin and colleagues (2019) conducted a systematic review investigating the relationship between sleep disturbances in children ASD and the psychological well-being of their parents. The review concluded that a significant correlation exists between sleep

disturbances in children with ASD and adverse psychological outcomes in their parents. Consistent with these findings a recent study in Ireland conducted by Leader and colleagues (2021) indicated that parents do not get enough sleep and experience fatigue, stress, depression, and decreased well-being, this is because they are affected by sleep disturbances in autistic children.

In the Arab world Saudi Arabia a cross-sectional study(Al-Jabri et al., 2022) and Egypt a quasi-experimental study (Ezzat, 2017), show the same result caregivers of children with ASD have a lower quality of life compared to TD children, but in Qatar cross-sectional study(Kheir et al., 2012) there was no statistically significant difference between QOL scale between ASD parents and TD parents. However, parents of children with ASD regarded their health as bad and expected it to worsen.

Despite growing global awareness, there is a glaring absence of research addressing this issue in Palestine. The unique sociopolitical environment—marked by decades of military occupation, restricted mobility, economic instability, and limited access to health and educational services—exposes Palestinian families to chronic stress and trauma (El-Khodary & Samara, 2019). In such a context, raising a child with ASD can present compounded psychological and functional burdens that are distinct from those experienced elsewhere. While some regional studies (e.g., Al-Jabri et al., 2022; Ezzat, 2017) have explored caregiver stress and QoL in broader Arab contexts, no study to date has examined the intersection of sleep disturbances in children with ASD and parental QoL in Palestine.

This knowledge gap is particularly problematic for the field of occupational therapy, which emphasizes holistic, context-sensitive interventions that consider both the individual and their environment. Sleep is a critical daily occupation that influences not only a child's cognitive and behavioral functioning but also the occupational performance and mental health of their caregivers. Understanding how sleep disturbances in children with ASD affect parental QoL is essential for developing effective, evidence-based interventions in occupational therapy—especially in Palestine, where services are often under-resourced and underdeveloped.

Moreover, although international evidence supports the link between children's sleep disturbances and reduced parental well-being, it cannot be assumed that these findings apply equally to Palestinian families. The high prevalence of trauma, financial constraints, and limited access to specialized support may exacerbate or alter the nature of these relationships. Therefore, localized research is urgently needed to inform culturally and contextually appropriate interventions and policies.

1.2 Research Problem

Sleep disturbances are among the most common comorbidities in children with ASD, affecting between 40% to 80% of this population depending on context and severity (Posar & Visconti, 2020). However, the effects of these sleep disturbances go beyond the children and have a substantial impact on their parents' mental, emotional, and physical well-being, ultimately lowering their overall quality of life (Kheir et al., 2012).

While around the world studies have shown a link between child sleep issues and lower parental QoL, no similar study is currently available in the Palestinian context. This is especially alarming considering Palestinian families' chronic instability, psychological stressors, and limited access to specialist services as a result of the long-term occupation.

Thus, the study concern is a lack of localized understanding of how sleep disturbance in children with ASD affect the quality of life of their parents in Palestine. Addressing this gap is critical for developing contextually relevant, family-centered occupational therapy interventions and providing greater support to these families.

1.3 Research Objectives

Purpose of this Study

The aim of this study is to:

1) To explore sleep disturbances among Palestinian children with ASD.

2) To assess QoL of Palestinian parents of children with ASD.

3) To investigate the relationship between sleep disturbance of children with ASD and parental QoL.

Objectives of the study:

To explore and report sleep disturbances among Palestinian children with ASD

To make a comparison between sleep disturbances between typical children and autistic children in Palestine.

To make a comparison between the QoL of parents of children with ASD and parents of TD children.

To examined the relationship between sleep disturbance among Palestinian children with ASD and parents' quality of life based on the Arabic version of SF-36 v2 and an Arabic version of the children's sleep habits questionnaire (CSHQ).

1.4 Research Significance

This work has major academic and practical implications. The study is the first of its type in Palestine to look into the relationship between sleep disturbances in children with Autism Spectrum Disorder (ASD) and their parents' quality of life (QoL). While worldwide literature affirms this association, the Palestinian context, with its complicated sociopolitical backdrop, chronic stressors, and limited health infrastructure, necessitates more localized research to better understand the lived experiences of families raising children with ASD.

This study fills a unique and significant gap in the regional literature by focusing on sleep as a vital but underexplored element impacting parental quality of life. By doing so, it not only contributes to the global discourse on ASD caring, but also provides much-needed focus to how sleep-related difficulties particularly

The findings are predicted to influence occupational therapy practice in Palestine by emphasizing the significance of incorporating sleep hygiene therapies and caregiver well-being into family-centered care plans. These findings may help clinicians, therapists, and legislators create better culturally responsive and context-sensitive programs for children

with ASD and their families. Furthermore, the study supports occupational therapists' roles as crucial stakeholders in addressing both child functioning and caregiver resilience in a comprehensive manner.

Finally, this research seeks to empower families, improve service delivery, and advocate for evidence-based treatments that reflect the realities of Palestinian life under occupation.

Chapter 2 Literature Review

2.1 Introduction

This literature review discussed the relationship between children's sleep disturbances and parent's quality of life of children with an autism spectrum disorder.

2.2 Autism spectrum disorders (ASD)

Autism spectrum disorder (ASD) is a neurodevelopmental disorder manifested with chronic deficits in social interactions and communication, and showing repetitive patterns of attention, attitude, or activities (American Psychiatric Association (APA), 2013). ASD is a general name for a group of developmental problems (NIMH, 2023). The variety of the diagnosis of autism, where symptoms and degree of diagnostics may range between mild to severe, is referred to as the "spectrum." Communication difficulties, social impairment, behavioral issues, sleep abnormalities, and repetitive movements can all be signs of ASD (APA, 2013; CDC, 2023; NIMH, 2023). Additional diagnoses of mental or behavioral problems, as well as other comorbidities and medical requirements, are possible in people with ASD and may increase the severity of their symptoms generally (APA, 2013).

CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network indicates that one in 44 children is diagnosed with autism spectrum disorder (ASD)(CDC,2022). Compared to earlier research from 2000, where 1 in 200 children were diagnosed with ASD, the prevalence of the disorder has considerably grown (MMWR, 2012). Over 75,000,000

people worldwide—or about 1% of the population—have autism spectrum disorder, according to the CDC(CDC,2022).

2.3 Sleep and sleep disturbances

Rest and sleep have been considered as one of the major human occupations according to the American Occupational Therapy Association (AOTA, 2014). Occupational Therapy Practice Framework (OTPF) suggests that Activities of daily living (ADLs), rest, and sleep are some of the first occupations children engage in from birth (OTPF; AOTA,2014). Sleep disturbance are conditions that disrupt normal sleep patterns, leading to insufficient or poor-quality sleep. These disorders can significantly impact physical, mental, social, and emotional functioning, affecting overall health and quality of life.

Sleep and rest are crucial for a child's development and well-being because they give children and their parents a chance to recharge for activities of daily living, such as ADLs. Muscles unwind and the brain processes the day's experiences while sleeping. Lack of sleep can affect a child's ability to function at work as well as their physical development, health, and capacity for learning and behavior. Memory, muscle regeneration, and hormone release are all stunted when there is little sleep, which also shortens the cycles of REM and NREM sleep. As a result, a disease or its symptoms could worsen (Park et al., 2012).

Lack of sleep and rest can make kids unfocused, agitated, and prone to behavioral outbursts (Tempesta et al., 2020). Obesity, academic issues, and diminished daytime functioning are all linked to sleep deprivation (Ho & Siu, 2018). Recent advances in neuroscience have highlighted the importance of sleep for the pediatric population (Al-Farsi et al., 2018). Disruptions in sleep patterns can lead to or exacerbate emotional dysregulation, attention deficits, and behavioral issue.in the pediatric population (Fulfs et al., 2024).

2.4 Children with ASD and sleep disturbances

A recent systematic review has found that the prevalent of sleep co-morbidities in individuals with ASD can be as high as 72.5% and are more prevalent in children and adolescents (Bougeard et al, 2021).

Sleep disturbance in children with ASD may not be fully explained by the child's characteristics alone. Waddington et al., (2020) discovered that increasing sleep disturbance was associated with increased ASD symptom severity, child seizures, maternal autism features, anxiety, and depression, lower paternal education, and poorer family income. Children with ASD may experience ongoing sleeping disturbances at various cognitive levels (Souders et al., 2017). Other studies indicated different factors affecting sleep quality. For example, short sleep duration in ASD has been linked to higher rates of stereotypical behavior, higher autistic severity scores overall, and lower social skills (SCHRECK, 2004). Similarly, on the Repetitive Behavior Scale, more repetitive behaviors and a need for consistency have been linked to sleep issues (Gabriels et al., 2005). Sensory processing impairments were found to be more prevalent in children with

ASD who were considered “poor sleepers” compared to their counterparts who were considered “good sleepers” (Mannion & Leader, 2013). In addition, several studies have shown that the primary symptoms of ASD as well as daytime activities can be affected by sleep disruptions (Johnson et al., 2018; Mazzone et al., 2018).

2.5 Sleep and Parents of Children with ASD

Sleep issues has an adverse **effect on parents' health and well-being**. It would be difficult for parents and other household members to fulfill their roles (at school, home, work, or in the community) when they are sleep-deprived due to a child's trouble sleeping. Parents who lack sleep are more likely to experience stress, irritation, diminished attention, increased daytime sleepiness, and poorer quality sleep at night (Mindell et al., 2015).

Mothers of children with ASD reported more issues with their own sleep, their children's sleep, higher levels of stress, and worse mental health (Hodge et al., 2012). In a more recent study, Hodge and colleagues (2013) studied the connection between children's sleep and mothers' mental health for moms of children with and without ASD in the ASD literature. The researchers found that children's sleep all significantly predicted maternal stress, sleep, and stress levels. In addition, sleep disturbances affect mental health and depression as indicated by Meltzer (2011) included both mothers and fathers and employed actigraphy to look at characteristics related to parent depression symptoms. Shorter child naps, more frequent child sleep disturbances, shorter mother naps, and poorer maternal sleep quality have all been linked to maternal depression symptoms. The amount of sleep a child gets was found to predict depressed symptoms in the mother. Paternal depressive symptoms

were linked to worse paternal sleep quality and more frequent child sleep disruptions in fathers. Sleep quality predicted depression symptoms in fathers (Meltzer, 2011).

2.6 Quality of Life (QOL)

The definition of quality of life according to the World Health Organization (WHO) is the individual's perception of his situation in life within the framework of value systems and culture in which he lives and concerning his expectations, hopes, interests, and goals (World Health Organization [WHO], 1995). It is crucial to remember that the concept of QOL is a subjective report and that it is a sophisticated and comprehensive measure with numerous elements, or domains, rather than just a measure of physical health. Physical health, psychological health, level of independence, social interactions, environment, and spirituality are the six dimensions of quality of life that the (WHO) has recognized (WHO, 1997). The Patient-Reported Outcomes Measurement Information System (PROMIS) have expanded and refined these domains. PROMIS: A Modern Approach to QoL Assessment developed with funding from the National Institutes of Health (NIH), PROMIS offers a comprehensive set of tools to measure health-related quality of life (HRQoL) from the patient's perspective. PROMIS domains are structured into three primary categories: Physical Health,Mental Health and Social Health(Manoharan et al., 2023).

Vasilopoulou and Nisbet, (2016) systematic review found when compared to parents of TD children or the general population, this review found that parents of children with ASD had lower quality of life. Child behavioral issues, being a mom, a low level of social support, and being unemployed were all factors linked to lower parental quality of

life in this group. Another study has found the educational level of the parents and the child's ASD severity levels were related to lower parental QOL (Turnage and Conner, 2022).

Families' QOL may be negatively affected by distinguishing traits such as stereotyped behaviors, irrational outbursts, and a lack of social reciprocity (Allik et al., 2006; Khanna et al., 2010; Bourke-Taylor et al., 2012; McStay et al., 2014). Parents of children with ASD may experience decreased QOL across all areas as a result of the daily tensions and difficulties they must deal with (Turnage & Conner, 2022). Parents of children with ASD are subjected to the difficulties that come with caring for a child with a developmental handicap daily. These strains may harm parents' quality of life (QOL) (Turnage & Conner, 2022).

2.7 Sleep disturbance in children with ASD and Parent Quality of Life (QOL)

The QOL for the family is negatively impacted by the behavioral characteristics of children with ASD, such as sleep disturbances, food rigidities, stereotyped behaviors, violent outbursts, and a lack of social cooperation (Khanna et al., 2010; Øien & Eisemann, 2015). More specifically, the parent's sleep patterns are impacted by the child's sleep issues, which makes them agitated and impatient with the youngster (Liu et al., 2006; Wang et al., 2015). In addition, parenting a child with ASD is inherently tough because of the child's emotional, behavioral, and communication challenges (Dabrowska & Pisula, 2010). Additionally, issues with children's sleep may worsen existing family stress, which in turn affects how well parents sleep (Liu et al., 2020)

According to Liu et al., 2020 a case–control study examined how and to what extent the QOL of parents of children with ASD was affected by their sleep issues. The findings suggested that sleep issues in ASD may have different effects on parental QOL than they do in TD children and may have independent effects on the physical health of parents.Parents of children with ASD and sleep disturbance have poor parental sleep quality (Lollies et al., 2022). Poor quality of sleep for parents with ASD affects parent QoL, The study that assessed quality of sleep demonstrated that poor sleep quality is related to a reduced QoL (Lee et al., 2021).

2.8 Conclusion

Sleep disturbances are prevalent in children with ASD. QOL is a crucial aspect of family management that demands investigation and focus. It is essential to conduct current research to evaluate the quality of life of parents with ASD children in relation to their children's sleep disturbances. The results of this study would have an impact on occupational therapy interventions with children with ASD and their parents with regard to plan goals directed towards enhancing the sleep hygiene of children and QoL for their parents.

The primary objective of this study in occupational therapy examine the relationship between sleep disturbance among Palestinian children with ASD and parents' quality of life based on the Arabic version of SF-36 V2 and an Arabic version of the children's sleep habits questionnaire (CSHQ), and explore and report sleep disturbances among Palestinian children with ASD.

Chapter 3 Method

This study examined the relationship between sleep disturbance among ASD children and parents' quality of life in Palestine. This chapter details the methods and procedures used to examine the relationship between sleep disturbance among ASD children and parents' quality of life and to explore and report sleep disturbances among ASD children from Palestine.

Purpose

The primary objective of this study is to examine the relationship between sleep disturbance among Palestinian children with ASD and parents' quality of life based on the Arabic version of SF-36 v2 and an Arabic version of the children's sleep habits questionnaire (CSHQ) and explore and report sleep disturbances among Palestinian children with ASD, also to compare the quality of life outcomes for parents of autistic children with those of parent-typical children and to make a comparison between sleep disturbances between typical children and autistic children in Palestine.

Research Questions

1. What is the relationship between children's sleep disturbances and parents' quality of life of children with an autism spectrum disorder in the age group of 3 to 18 years from Palestine?
2. What is the prevalence of sleep disturbance among autistic children in Palestine?
3. Is there any difference in sleep patterns between children with ASD and typically developing children?

4. Is there a difference in the quality of life between parents of children with autism compared to parents of typically developing children?
5. Is there a difference in the quality of life of parents of children with autism between good sleepers and bad sleepers?

3.1 Study design

Cross-sectional observational study.

The study is a cross-sectional design, this design is a type of observational study. As discussed in the earlier articles highlighted in an observational study, the researcher does not change the variable's status. The outcome and variables in the population are measured and their correlation may be studied (Setia, 2016). In this study, we observe the sleep disturbance of children with autism and whether is there a relationship with the quality of life of their parents without changing the variables.

3.2 Study setting

The study took place in the West Bank Authority. In northern, central, and southern Palestine, including Nablus, Tulkarm, Jenin, Bethlehem, Ramallah, and Hebron.

3.3 Study population

Table (1)

Inclusion Criteria	Exclusion Criteria
Palestinian native Arabic speakers' parents were included in the study.	Parents who were non-Arabic-speaking were excluded from the study as they would not be able to fill out assessments.

Parents should be 18 years or older	Parents with mental health issues that could probably affect their sleep and QoL were excluded.
Parents can read and write in Arabic.	Children residing with their families but were over 18 years old were excluded.
For the ASD sample children with an independent diagnosis of ASD, as confirmed by clinical reports, were included.	Children with no conferment diagnosis or had any other formal diagnosis were also excluded from the study.
Children should be between 3 and 18 years of age.	
As for a comparison sample; typically developing children aged 3 to 18 years.	

3.4 Sampling method and sample size

A convenience sampling method will be adopted as there are no statistics in Palestine showing the number of autistic children which would make it difficult to choose another sampling method. According to similar previous studies, the sample is expected to include (93 parents of autistic children).

The standard deviation of the SF-36 (mental component) among caregivers of autistic children has been reported to be ± 11.98 (Kheir et al., 2012). Therefore, a sample size was calculated and it revealed a sample size of 89 participants is sufficient for being able to estimate the mean score with a 95% confidence interval of ± 5%. To compensate for the

eventual drop out, the calculated sample size was increased by 10%, resulting in 98 participants.

The non-probability sampling method is the most widely used and applicable in clinical research, although the participants are recruited according to their availability and accessibility. Therefore, Convenience sampling is used because it is fast, cheap, and proper. Convenience samples are useful for specific purposes, and they require little planning (Elfil &Negida, 2016).

3.5 Participant recruitment procedure

A group of parents of children diagnosed with ASD and a matched group of parents of TD children were recruited from rehabilitation centers in the northern, south, and center West Bank. The centers were provided with detailed information about the objectives of the study and the criteria for the inclusion and exclusion of the participants. The matched sample was based on the child's gender and age.

In cooperation with the centers, some parents were nominated to participate in the research. They were contacted and given more information about the study and objectives, and it was explained to them that whether they participated in the research or not, this would not affect their receipt of the service. Initial oral consent was obtained from the parents for participation and an appropriate date was set to complete the questionnaires.

3.6 Data collection instrument

Measures

Two standardized questionnaires along with a developed demographic questionnaire, were used for this study.

3.6.1 Short Form 36 Health Survey Questionnaire – Version 2 (SF-36v2)

The SF-36 is one of QoL's most popular patient-reported outcome measures (Pappa et al., 2005). It is a self-reported outcome measure assessing the impact of health on an individual's everyday life.

The SF-36v2 Health Survey (Ware et al., 2007) is an updated version of the original SF-36 Health Survey (Ware et al., 1993). It includes 35 items that assess eight dimensions of health-related quality of life (HRQOL). The responses to these eight health domain scales are combined to generate summary measures of a respondent's physical and mental well-being. Additionally, the SF-36v2 features an unscored item that evaluates health status over the past year.

The SF-36v2 uses the same eight domains as the SF-36: 10 items of Physical Functioning (PF),4 items of Role-Physical (RP), 2 items of Bodily Pain (BP),5 Items of General Health (GH), 4 items of Vitality (VT), 2 items of Social Functioning (SF), 3 items of Role-Emotional (RE),5 items of Mental Health (MH)

Two comprehensive Summary Measures, Physical Component Summary (PCS) and Mental Component Summary (MCS) The SF-36v2 scale score ranges from 0 to 100, with higher scores indicating better QoL.

The validity, reliability, and responsiveness of SF 36 V2 have been documented across many groups, including age, gender, socioeconomic position, geographical region, and clinical conditions (Ware et al., 1993)

The researcher was contacted via email and asked for permission to use SF36 v2 by QualityMetric, an IQVIA business, and provided with the PRO CoRE software to enable to entry of data and the software calculates the score for SF36 v2.

SF 36 v2 was translated into Arabic and the validity and reliability of the Arabic SF-36v2 were confirmed by AbiAbat (2020).

3.6.2 Children Sleep Habits Questionnaire (CSHQ)

Sleep disturbance was assessed using the CSHQ (Owens et al., 2000). The CSHQ is a parent-reported outcome measure assessing sleep disturbance in children. It is not meant to be used to diagnose specific sleep disturbance, but rather to identify sleep disturbances.

According to Malow and colleagues (2009), the assessment of the CSHQ is the measure widely used with ASD because is valid and reliable to measure sleep disturbances in children with ASD.

The researcher was contacted via email and asked for permission to use the Arabic version of the Children's Sleep Habits Questionnaire.

The CSHQ scale consists of 33 items divided into eight sub-scales; **6 items for** Bedtime Resistance, 1 item for Sleep Onset Delay, 3 items for Sleep Duration, 4 items for Sleep Anxiety, 3 items for Night Wakings,7 items for Parasomnias,3 items for Sleep Disordered Breathing,8 items for Daytime Sleepiness (Owens et al., 2000). Each item is scored on a 3-point Likert scale, usually, sometimes, and rarely. A score for each subscale can be calculated as well as a total score, and higher scores indicate greater sleep disturbances. Children were further divided into good and poor sleepers based on the cutoff score of 41 (Owens et al., 2000).

Almerdasi and colleagues (2024), this study aimed to Arabize and explore the global construction and verify the psychometric characteristics of the Arabic version of the Child Sleep Habits Questionnaire on a sample of children with autism spectrum in Kuwait. The tool's stability was verified by calculating Cronbach's alpha stability coefficient, which was 0.829 for the tool as a whole, and its degree for the sub-dimensions ranged from 0.663 to 0.797.

3.6.3 The demographic and medical data questionnaire

Demographic data was collected for the children as well as their parents. Parents' age, educational level, whether the participant is the father or the mother, socioeconomic status, and residence.

As for children, information regarding age, gender, living situation, child's sleeping place, and whether the child takes any supplements.

Additional data were collected regarding children with ASD including diagnosis, another diagnosis, degree of autism, siblings with ASD, child going to rehabilitation center, rehabilitation services.

3.6.3.1 Data collection procedure

The researcher contacted the nominated parent. The researcher assessed the eligibility of the potential participants using the inclusion and exclusion criteria. An appointment was set with qualified parents to fill the questionnaires. During the meeting, the researcher explained the objectives of the study and addressed any parental concerns. After informed consent (IRB), the questionnaires were filled by the parents and the researcher was available in case there were any questions. The researcher was careful that answers did not affect the participants' responses. The SF-36v2 was filled there, followed by the CSHQ, and the demographics. Total time was about 40 minutes. Parents took breaks if they wished.

The pilot study

The representatives of pilot study are considered important to enrich the current study on sleep disturbances in autistic children and their relationship to the quality of life of their parents and test the assessments in a pilot study where listening to the participants will help in a greater understanding of the research, whether it needs modifications in the design before starting and that the questions in the assessments are clear and understandable.

In this study, ten parents of children with ASD filled in the assessments in Arabic versions after discussing the research and its objectives to obtain feedback.

Initially, the quality of life assessment with a 15-20 minute filled by SF36 V2, and sleep quality was assessed using CSHQ for a 10-minute, then the demographic information was collected in 5 minutes.

The ten participants were of different ages, educational, and economic statuses, and for child was different ages and all diagnosed with ASD.

No one asked for a break and no one took more than 35 minutes to fill out all the questionnaires. All the questions were clear.

Therefore, no modification was made. The sample was merged with the thesis sample.

3.7 Ethical consideration

The researcher obtained ethical approval (IRB) for the study from the AAUP Deanship of Scientific Research number 2023/A/83/N. Participants' written consent was obtained. The rights of the research participants were protected and they had the right to self-determination, the right to ask questions, participate, the right to refuse to provide information, and also to terminate their participation whenever they wanted without giving any reason. It was assured that Participation in this study is voluntary and does not affect their children's receipt of the service. Anonymity and confidentiality were considered and maintained; the data was used for scientific purposes only. The data is kept in a secure

place to ensure confidentiality. Finally, the nature of the study was fully described to the participants, without holding any information about the study.

3.7.1.1 Data analysis

The researcher used the latest version (26) of the Statistical Package for Social Sciences (SPSS) to analyze the data, to perform the appropriate tests that are appropriate with the study questions and hypotheses. Descriptive statistics, mean and standard deviation used in this study to describe the characteristics of the sample and to summarize all the results obtained. If data is not normally distributed, median and interquartile obtained. Categorical variables given as percentages and frequencies. Continuous variables expressed as the means and standard deviations. A p-value of <.05 considered statistically significant (Greenland et al., 2016). If data is normally distributed use the t-test. If data is not normally distributed use the Mann-Whitney test.

To determine the relationship between two quantitative variables (such as SF-36 v2 subscales and sleep disturbance of children with ASD), the study will be using Pearson's Correlation Coefficient (data parametric test). According to the data, distribution will be using Spearman's correlation coefficient if the data is tested non-parametrically.

Data normality was tested using histograms and QQ plots visually and statistically using Kolmogorov-Smirnov(K-S) test.

Chapter 4 Results

4.1 Recruitment

Participants were recruited between March 2023 and December 2023. This study used a convenience sampling procedure to recruit 186 Palestinian parents of children with ASD and 93 parents of TD children. The groups were matched based on the age and gender of the child. Participation consent was ensured before data collection for all participants' data collection.

4.2 Data completeness and characteristics

The researcher entered all the data into SPSS® 26. The principal investigator completed, checked, and cleaned the data. Using SPSS® 26, the data was analyzed using appropriate reporting and statistical tests to address the research questions. The final data had no missing values.

Data normality was tested using histograms and QQ plots visually and statistically using Kolmogorov-Smirnov(K-S) test. Shows the data set contains outliers. Subsequently, keeping outliers might provide deeper, more complex insights into the underlying characteristics and qualities of the data (Aguinis et al., 2013). Parametric tests, such as Pearson's correlations, were used with normally distributed data, while non-parametric tests, such as Mann-Whitney and Spearman's, were used with non-normally distributed data. Significance was set at <.05 for all analysis. It was found that the data was not normally distributed, and thus non-parametric tests were used.

Table (2)	Children with ASD (n = 93)[27]	TD Children (n = 93)	Group Difference
Caregivers' Characteristics			
Respondent (n, %) Mother Father	 77(82.8) 16(17.2)	 69 (74.2) 24 (25.8)	X^2 (1,186) = 2.038 *p* = .153
Age (n, %) 20 – 29 yrs. 30 – 39 yrs. 40 – 50 yrs. >50 yrs.	 19(20.4) 55(59.1) 18(19.4) 1(1.1)	 21(22.6) 56(60.2) 15(16.1) 1(1.1)	X^2 (3,186) = .382 *p* = .944
Parent education level (n, %) High school or lower Diploma BSc Postgraduate	 41(44.1) 46(49.5) 6(6.5)	 29(31.2) 61(65.6) 3(3.2)	X^2 (2,186) = 5.160 *p* = .076
Area of residence (n, %) Tulkarm Jenin Nablus Ramallah Qalqilya	 37(39.8) 18(19.4) 23(24.7) 11(11.8) 4(4.3)	 69(74.2) 8(8.6) 12(12.9) 2(2.2) 2(2.2)	X^2 (2,186) = 23.861 *p* = <.001
Socioeconomic level (n, %) < 1,500 shekels 1,500 - 4,000 shekels > 4000 shekels	 14(15.1) 55(59.1) 24(25.8)	 12(12.9) 59(63.4) 22(23.7)	X^2 (2.186) = .381 *p* = .826
Other children with sleep disturbance (n, %) Yes No	 19(20.4) 74(79.6)	 18(19.4) 75(80.6)	X^2 (1,186) = 2.756 *p* = .097
Child's Characteristics			
Child age (*Mean, SD*) Range	 7.96 (4.0) 3.11 – 17.43	 8.13 (3.95) 3.02 – 17.47	*t* = -.305 *p* = .761
Child gender (n, %) Male Female	 70(75.3) 23(24.7)	 70(75.3) 23(24.7)	X^2 (1,186) = 0.00 *p* = 1.0
Living situation (n, %) with parents with the others	 84(90.3) 9(9.7)	 84(90.3) 9(9.7)	X^2 (1,186) = 0.00 *p* = 1.0
Child's sleeping place (n, %) Sleeps in same room with parents Sleeps in the same room with siblings	 23(24.7) 61(65.6) 9(9.7)	 18(19.4) 60(64.5) 15(16.1)	X^2 (2,186) = 4.781 *p* = .092

Sleeps in a separate room alone			
Child take any supplements (n, %) Supplements and/or Medicines Nothing	28(30.1) 65(69.9)	9(9.7) 84(90.3)	X^2 (1,186)= 12.180 *p* = <.001
Degree of autism (n, %) Mild Moderate Severe		 35 (37.6%) 47 (50.5%) 11 (11.8%)	
Other diagnosis (n, %) Yes No		 4 (4.3%) 89 (95.7%)	
Siblings with ASD (n, %) Yes No		 10 (10.8%) 83 (89.2%)	
Child goes to rehabilitation center (n, %) Yes No		 85(91.4%) 8(8.6%)	
Rehabilitation and educational centers (n, %) School (Special needs or Regular) Rehabilitation center At home		 55(59.1%) 33(35.5%) 5(5.4%)	
Rehabilitation services (n, %) One rehabilitation Services Multiple rehabilitation services No services		 17(18.3%) 71(76.3%) 5(5.4)	

4.3 Sociodemographic characteristics

The sample's sociodemographic characteristics are presented in Table 2. The groups did not significantly differ from each other in most demographics. Mothers represented the majority of the sample with 77(82.8%) mothers of children with ASD and 69(74.2) mothers

of TD children. More than half of the parents of the children were between 30 – 40 years; 59.1% and 60.2% of parents of children with ASD and of parents of TD children, respectively. In addition, educational and socioeconomic levels were somehow similar.

The children were matched on age and gender with children being around 8 years of age and mostly males (75.3%) in each group. For the ASD group, there were differences in the average degree of autism with 37.6% mild, 50.5% moderate, and 11.8% severe. More than half of the ASD children (59.1%) were enrolled in rehabilitation or educational settings with most of them (76.3%) receiving multiple rehabilitation services.

As the data for the SF-36 v2 and the CSHQ was found to be not normally distributed, a Mann-Whitney U test was performed to evaluate the difference between the QoL of parents of children with ASD compared to parents of TD children as well as the sleep habits of children with ASD compared to TD children.

4.3.1 Quality of Life

Our results revealed significant differences between parents of children with ASD and parents of TD general health ($U = 3173.50$, $p = .001$), vitality ($U = 3099.00$, $p = .001$), social functioning($U = 3286.00$, $p = .004$), role limitation due to emotional functioning ($U = 3068.500$, $p = .001$), mental health ($U = 3234.000$, $p = .003$), and mental component scale ($U = 2884.500$, $p = .001$) with consistently parents of children with ASD scoring lower indicating poorer QoL compared to parents of TD children (Table 3).

Table 3: Mann-Whitney U Tests of differences in Quality of Life between Parents of Children with ASD and Parents of TD Children**.**

Table 3	**Parents of Children with ASD (Mean Ranks)** n = 93	**Parents of TD children (Mean Ranks)** n = 93	**U**	**Z**	***p***
Physical Component Scale	95.05	91.95	4180.500	-.392	.695
Mental Component Scale	78.02	108.98	2884.500	-3.922	**<.001**
Physical Function	89.38	97.62	3941.500	-1.054	.292
Role limitations due to Physical problems	94.27	92.73	4252.500	-.197	.844
Bodily Pain	92.23	94.77	4206.500	-.324	.746
General Health	81.12	105.88	3173.500	-3.142	**<.001**
Vitality	80.32	106.68	3099.000	-3.354	**.001**
Social Functioning	82.33	104.67	3286.000	-2.862	**.004**
Role limitation due to Emotional problems	79.99	107.01	3068.500	-3.444	**.001**
Mental Health	81.77	105.23	3234.000	-2.977	**.003**

4.3.2 Children's sleeping habits

Children with ASD consistently and significantly scored higher on the CSHQ compared to TD children indicating poorer sleep habits on all subscales except for "sleep disordered breathing" and "Daytime sleepiness" (Table 4).

Table 4: Mann-Whitney U Tests of differences in sleep habits between Children with ASD and TD Children.

Table 4	Children with ASD (Mean Ranks) n = 93	TD Children (Mean Ranks) n = 93	U	Z	*p*
Bedtime resistance	110.82	76.18	2713.500	-4.423	**<.001**
Sleep onset delay	107.16	79.84	3054.500	-3.755	**<.001**
Sleep duration	110.55	76.45	2739.000	-4.638	**<.001**
Sleep anxiety	111.04	75.96	2693.000	-4.484	**<.001**
Night awakenings	103.90	83.10	3357.000	-2.700	**.007**
Parasomnias	103.63	83.37	3382.000	-2.659	**.008**
Sleep disordered breathing	96.64	90.36	4032.500	-1.088	.277
Daytime sleepiness	98.22	88.78	3886.000	-1.203	.229
CSHQ Total Score	112.89	74.11	2521.000	-4.916	**<.001**

Children were further divided into good and poor sleepers based on the cutoff score of 41 (Owens et al., 2000). When applying the cutoff score, 77 out of 93 (82.8%) children

with ASD were considered "poor sleepers compared to 54 out of 93 (58.1%) TD children. The difference in the percentage of poor sleepers between children with ASD and TD children was found to be significant ($\chi 2 = 8.932$, $p = 0.003$).

4.4 QoL and good vs. poor sleep habits of children with ASD

To further study the association between QoL and sleep patterns, the QoL of parents of children with ASD was compared between the good and poor sleepers based on the cutoff score of 41 (Owens et al., 2000). With the exception of the physical component scale and physical function subscale, we found significant differences in QoL in all other SF-36 v2 consistently reflecting poorer QoL of parents of ASD children who have poor sleep habits compared to parents of children with ASD who have good sleep habits (Table 5).

Table 5: Mann-Whitney U Tests of differences in Quality of Life between Parents of "good sleepers" Children with ASD and "poor sleepers" children of ASD**.**

Table 5	Parents of good sleepers Children with ASD (Mean Ranks) n = 55	Parents of poor sleepers Children with ASD (Mean Ranks) n = 131	U	Z	*p*
Physical component scale	57.00	44.92	456.000	-1.629	.103
Mental component scale	62.81	43.71	363.000	-2.575	**.010**
Physical function	50.41	46.29	561.500	-.559	.576

Role limitations due to Physical problems	65.56	43.14	319.000	-3.040	**.002**
Bodily Pain	61.03	44.08	391.500	-2.298	**.022**
General Health	62.81	43.71	363.000	-2.580	**.010**
Vitality	60.09	44.28	406.500	-2.143	**.032**
Social Functioning	58.84	44.54	426.500	-1.951	**.051**
Role limitation due to Emotional problems	64.72	43.32	332.500	-2.907	**.004**
Mental Health	63.47	43.58	352.500	-2.691	**.007**

4.4.1 The relationship between QoL and selected demographics

To further examine the QoL of parents of children with ASD (n = 93), several associations were investigated between the Physical Component Scale and Mental Component Scale with selected demographics (Table 6)

Table 6	Physical Component Scale	*p*	Mental component Scale	*p*
CSHQ total score	-.214	**.040**	-.166	0.112
Child gender	.005	.965	-.049	0.643
Child's sleeping place	.010	.922	.233	**0.024**
Participant age	.164	.115	-.049	0.639
Salary	.123	.242	.023	0.829
Degree of ASD	-.090	.391	-.250	**0.016**
More than one autistic child	-.092	.381	-.028	0.787
Child go to rehabilitation centre	.071	.496	-.097	0.354
Parent education level	.250	**.015**	.073	0.484

or the physical component scale, there were only two significant correlations; a weak correlation with the parent level of education (r_s = -.214, p = .04), and a very weak correlation with the CSHQ total score (r_s = .250, p = .015). The same was found for the mental component scale; a very weak correlation with the child's sleeping place (r_s = .233, p = 0.024), and a weak correlation with the degree of ASD (r_s = -.250, p = 0.016).

To further explore these correlations, we have investigated the differences in the physical component scale among different parent educational levels, and the differences in the mental component scale between the levels of the degree of ASD, and the child's sleeping place. Parents who had a Diploma or BSc. Showed higher QoL compared to other parents (Table 7).

Parent education level	Physical Component Scale(n)		
	N	M	SD
High school or lower	41	49.14	8.57
Diploma/BSc	46	54.06	7.06
Post-graduate	6	50.82	7.71

As for the mental component scale, our results show that parents who have their children sleeping in the same room have poorer QoL compared to other parents. In addition, we found that with increasing degree of ASD, parent's QoL tends to be lower (Table 8)

	Mental component Scale		
	n	M	SD
Child's Sleeping Place			

Sleeps with parents	23	31.016	10.43
Sleep with sibling	61	33.65	11.41
Sleeps in a separate room alone	9	41.76	6.2
Degree of autism			
Mild	35	37.86	11.58
Moderate	47	31.5	10.41
Severe	11	30.6	8.81

Table 9: Comparison of sleep hours between children with ASD and TD.

Table 9	Children with ASD (mean, SD)	Typically developing children (mean, SD)	t(df)	P value
The number of minutes of nocturnal awakening	16.76(21.35) Minimum 0 Maximum 90	5.41(8.27) Minimum 0 Maximum 60	4.78(119)	> .001
The amount of sleep the child	Minimum 3 Maximum 14	Minimum 5 Maximum 13		
How much a child sleeps with a nap	9.49(1.51) Minimum 3 Maximum 14	9.23(1.58) Minimum 5 Maximum 13	1.11(184)	.268

Chapter 5 Discussion and Conclusion

5.1 Discussion

This cross-sectional study aimed to investigate the QoL of Palestinian parents of children with ASD and compare it to the QoL of Palestinian parents of TD children as well as investigate the sleep habits of Palestinian children with ASD compared to Palestinian TD children, and investigate if there is any relationship between sleep habits of children and their parents' QoL. To our knowledge, there have been no prior studies addressing QoL and sleep patterns for children with ASD in Palestine.

5.1.1 Quality of Life of Palestinian Parents of Children with ASD

Our findings were consistent with previous findings regarding parents of children with ASD QoL. In a recent integrative systematic review, Turnage and Conner (2022) found that parents of children with ASD had a poorer quality of life in social, physical health, and psychological health compared to adults who don't have children with ASD.

Specifically to the Arab world we compared our results with three other studies that have investigated the QoL of parents of children with ASD and compared it to the QoL of parents of TD children in Saudi Arabia (Al-Jabri et al., 2022), Egypt (Ezzat, 2017), and Qatar (Kheir et al., 2012). We opted to compare our results to the studies in the Arab region as we share a very close geographical area and comparable cultures. Our results were highly similar, with slight variations in some subscales. This reiterates that the QoL of Palestinian

parents of children with ASD is not different from other parents in the area and is poorer compared to parents who have TD children.

Not to our expectations, all items related to physical health were not significantly different between parents of children with ASD and parents of TD children. This might indicate that the emotional and mental burden of having a child with ASD is more prominent and has more impact on the parents. This might be because Palestine is under occupation, and Palestinians are already under high-stress levels, so their mental health is already compromised making them more susceptible to the risks of developing mental health issues. It can also be directly related to the considerable obstacles faced by parents of children with ASD related to resources, lengthy diagnostic processes, stigma for families, limited direction from health professionals, and low knowledge of ASD (Reddy et al., 2019).

The results regarding parental QoL highlight adopting of a holistic approach that includes components that enhance parents' function, expand support systems, and aid families in building effective coping abilities(Khanna et al., 2011). For occupational therapists, it is important to stress that in addition to providing care to a child, it is necessary to support the role of parents, provide social and health support, and family support groups, and understand their needs, which improves their quality of life. Studies indicate that family support groups have a role and benefits in caring for a child with ASD (Mandell et al., 2006). Thus, understanding parental QOL can help occupational therapists provide better outcomes for both parents and children, with careful attention to mental and psychological assessment and support early in the rehabilitation process.

5.1.2 Children with ASD Sleep Habits.

In the current study, utilizing CHSQ, children with ASD consistently and significantly scored higher on the CSHQ compared to TD children indicating poorer sleep habits on all subscales except for “sleep-disordered breathing” and “Daytime sleepiness”. This is consistent with previous studies that have found that sleep issues are prevalent in children with ASD (Usman Baig et al., 2020; Reynolds & Malow, 2011; Liu et al., 2006) and more prominent compared to TD children (Liu et al., 2020; Al-Farsi et al., 2018; Souders et al., 2017; Khanna et al., 2011).

5.1.3 Parental QoL and Sleep Habits of Children with ASD

In our attempt to better study the relationship between parental QoL and sleep habits of children with ASD, we compared the QoL between parents of “good” and “poor” sleepers. With the exception of the physical component scale and physical function subscale, we found significant differences in QoL in all other SF-36 v2 consistently reflecting poorer QoL of parents of children with ASD who have poor sleep habits compared to parents of children with ASD who have good sleep habits, further reflecting on the relationship between sleep and QoL.

Using the cut-off score, the prevalence of “poor” sleepers in our sample of children with ASD was high (82.8%) and almost similar to what was observed in the Arab world specifically in Oman(87.4%; Al-Farsi et al., 2018), and internationally observed by others poor sleep affect up to 80% of ASD children (Cohen et al., 2014; Johnson et al., 2018;

Sultana et al., 2021). One study reported a lower prevalence of 46%, However, this study only included preschool children (Distefano et al., 2023).

Recognizing poor sleeping behaviors in children is critical for planning quick prevention and intervention. When sleep disturbances are recognized early and properly managed it results in enhanced QOL for both children with ASD and their parents (Inthikoot & Chonchaiya, 2021). Parents of children with ASD and sleep disturbances have poor parental sleep quality (Lollies et al., 2022). Poor quality of sleep for parents with ASD affects parent QoL, The study that assessed quality of sleep demonstrated that poor sleep quality is related to a reduced QoL (Lee et al., 2021).

Children with sleep issues display more challenging behaviors than those without sleep disturbances. Research indicates that children with ASD with sleep disturbances exhibit more stereotypical and aggressive behaviors, emotional issues, anxiety, social difficulties and impaired social and academic performance (Reynolds & Malow, 2011; Sikora et al., 2012; Mutluer et al., 2015; Galli et al., 2022).

Sleep issues were found to be associated with co-sleeping, hypersensitivity, and bedtime practices (Liu et al., 2006). Mazurek and Petroski (2015) investigated whether sensory issues could increase sleep disturbances in children with ASD. They found that existing sensory processing issues had a significant connection to sleep (Mazurek & Petroski, 2015). We have not investigated the sensory processing of our sample of children with ASD in our study. Thus, we encourage further research to be done to explore them in

relation to sleep and also for Palestinian occupational therapists to assess sensory processing along with sleep.

Distefano et al., (2023) suggested that screening for sleep disturbances, followed by early management, should be a standard element of therapeutic practice for children with ASD. The search for effective mechanisms to reduce sleep issues has the potential to reverse the negative impact of insufficient sleep on cognition, emotions, and behavior, also affecting QoL for children and their caregivers (Bourke-Taylor et al., 2013).

Occupational therapists are encouraged to include sleep assessments in their evaluations and plan interventions that include sleep education for parents and behavioral interventions tailored to the child's and parents' needs. Environmental modifications and changes in routine can also be included in the intervention plan aimed at enhancing sleep participation in children. By integrating sleep assessments and personalized interventions, occupational therapists significantly contribute to enhancing sleep participation in children. Their holistic approach addresses the multifaceted nature of sleep issues, involving the child, family, and environment to foster healthier sleep habits and improved quality of life.

5.1.4 Other Factors Related to QoL

Although previous studies have found that better QoL was associated with higher educational levels (Fávero-Nunes and Santos ,2010 ; Turnage & Conner ,2022), our study found that parents with bachelor's or a diploma had the best QoL. This could be due to the small number of parents in our study who had postgraduate degrees or it could be related to geographical-cultural factors related to job affordances and job satisfaction.

As for the child's sleeping location, our results show that parents with their children sleeping in the same room had poorer QoL than other parents. A study that looked at the sleep of children who slept in the parents' room and in a separate room found that sleeping in a separate room improves the quality of sleep for both the child and his parents, as the parents are less likely to wake up at night and sleep longer.(Mindell et al., 2017).This, in turn, improves the quality of life of parents (Lee et al., 2021). It seems that sleep location is also related to parents' QoL. Further research is needed to understand other factors such as child age and parents' sleeping habits.

The severity of ASD symptoms has been associated with poor QoL in our sample, similar to what is reported in previous studies (Cappe et al., 2017; Alhazmi et al., 2018; Turnage & Conner,2022). This significant, however, weak relationship was evidenced only in the mental health component. Previous studies have also found that parents of children with ASD had higher stress levels compared to parents of TD children(Lyons et al., 2009) and parents of children with other disabilities (Zablotsky et al., 2012) with the level of stress being higher as the ASD symptoms are more severe (Hutchison et al., 2016).

5.2 Conclusion

This study addresses how caring for an ASD child affects a parent's life and examines how sleep disturbances in children with or without ASD affect parental quality of life.

The main findings of our study revealed significant differences in QOL between parents of children with ASD and parents of TD; sleep disturbances are more common in children with ASD than in TD children, and sleep disturbances in children with ASD affect parental QOL.

This study demonstrates that enhancing children's sleep quality can also improve parental quality of life, building on prior findings. However, more specific investigations are still needed to discover and study the explanation for sleep disturbance in children with ASD.

Attention is needed to prioritize the QOL for parent children with ASD and assess the sleep disturbance in children with ASD; engaging in occupational therapy intervention for sleep disturbance is important for the treatment plan for ASD.

These findings could assist Palestinian health policymakers in providing better and more targeted support to ASD children and their parents.

5.3 Limitations

Our study's major limitations include using mainly subjective tools such as parent-completed CSHQ questionnaires. Such an instrument is certain to be influenced by the parents' own perceptions of the situation. Future research employing objective metrics such

as polysomnography-EEG and actigraphs will be required. In addition, due to multiple integrated factors, the causality between sleep and QoL cannot be determined. With a bigger sample, more in-depth and sophisticated analyses could be conducted to describe the effect of sleep on QoL better. Generalization of our results may be restricted due to a lack of representation from the South of Palestine. need a bigger sample size and more graphical representation and this proplity may help the reality in statistical analysis.

5.4 Clinical implications of this study

Impact on Parent Mental Health

i. Stress and Sleep Deprivation: Parents of children with ASD who witness severe sleep disruptions in their kids frequently suffer from sleep deprivation themselves. Parents who have chronic sleep deprivation are more likely to experience stress, worry, and sadness. Therefore, resolving the child's sleep disturbances may directly improve the mental health of the parents.

ii. Interaction between Parent and Child: In addition to causing irritation, heightened emotional dysregulation, or behavioral problems, poor sleep in children with ASD may also make it more difficult for parents to communicate positively with their children.

Improved Caregiving Ability:Better sleep in children with ASD might improve parental capacity to engage in caregiving.

Support for Clinical Interventions: Sleep Intervention Programs.

Guidance on Family-Centered Care.

These researches have the potential to influence legislative changes and motivate healthcare systems to incorporate sleep management as a vital component of autism treatment. Funding for counseling services, parent support groups, or respite care, for instance, should be allocated to better assist families dealing with these difficulties.

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Appendix (1)

Arab American University- Palestine
Deanship of Scientific Research
IRB committee
Tel: 04-241-8888, ext 1196
E-mail: irb.aaup@aaup.edu

الجامعة العربية الامريكية- فلسطين
عمادة البحث العلمي
لجنة أخلاقيات البحث العلمي
تلفون: 04-241-8888 ext 1196
البريد الالكتروني: irb.aaup@aaup.edu

IRB Approval Letter

Study Title: Sleep disturbance and their impact on parents of ASD children

Submitted by: Ghena Hammad Saeed Ziad

Date received: 14th April 2023

Date reviewed: 12th May 2023

Date approved: 12th May 2023

Your Study titled **"Sleep disturbance and their impact on parents of ASD children"** With archived number 2023/A/83/N was reviewed by the Arab American University IRB committee and was approved on 12th May 2023.

Reham Khalaf-Nazzal, MD, PhD
IRB committee chairman
Arab American University of Palestine

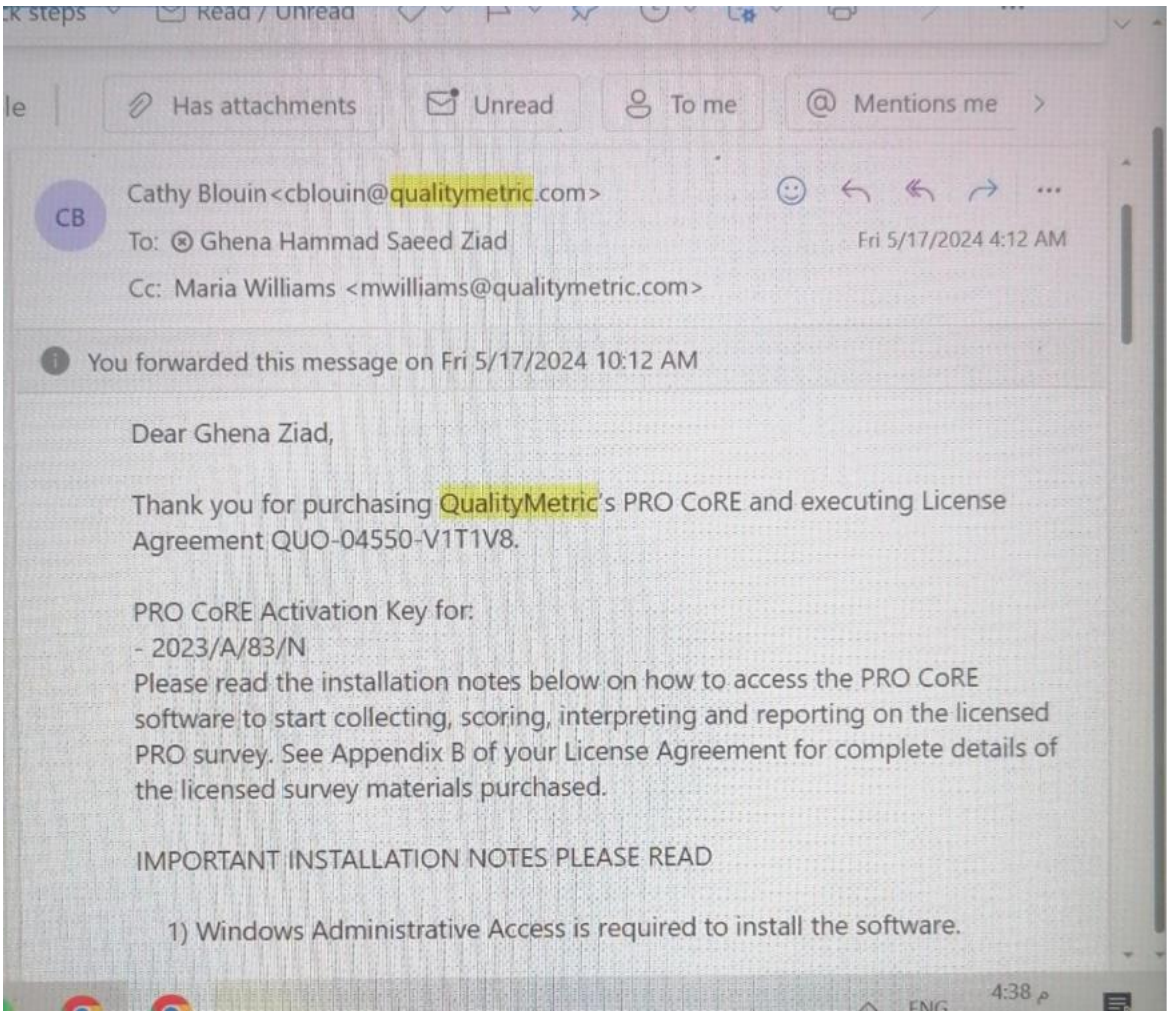
General Conditions:

1. Valid for 4 months from date of approval.
2. It is important to inform the committee with any modification of the approved study protocol.
3. The committee appreciates a copy of the research when accomplished.

لجنة أخلاقيات البحث العلمي في الجامعة العربية الامريكية

IRB at Arab American University

Appendix (2)



Has attachments | Unread | To me | Mentions me

CB

Cathy Blouin<cblouin@qualitymetric.com>

To: Ghena Hammad Saeed Ziad

Fri 5/17/2024 4:12 AM

Cc: Maria Williams <mwilliams@qualitymetric.com>

You forwarded this message on Fri 5/17/2024 10:12 AM

Dear Ghena Ziad,

Thank you for purchasing QualityMetric's PRO CoRE and executing License Agreement QUO-04550-V1T1V8.

PRO CoRE Activation Key for:
- 2023/A/83/N
Please read the installation notes below on how to access the PRO CoRE software to start collecting, scoring, interpreting and reporting on the licensed PRO survey. See Appendix B of your License Agreement for complete details of the licensed survey materials purchased.

IMPORTANT INSTALLATION NOTES PLEASE READ

1) Windows Administrative Access is required to install the software.

الملخص

الخلفية: تشير الدراسات المتوفرة إلى أن نسبة كبيرة من الأطفال المصابين باضطراب طيف التوحد يعانون من اضطراب طبي أو سلوكي إضافي واحد على الأقل، ويُعد اضطراب النوم أحد أكثر الاضطرابات المصاحبة شيوعًا. قد تؤثر اضطرابات النوم لدى الأطفال المصابين باضطراب طيف التوحد على جودة حياة الوالدين.

الأهداف: تهدف الدراسة إلى دراسة العلاقة بين اضطراب النوم وجودة حياة الوالدين لدى الأطفال المصابين باضطراب طيف التوحد من فلسطين.

الهدف: دراسة العلاقة بين اضطراب النوم لدى أطفال اضطراب طيف التوحد وجودة حياة الوالدين، واستكشاف اضطرابات النوم لدى أطفال اضطراب طيف التوحد من فلسطين والإبلاغ عنها.

المنهجية: استخدمت هذه الدراسة تصميمًا كميًا مقطعيًا من خلال البيانات الديموغرافية وتقييمين، النسخة العربية من SF-36 v2 والنسخة العربية من استبيان عادات نوم الأطفال (CSHQ) ، واثنان من التقييمات صالحة وموثوقة. باستخدام أسلوب الملاءمة كأسلوب أخذ عينات، شملت العينة 98 من آباء وأمهات أطفال مصابين باضطراب طيف التوحد، ناطقين باللغة العربية كلغة أم، و98 من آباء وأمهات أطفال مصابين باضطراب طيف التوحد. أُجريت الدراسة في شمال ووسط فلسطين.

النتيجة: كشفت النتائج الرئيسية لدراستنا عن فروق جوهرية في جودة حياة آباء وأمهات أطفال مصابين باضطراب طيف التوحد، حيث تُعدّ اضطرابات النوم أكثر شيوعًا لدى الأطفال المصابين

باضطراب طيف التوحد مقارنةً بالأطفال المصابين باضطراب طيف التوحد، كما تؤثر اضطرابات النوم لدى الأطفال المصابين باضطراب طيف التوحد على جودة حياة آبائهم.