



QUALITY OF LIFE, SLEEP QUALITY AND SELF ESTEEM IN PARENTS OF CHILDREN DIAGNOSED AS AUTISM SPECTRUM DISORDER: INDIAN PERSPECTIVE

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ABSTRACT

It has been found that parents of children with Autism Spectrum Disorder (ASD) have greater levels of stress and lower physical health than parents of typically developing children. However, most of the research in this area has relied on parents' assessments of their levels of stress and health. There is a lack of consensus on the physiological impacts, if any, of stress associated with parenting a child with ASD, despite the expansion of research on physiologic outcomes in recent years. Despite the widespread belief that children on the autism spectrum have a more challenging time falling or staying asleep than their typically developing peers, research on the link between sleep disturbance and HRQoL in this young group is lacking. Furthermore, the HRQoL of children with ASD is little known. Sleep problems affect more than 40% of autistic children, and impairments in social interaction are central to autism. It is yet unclear how sleep quality affects social functioning and behaviour, however. In this meta-analysis, we looked at how good sleep affects social functioning and behavioural issues in children and adolescents with autism.

Keywords: autism; quality of life; public mental health; gender, night waking, insomnia, behaviour, anxiety, bedtime resistance

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I. INTRODUCTION

It has been suggested [1, 2] that parenting challenges are amplified for parents of children with special needs. Parents of children with ASD have much higher levels of parental stress than parents of typically developing children and children with other disabilities, according to previous research. "Parents of children with ASD report worse health and more diseases than parents of typically developing children

(e.g., [3]) and children with various impairments [2], which is not surprising given the known negative consequences of persistent stress on both physical and mental health." However, most studies on stress and health in parents of children with ASD have relied on parental self-reports of stress, which are prone to bias [4] and provide little information on underlying mechanisms of action.



Only lately has science begun to investigate the physiological effects of stress on caring for a kid with autism spectrum disorder (e.g., [5]). Salivary biomarkers have been one of the primary areas of study. In particular, salivary cortisol has been used to evaluate HPA axis activity, and salivary alpha-amylase (sAA) has been used to measure sympathetic nervous system (SNS) activity (e.g., [6]). There is evidence that health problems are linked to the dysregulation of these systems (e.g., [7]).

To quantify an individual's total functioning and well-being, researchers have developed a method called health-related quality of life (HRQoL). "Health-related quality-of-life (HRQoL) assessment stands out from other approaches to measuring health because it is multi-dimensional and focuses on capturing subjective experiences of health, placing more weight on an individual's own assessment of his or her own well-being than on objective measures." Standardized HRQoL tests cover the bases by gauging a person's physical, mental, emotional, and social well-being. However, many instruments assess extra, finer-grained dimensions of happiness, such as family harmony and a sense of self-worth. In addition to gauging the general population's health, HRQoL measures are often used to examine the effects of a disease and its treatment on persons with chronic diseases.

All available HRQoL tools are questionnaires, either general or condition-specific. While HRQoL exams measure well-being across various health states, condition-specific surveys are meant to evaluate health and functioning among persons with a specific disease or illness. In this way, generic evaluations make it possible to compare healthy normative groups and populations with chronic diseases side-by-side. HRQoL is often used to evaluate outcomes among children with chronic medical illnesses. It has received much attention recently as an essential outcome to measure in evaluating pediatric therapies and clinical trials. Conditions like ASD, which have far-reaching and complex effects on people's lives, lend themselves exceptionally well to HRQoL evaluations because of the breadth and depth of HRQoL assessment (ASD).

The autism spectrum disorders (ASD) recognized by the American Psychiatric Association are characterized by deficits in social and communication

skills and confined, repetitive, and ritualistic patterns of behaviour, interests, or activities (2013). ASD is predicted to affect 2% of the U.S. population and 1.7% of the U.K. population [8]. The increased incidence of ASD emphasizes the need to detect the disorder in young children and provide individualized treatments to improve their outcomes.

A. Autism spectrum disorder

Autistic spectrum disorder (ASD) is a developmental illness marked by poor social communication and restricted, repetitive behavioural patterns [9]. Findings from this study indicate that the intensity of these behaviours is a good predictor of the severity of autism. Many people now refer to ASD instead of high-functioning autism since that term has been widely acknowledged to be inaccurate. Comorbid illnesses, such as anxiety, attention deficit hyperactivity disorder (ADHD), comorbid physical problems, and behavioural challenges, are common among people with ASD.

According to a meta-analysis conducted on adults with ASD by Zimmerman, O'Nsworth, O'Donovan, Roberts, and Gullo [10], the severity of ASD symptoms is correlated with a wide variety of adverse outcomes, such as low mood, social isolation, stress, low self-esteem, low marital satisfaction, and even thoughts of suicide. "However, other studies showed that people with ASD, who were thought to have poor adult outcomes as children owing to their delayed intellectual or language development, actually went on to enjoy satisfying lives [11]." Because there is such a wide variety of potential long-term outcomes for persons with ASD, it is necessary to analyze outcomes more comprehensively, including subjective factors like quality of life (QoL; [12]), and to find predictors that may be improved by the therapeutic intervention [13]. Even though the quality of life is a multifaceted outcome measure, many outcome studies have solely focused on a single dimension [12].

B. Quality of life in ASD

QoL scores are a comprehensive indicator of a person's health and happiness [14], measuring not only their body but also their mental and social well-being, as well as the quality of their relationships and outlook on life. Over time, the Quality of Life idea has been extended to include those with intellectual impairments (I.D.; [15]). While the quality of life in



individuals with autism spectrum disorder (ASD) has been studied, there are just a few examples.

Rent and Roeyers [12] discovered a connection between the quality of life. They perceived social support among persons with ASD but no connection between the severity of autism and quality of life. Jennes-Coussens, Magill-Evans, and Koning [16] looked at the quality of life of adult men with ASD and found that they had worse evaluations of their social and physical health than controls. Adults and adolescents with ASD were shown to have worse physical, psychological, and social health compared to typically developing controls by Kamp-Becker, Schroder, Remschmidt, and Bachmann [17]. "Both Renty and Roeyers [12] and the current study conclude that there is no correlation between autism severity and quality of life." Kamio et al. [18] investigated the quality of life and its antecedents among Japanese persons with an autism spectrum disorder. Findings have indicated that adults with ASD had worse assessments of their quality of life in psychosocial and social health domains than the general adult population, which is consistent with the previous studies. Having an early diagnosis of ASD, having supportive parents, and not having any other mental health issues were also associated with a better quality of life. Those who exhibited aggressive and mentally disordered behaviours had a worse quality of life.

Khanna et al. [19] examined health-related quality of life (HRQoL) and associated features in individuals with autism spectrum disorder (ASD). HRQoL describes how you feel about your health and about things you can do anything about. For their study, Khanna et al. [19] analyzed people with ASD to see whether there was a correlation between HRQoL, coping and perceived social support (family, friends, and significant other). People with ASD had a worse physical and mental quality of life than the general population, indicating lower human resource quality. "Khanna et al. [19] Poor social support from friends, maladaptive coping, low insurance status, not living in a support group, and the existence of concomitant physical disease all had detrimental effects on quality of life." Increased social support and advancing years both have beneficial effects on quality of life, as shown by research by Khanna et al. [19]. Overall, QoL was higher in those with lower autism severity, while

mental QoL declined with increasing autism severity. According to Khanna et al.[19].

C. Psychological disorders

The ASD community has a much higher than average prevalence of mental health problems [20], including depressive and anxious disorders. Among people with ASD, AS, or PDD-NOS who were of average intelligence, 53% were diagnosed with a mood illness and 50% were diagnosed with an anxiety condition, according to research by Hofvander et al. [21]. Seventy percent of persons with ASD in Swedish research had at least one significant episode of depression, fifty percent had recurring depressive episodes, and fifty percent had an anxiety condition. It seems that adult individuals with ASD have an effective rate of comorbid diagnoses of AD/HD. Forty-three percent of people with ASD and average I.Q. also met the criteria for an attention deficit hyperactivity disorder diagnosis, according to research by Hofvander et al. [21]. A mixed AD/HD subtype was detected in 44% of the adolescents in the ASD group.

D. Sleep problems

Physical comorbid illnesses, such as sleep problems and gastrointestinal difficulties, also appear often in the ASD population. Studies show that people with ASD often struggle with insomnia. "The inability to get a good night's sleep is a well-documented symptom of autism spectrum disorder (ASD) that persists into adulthood." People with ASD are at increased risk for insomnia and other sleep disorders. Prior studies have shown that people with ASD tend to have sleep interruptions, later onset latencies, and less adequate sleep.

Multiple recent studies have shown that patients with ASD have disturbingly high rates of sleep disruptions. Rzepecki et al. [22] found that 77.2% of autistic youngsters reported difficulty sleeping. Consistent with these findings, Mannion et al. [23] found that 80.9% of children with ASD had trouble sleeping. "Only 33 per cent of the population surveyed by Goldman et al [24] were considered poor sleepers. Park et al. found that 47 percent of children with ASD had at least one sleep problem [25]."

II. REVIEW OF LITERATURE

About 1 in 68 children is affected by autism, a neurodevelopmental condition [26]. Repetitive behaviours, limited interests, issues with emotion and social contact, and so on are the hallmarks of autism.



The capacity to "navigate the social environment" and "establish and sustain connections including home, school, and job," respectively, is what is meant by "social functioning" (p2). Autistic children may have difficulty fitting in with their peers, maintaining positive relationships with adults, and participating in group activities. [27] In many aspects, autistic children's social skills are different from those of typically developing (N.T.) youngsters. People may be less able to perceive emotions, comprehend oral and visual signals, and mimic behaviour based on social cues. They may be less likely to direct their attention toward social stimuli [28] or to begin and share attention cooperatively with others people. In addition, autistic children absorb facial information

differently, placing more importance on features and the lips than the eyes. [29] Motive, perspective, anxiety, social skills, and emotional difficulties affect social functioning.

Sleep disorders, or dyssomnias, usually affect a person's ability to fall asleep, remain asleep, or wake up. [30] "Also included are parasomnias caused by physiological events or actions that disrupt sleep, such as arousal and partial arousal disorders and sleep disruptions during REM and NREM sleep." Bedtime resistance, sleep start delay, sleep length, sleep anxiety, nighttime awakening, parasomnias, snoring, and daytime drowsiness are all examples of operationalizations that have been used to study children's sleep difficulties [31].

Study ID	Aims	ASD Diagnosis	Measures	Critical Results for ASD Participants
Abel et al (2018) [32] USA	We looked at variations in sleep and problematic behaviours on a nightly and weekly basis.	S.Q.	Clinicians' observations of problematic conduct throughout the day, sleep logs, and an activity tracker.	WASO was linked to negative emotions (p 0.001), whereas TST was not. A negative influence is added for every hour of sleep lost throughout the night (p 0.001).
Chong et al (2021) [33] USA	We recorded EDA throughout the day to investigate its possible links to sleep disruption and insufficiency.	SCQ, with a (>11) cut-off point	VABS-II, Actigraphy, Sleep diaries.	The DysS group was older (M = 22.5, SD = 6.35) and had lower Social communication scores (M = 17.6, SD = 4.28) than the RegS group (M = 22.5, SD = 4.28). The sample size is too small to draw any firm conclusions.
Gunes et al. (2019) [34] Turkey	looked at the connection between sleep problems and autism spectrum disorder symptoms.	DSM V, CARS & dev. histories	It is on ABC, ABC-C, and CARS/CSHQ. Preschoolers take the Denver II. Comprehensive WISC-R administration to kids older than 6.	Overall CARS scores were associated with Bedtimeresistance (r = 0.19, p = 0.048) and nocturnal wakings (r = 0.20, p = 0.045). Bets on a correlation between two variables show little to no value. Total CSHQ, ABC, and AbBC ratings. Children with CSHQ scores greater than 56 showed a statistically significant increase in inattention (t(110) = 1.98,= p = 0.045).



Study ID	Aims	ASD Diagnosis	Measures	Critical Results for ASD Participants
Johnson et al. (2018). [35] USA	The effect of P.S. on children's daily behaviour issues and parents' stress was evaluated.	DSM IV, ADOS, ADI-R	ABC, CSHQ, PSI.	Higher levels of irritation ($t(2.85)$, $p = 0.005$) and hyperactivity/noncompliance ($t(3.11)$, $p = 0.002$) were seen among poor sleepers compared to excellent sleepers.
Kang et al (2020) [36] China	studied the connection between insomnia and emotional/behavioural issues and compulsions	DSM V & CARS.	SDQ, CSHQ, PPVT-C (completed by N=114 children, parents completed RBQ-2).	There are statistically significant links ($p < 0.001$) between SDQ, CSHQ, and late sleep start. The overall SDQ score was most well explained later (adjusted $R^2 = 0.173$), which accounted for 17.3% of the total variance—betting on a somewhat significant association ($p < 0.01$)—anxiety at night and the SDQ.
Kelmanson et al (2020). [37] Russia	Analyzed the relationship between insomnia and emotional/behavioural issues	No Details provided	CBCL, CSHQ.	Sleep disruption predicted the likelihood of anxiety and affective issues, although emotional and behavioural disorders were poor predictors of either.
Kirkpatrick et al (2019). [38] Ireland	We used a qualitative method to understand how parents think about sleeplessness.	Parent-reported	CSHQ, Focus groups (n=2)	Children's sleep anxiety causes them trouble getting to sleep, waking up throughout the night, and acting out while sleeping (86%). Sleep deprivation was linked to fewer social connections throughout the day (60 per cent), more aggressive behaviour (26 percent), and fewer academic chances (87 percent).
MacDuffie et al. (2020). [39] USA	Sleep characteristics and their correlations with brain development in at-risk, low-risk, and ASD-free children.	ADOS	ADOS, IBQ-R, VABS.	The intensity of social and emotional symptoms was not correlated with sleep issues ($r = 0.26$, $p = 0.15$). Repetitive behaviour increased with time for kids



Study ID	Aims	ASD Diagnosis	Measures	Critical Results for ASD Participants
				who had trouble sleeping (2(1) = 5.59, p = 0.02).
Malhi et al (2019) [40] India	Analyzed whether or if kids with ASD also had problems concentrating during the day, a sign of sleep disruptions.	DSM V	D.P. 3, CSHQ.	Daytime behaviour problems correlate significantly with sleep disturbance (r = 0.53; p 0.01).
Manelis-Baram et al (2021) [41] Israel	We looked at the wagger's longitudinal implications—sleep problems and hypersensitivity to stimuli.	ADOS-2	ADOS-2, CSHQ, SP	It was shown that changes in sleep disruptions over time were strongly connected with changes in sensory sensitivity (r = 0.42, p 0.001) but not with changes in ASD severity (r (57) = 0.04, p = 0.75).
Mazurek et al (2019) [42] USA	We looked at how long sleep issues last and how they are connected to other symptoms.	DSM IV & ADOS	CBCL, CSHQ.	“Aggression (r = 0.431), anxiety (r = 0.582), somatic symptoms (r = 0.435), and Sensory over-responsivity (r = 0.602) were all strongly connected with sleep issues (p 0.01).”
McLay et al. (2021) [43] New Zealand, USA	Functional Behavioral Sleep Interventions for Autism Spectrum Disorder: Effects on Severity, Behavior, Parental Relationships, and Sleep Quality, as well as Depression, Anxiety, and Stress.	Psychologists, psychiatrists, or paediatricians verified it.	CBCL, GARS. VABS-II PSQI.	“Effect size for improved social interaction after sleep intervention is moderate (E.S. = 0.51; PSES = 74%). Emotional reaction (ES = 0.35; PSES = 61%) and interpersonal communication (ES = 0.25; PSES = 66%) both had small effects. Changes in both internal and exterior behaviors (PSES = 73% and 69%, respectively).”
Naito et al. (2019) [44] Japan	looked at the correlation between nighttime body activity and sociability.	DSM V, ADOS	SRS, Vineland-11 MBS, Accelerometer.	There was a negative correlation between increased body movement during the first hour following the commencement of stillness and both social competence and maladaptive behaviour (r = 0.507, p = 0.036; r = 0.529,

Study ID	Aims	ASD Diagnosis	Measures	Critical Results for ASD Participants
				p = 0.028).
Ng et al (2020) [45] USA	Associations between sleep disruptions and conduct/anxiety disorders, attention deficit hyperactivity disorder and social impairment were evaluated.	DSM V, ADOS-2	CBCL, PSQ. Psychiatric, Neuropsychological, Speech and Language evaluations.	Sleep difficulties were associated with externalizing issues among those with ASD and ADHD (r = 0.39, p = 0.003). The ASD group did not show any correlations between behavioural scores and sleep (rs 0.36, ps > 0.061). Variations in externalizing difficulties (17%), hyperactivity/impulsivity (16%), and attention (15%) were partially explained by sleep characteristics.
Papadopoulos et al (2019) [46] Australia UK	Short-term behavioural sleep intervention program effectiveness assessed.	It is diagnosed by questioning parents.	Parent & teacher reported SDQ, CSHQ, PedsQL, DASS, and Sleep diary.	There was a strong correlation between challenging daytime behaviour and sleep issues (r = 0.42, p 0.01), night waking (r = 0.49, p 0.01), and poor sleep quality (r = 0.45, p 0.01).
Saré & Smith (2020). [47] USA	Whether or whether autistic behaviour is linked to sleep disturbances were investigated.	S.Q.	Q.	There is a statistically significant correlation (p 0.001) between repeated actions and insomnia. Association is somewhat greater in females than in men.
Schroder et al. (2019). [48] France, USA, Netherlands, UK, Israel	Results of a study evaluating the efficacy of melatonin for treating sleeplessness in children with autism spectrum disorder were analyzed.	DSM IV/V	SDQ, Sleep diaries.	Forty-one per cent of kids had an improvement in their sleep quality after 13 weeks of therapy, and the mean SDQ features for behavioural problems all improved (p = 0.077). There was a statistically significant increase in externalizing behaviour (p = 0.021) but not internalizing behaviour (p = 0.770).
Yang et al (2018)	We examined	DSM IV, ADI-	ABC, VABS, PDDSQ,	SRS overall scores, social



Study ID	Aims	ASD Diagnosis	Measures	Critical Results for ASD Participants
[49] China	association. Bet. Gastrointestinal, sleep problems and behaviour and risk factors.	R, ADOS	SRS, CSHQ, VABS, PPVT, CARS, CABS	cognition item scores, and social communication item scores were all substantially different between children with and without sleep difficulties (p 0.004).
Yavuz-Kodat et al (2020) [50] France	Analyzed the role of sleep and the circadian rest-activity cycle in inappropriate actions.	ADOS, ADI-R		

III. CONCLUSION

In order to better understand the connection between sleep, social functioning, and behavioural issues, this review analyzed relevant research. According to the research, poor sleep quality has been linked to difficulties in social functioning and conduct. Some evidence supports the idea that the quality of one's sleep affects one's ability to interact with others. Problematic externalizing and internalizing behaviour tend to be exacerbated by delayed sleep start, lower sleep length, and fragmented sleep across many days. Anxiety, hyper-arousal, and heightened sensitivity may interfere with a good night's rest. Randomized controlled trials and future research must establish causality. Confounding variables, agreement on objective sleep assessment for autistic persons, the influence of sociocultural practices, and the internalizing behavioural repercussions of poor sleep quality are all areas that require further investigation.

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