



Research article

QUALITY OF SLEEP AND LIFE OF PARENTS OF CHILDREN WITH SPECIAL EDUCATIONAL NEEDS

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Abstract

The number of children with special educational needs (SEN) is constantly increasing. This fact puts in the focus of the research objectives the problems of the mental functioning of their parents. While substantial research exists, there are still gaps in understanding the full extent of the challenges faced by parents caring for children with SEN. The present study investigates and compares quality of life and sleep in parents of children with SEN and parents of children without SEN. Tendency have been found that confirm the complex influence of SEN on the quality of the studied phenomena in parents.

Keywords: special educational needs, parents, quality of life, quality of sleep

Special Educational Needs (SEN) is a term used in the field of education to describe the needs of individuals who require additional support and assistance due to learning, physical, or behavioral differences. The definition and understanding of SEN can vary by country and educational system, but there are common principles that underlie the concept.

In the United Kingdom, the definition of SEN is provided under the Special Educational Needs and Disability (SEND) Code of Practice, which is statutory guidance issued under the Children and Families Act 2014. The Code of Practice defines SEN as follows:

"Special educational needs for a child or young person under 18 are defined in the Children and Families Act 2014 as follows: A child or young person has special educational needs if they have a learning difficulty or disability which calls for special educational provision to be made for him or her. A child of compulsory school age or a young person has a learning difficulty or disability if he or she: (a) has a significantly greater difficulty in learning than the majority of others of the same age, or (b) has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions."

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In the United States, the definition and legal framework for special education are provided under the Individuals with Disabilities Education Act (IDEA). IDEA defines children with disabilities as follows:

"The term 'child with a disability' means a child evaluated in accordance with §300.304 through §300.311 as having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as 'emotional disturbance'), an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deafblindness, or multiple disabilities, and who, by reason thereof, needs special education and related services."

It's important to note that the specific definitions and legal frameworks for special educational needs may vary from one country to another, and even within different regions or states in the same country (Tutt & Williams, 2015).

Parents of Children with Special Educational Needs

Raising a child is a journey filled with joys, responsibilities, and challenges, but when a child has Special Educational Needs (SEN), parents face unique and often complex difficulties. These difficulties can manifest in various aspects of daily life, from emotional and financial strains to navigating an often overwhelming healthcare and educational system.

Emotional and Psychological Strain:

Parents of children with SEN often encounter emotional and psychological difficulties. The stress and anxiety of managing their child's needs can be overwhelming (Bailey et al., 2019). The sense of grief over unmet expectations and the challenges of advocating for their child's rights can lead to feelings of isolation, depression, and helplessness (Hayes & Watson, 2013).

Financial Burden:

The financial burden is another significant challenge. The costs associated with therapies, specialized equipment, and educational support can be substantial. Families may face difficulties in accessing adequate insurance coverage or public services (Mank, 2004). These financial concerns can contribute to stress and can be detrimental to the family's overall wellbeing.

Navigating the Healthcare and Educational System:

Parents often find themselves in a complex and confusing maze of healthcare and educational services. Understanding the available resources, managing appointments, and coordinating various specialists can be daunting (Beresford & Clarke, 2006). This challenge is compounded by the need to advocate for their child's unique needs within the healthcare and educational systems.

Stigma and Social Isolation:

Stigmatization is another difficulty parents may face. Society's lack of understanding about SEN can lead to social isolation and judgment. Families may feel excluded from social events or encounter insensitive comments that further intensify their emotional strain (Rabiee & Sloper, 2009).

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The Importance of Support:

Recognizing these challenges is essential, and offering support to parents is crucial. Professionals, community organizations, and support groups can provide guidance, empathy, and resources (Bruder, 2010). Collaboration between parents and healthcare and education professionals can help in navigating complex systems and accessing needed services (Bailey et al., 2019).

Parents of children with SEN often experience elevated levels of stress and anxiety. Advocating for their child's needs, navigating complex healthcare and educational systems, and facing societal stigmas can be emotionally draining. Poor sleep quality can exacerbate these emotional challenges, leading to heightened stress and anxiety (Estes et al., 2009). Parents of children with SEN may find themselves in a constant state of alertness, always anticipating and responding to their child's needs. This hyper-vigilance can make it difficult for them to relax and unwind, affecting their ability to get a good night's sleep (Lunsky et al., 2013). Caring for a child with SEN often involves intensive physical care, medical appointments, and constant attention. The physical demands can lead to fatigue and exhaustion. Sleep disturbances further exacerbate these physical challenges, impacting the overall well-being of parents (Hayes et al., 2017). Chronic sleep disturbances can weaken the immune system. Parents already managing the complex needs of their child may become more susceptible to illnesses, compounding the physical toll (Besedovsky et al., 2019).

Parents of children with SEN often face a multitude of challenges. These may include navigating complex education systems, advocating for their child's rights, managing emotional and practical demands, and grappling with financial burdens (Glasberg & Gelbar, 2017; Hastings et al., 2005; Resch, 2006).

Caring for a child with SEN can take an emotional toll on parents. Witnessing their child's struggles and facing the social stigma associated with disabilities can lead to increased anxiety and stress (Hastings et al., 2005). Parents may also experience feelings of isolation and inadequacy due to the unique challenges their child faces.

Caring for a child with SEN can be financially draining. Medical and educational expenses, therapy costs, and the need for specialized equipment can create a significant financial burden for families (Resch, 2006).

While parents of children with SEN encounter numerous challenges, the provision of support and resources can significantly enhance their quality of life. Parent education and empowerment, peer support networks, accessible information, and community-based services are instrumental in helping parents cope with their unique challenges and improving their wellbeing (Glasberg & Gelbar, 2017; Resch, 2006).

Parents of children with SEN are the unsung heroes, facing unique challenges and making enormous sacrifices to ensure the well-being and development of their children. Understanding the difficulties they encounter, providing tailored support, and offering resources that empower parents are essential steps in enhancing their quality of life.

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Recognizing their role and the challenges they face is crucial for creating an inclusive and supportive environment that fosters the well-being of both parents and children with SEN.

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Parents of children with SEN often experience elevated levels of stress and anxiety. Advocating for their child's needs, navigating complex healthcare and educational systems, and facing societal stigmas can be emotionally draining. Poor sleep quality can exacerbate these emotional challenges, leading to heightened stress and anxiety (Estes et al., 2009). Parents of children with SEN may find themselves in a constant state of alertness, always anticipating and responding to their child's needs. This hyper-vigilance can make it difficult for them to relax and unwind, affecting their ability to get a good night's sleep (Lunsky et al., 2013).

Caring for a child with SEN often involves intensive physical care, medical appointments, and constant attention. The physical demands can lead to fatigue and exhaustion. Sleep disturbances further exacerbate these physical challenges, impacting the overall well-being of parents (Hayes et al., 2017). Chronic sleep disturbances can weaken the immune system. Parents already managing the complex needs of their child may become more susceptible to illnesses, compounding the physical toll (Besedovsky et al., 2019). The quality of sleep is undeniably linked to the quality of life for parents raising children with SEN. Poor sleep quality can exacerbate the emotional and physical toll that parents endure while caring for their children with SEN. By recognizing the specific challenges associated with each category of SEN, and the importance of sleep quality, we can better tailor support and resources to

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empower parents in this journey. This approach not only enhances the well-being of parents but also enables them to provide the best possible care and support for their children.

Methods

Participants: The survey sample was coincidental and purposive, since the questionnaires were given targeted to individuals who met the criteria. 270 participants took part in this survey, of which 46.7% (N=126) are parents of children with SEN and 53.3% (N=144) of children without SEN. Regarding gender, the clinical population (with SEN) (N=126) consisted of 23.8% (N=31) males and 75.4% (N=95) females, while the non-clinical population (without SEN) (N=144) was composed of 13.9% (N=20) men and 86.1% (N=124) women.

Measures: Sleep Quality was assessed by the Pittsburgh Sleep Quality Index (PSQI) (Berman et al., 1989, Kotronoulas et al., 2011). The PSQI consists of 19 self-assessment questions, categorised into 7 domains, which ask questions about subjective sensation of quality of sleep, latency of sleep onset, duration of sleep, habitual sleep efficiency, sleep disturbances, sleep disorders, use of medication substances for sleep and daytime dysfunction in the last 30 days. The scoring of responses spans a 0-3 scale to provide a universal score for the Sleep Quality measure, ranging from 0 (high Sleep Quality) to 21 (low Sleep Quality). These distinct subcategories of PSQI, are summed to produce a total score, with a normal value of ≤ 5 . The higher scores indicate worse sleep quality. Therefore, an overall total 5 or greater indicates poor Sleep Quality, and higher scores indicate further decline in Sleep Quality. The Cronbach's internal reliability index α was found to be 0.76.

A quality of life scale was also used. This scale was created by the World Health Organization and recommends the short form of the WHOQOL-100 questionnaire, it aims to measure self-reported quality of life and consists of 26 questions. The questions refer to 4 dimensions: a) Physical health, b) Psychological health, c) Social relationships, d) Environment and two more questions, which assess health-related quality of life. The Greek version consists of the original 26 questions and 4 new ones, which were added during the development cultural adaptation and statistical processing of the pilot version of the questionnaire. The new questions refer to: 1) nutrition, 2) job satisfaction, 3) home life and 4) social life. A five-point Likert scale was used to answer the questions, where the higher scores are an indication of better quality of life with a range of scores 0-100 for the WHOQOL-100 and 4- 20 for the WHOQOL-BREF. The WHOQOLBREF questionnaire of the World Health Organization (WHO) has been used repeatedly in quality of life surveys. It is also important to note that some questions (3,4,26) need reverse scoring, according to the manufacturers' instructions. For the reliability testing, the Cronbach's method was applied and the alpha (α), which is considered to characterise a scale as reliable when it has a value $\geq 0,70$. According to the results, the internal consistency for all the variables of the WHOQOL-BREF was $\alpha = 0.841$ (Christodoulou et al., 2012).

Data Collection Process: The data collection process was carried out within the period October 2023-December 2023. The questionnaires were administered in paper form and delivered to parent-clients of the mental health service institute of psychiatrist Ms. Garofalaki

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in Athens, where I work as a psychologist and in electronic form via the Google Forms application and posted on social media (Facebook and Email). There was a detailed briefing in relation to this research and its purposes, privacy and confidentiality of personal information. The process of completing the questionnaire took no more than 15 minutes and the structure of the questionnaire did not allow for any omission of answers. Therefore, there was no data loss and there was no need to resort to specific statistical analyses in order to manage any loss of data. Participation in the survey was voluntary, free of charge, respecting the rules of anonymity and ensuring the right of the participants to withdraw from the process.

Results

The aim of this research project was the statistical analysis of the variables of quality of sleep and quality of life of parents with children with SEN and parents with children without SEN. The statistical analysis of the survey data was performed using the Statistical Package for Social Sciences (SPSS, Statistical Package for Social Sciences software, version 21.0). The tables below show the continuous variables with means and standard deviations.

The results of Table 1 show that parents of children without SEN have better sleep quality ($M=6.2$) than parents of children with SEN ($M=8.8$). The standard deviation of the second sample is larger. The range of the questionnaire score is from 0 (high Sleep Quality) to 21 (low Quality of Sleep). When the mean value is $M \leq 5$, it indicates good sleep quality, while as this value increases the lower the quality of sleep.

Table 1. Means and Standard Deviations on Sleep Quality in relation to the presence of SEN

	SEN		Without SEN			
Quality of Sleep	M	SD	M	SD	df	t
	8,8	4,5	6,2	3,2	268	-5,43*

Note. * $p < 0,001$.

Score ≤ 5 indicates good sleep quality. The $M \geq 5$, the lower the quality of sleep.

The results presented in Table 2 support a higher quality of life in parents of children without SEN ($M=14.5$) versus ($M=12.7$) in parents of children with SEN. Variability of responses is greater for the second ($SD = 3.4$)

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Table 2. Means and Standard Deviations on Quality of Life in relation to the presence of SEN

	SEN		Without SEN		
	M	SD	M	SD	P
General Quality of Life	12,7	3,4	14,5	2,9	0.000***
Physical Health	12,6	3,3	14,8	2,7	0.000***
Psychological Health	13,2	3,4	13,8	3,3	0.133
Social Relations	13,2	4,2	14,6	3,4	0.004**
Environment	13,5	2,9	13,8	2,3	0.361

Note. *** $p < 0.05$, ** $p < 0.01$, * $p < 0.001$.

Results: The closer to $M=20$, the better the quality of life.

The results in Table 3 show that in both groups there is a statistically significant inverse correlation between quality of life and sleep quality. The correlation is more visible in parents of children with SEN.

Table 3. Associations between Sleep Quality and Life Quality in the sample of parents with children without SEN and parents with children with SEN

Parents with children without SEN		
		Quality of Sleep
General Quality of Life	R	-0,528**
	P	0,000
Parents with children with SEN		
		Quality of Sleep
General Quality of Life	R	-0,577**
	P	0,000

**Correlation is statistically significant at 0.01 level of significance

" r: Correlation coefficient, p: Statistical significance "

Discussion

The challenges and experiences faced by parents raising children with Special Educational Needs (SEN) profoundly impact their quality of life (QoL) and quality of sleep. Parenting itself is a demanding role, but when navigating the unique complexities that come with caring for a child with SEN, the demands can be heightened.

Parents of children with SEN often encounter a myriad of stressors that can significantly affect their QoL. The emotional toll of managing their child's needs, arranging specialized care, advocating for educational support, and facing societal stigmas can be overwhelming. These parents may grapple with increased stress levels, anxiety, and feelings of isolation. The need to balance caregiving duties, employment, and personal well-being poses an ongoing challenge that can impede their overall QoL.

Moreover, the impact of a child's SEN on parental sleep quality cannot be overstated. The unpredictable nature of caregiving, frequent awakenings, and constant vigilance over their child's needs can disrupt parents' sleep patterns. These interruptions not only affect the quantity but also the quality of sleep, leading to sleep deprivation and fatigue. Parents may find themselves in a perpetual cycle of sleep disturbances, affecting their mental acuity, emotional regulation, and overall health.

The presence of SEN in a child often brings unique circumstances, creating disparities in the QoL and sleep quality of parents compared to those raising children without SEN. While parenting itself is rewarding, parents of children with SEN face distinct challenges that demand specialized support. Access to community resources, inclusive healthcare services, and robust support networks can significantly alleviate the burden on these parents, enhancing their QoL and sleep quality.

In essence, the journey of parenting a child with SEN is multifaceted, demanding resilience, patience, and unwavering dedication from parents. Understanding and addressing the unique challenges faced by these parents are vital steps in improving their QoL and sleep quality, ultimately fostering an environment conducive to their well-being and effective caregiving.

This research offers additional information in the field of research on parents with children with SEN and their quality of life and how this is influenced by the sleep factor. The results of the statistical analysis, firstly, confirm findings of previous studies related to the quality of life and sleep of parents with children with SEN and also between parents with children with learning disabilities, ASD, intellectual disabilities, speech, language, behavioral and emotional disorders and children with physical and/or sensory disabilities. The present study showed that parents who have children with SEN had lower scores on the quality of life and sleep questionnaires. The data showed this group of parents had significantly lower sleep quality compared to the control population, which also reported by other researchers. Studies often suggest that parents of children with SEN experience disrupted sleep patterns due to caregiving duties, frequent awakenings, and stress-related sleep disturbances (Gray et al., 2015). Of course this is logical, since this group of parents experience daily physical and

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psychological pain, which is long-lasting and occurs uncontrollably. Thus, poor sleep quality can cause daytime drowsiness, fatigue and dysfunction, reducing daytime sleepiness.

Studies have indicated that parents of children with SEN often face higher stress levels, increased caregiving demands, and challenges in balancing family life and work responsibilities (Hayes & Watson, 2013). While caring for a child with SEN can present substantial challenges, some studies have shown that parents also experience increased empathy, personal growth, and strengthened family bonds through their caregiving experiences (Friedrich et al., 2019). According to the parental sleep quality, studies often suggest that parents of children with SEN experience disrupted sleep patterns due to caregiving duties, frequent awakenings, and stress-related sleep disturbances (Gray et al., 2015). Comparatively, parents of children without SEN may experience fewer interruptions to their sleep routine, contributing to better sleep quality and overall well-being. Additionally, there are factors contributing to the differences in QoL and sleep quality between different types of SEN. It considers the impact of the child's specific SEN, severity of the condition, available support networks, socioeconomic factors, and access to healthcare and respite services. Research has indicated that access to support services, community resources, and respite care significantly influences parental well-being and sleep quality (Miodrag & Hodapp, 2010). Interestingly, in the present study it was found that although the lower non-control group's quality of life and sleep than the control group's, the latter did not have high scores in general. That is, although there were statistically significant differences between the two groups, sleep quality of parents with children without SEN was rated as moderate, while their quality of life was rated as moderate to low, with the Psychological Health subscale being the lowest. This could be attributed to modern human lifestyles, increasing daily stress and the various problems (economic, social, personal) that they are called upon to deal with.

Conclusion

In conclusion, the quality of sleep is undeniably linked to the quality of life for parents raising children with SEN. Poor sleep quality can exacerbate the emotional and physical toll that parents endure while caring for their children with SEN. By recognizing the specific challenges associated with each category of SEN, and the importance of sleep quality, we can better tailor support and resources to empower parents in this journey. This approach not only enhances the well-being of parents but also enables them to provide the best possible care and support for their children.

Parents of children with SEN are heroes, confronting extraordinary challenges with determination and love. While these challenges can be emotionally and financially taxing, awareness of the difficulties is the first step in addressing them. Society can play a vital role by reducing stigmatization, ensuring adequate financial support, and simplifying access to essential healthcare and educational services. By understanding the challenges faced by these parents, we can collectively work toward creating a more inclusive and supportive environment for both children with SEN and their families.

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