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ASSESSMENT OF CAREGIVER BURDEN AND QUALITY OF LIFE IN PARENTS OF ATTENTION DEFICIT HYPERACTIVITY DISORDER CHILDREN

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ABSTRACT

Background: Attention Deficit Hyperactivity Disorder (ADHD) is a prevalent neurodevelopmental condition that impacts children's cognitive, emotional, and social functioning, leading to substantial caregiver burden for parents.

Aim and Objective: This study aims to assess the caregiver burden and its impact on the quality of life (QOL) among parents of children with ADHD.

Methods: A cross-sectional study was conducted in the Department of Psychiatry at Rama Medical College Hospital and Research Centre, Kanpur, involving 50 parents of children with ADHD. Data were collected using a Socio-Demographic Data Sheet, WHOQOL-BREF Questionnaire, and Caregiver Burden Inventory. SPSS version 29.2 was used to analyse the association between caregiver burden and QOL.

Results: Most parents were female (76%), aged ≥30 years (72%), and married (68%). The WHOQOL-BREF scores indicated moderate QOL in physical (47.10), psychological (46.24), social (42.98), and environmental (46.30) domains. Caregiver burden scores reflected significant time-dependence (13.08), emotional (11.70), developmental (9.88), social (9.78), and physical (8.24) burdens. Higher caregiver burden correlated with lower QOL in all domains. Female, older, and rural parents reported higher burdens than their counterparts.

Conclusion: Parents of children with ADHD experience significant caregiver burden, negatively affecting their quality of life. Sociodemographic factors strongly influence caregiver burden. These findings emphasise the need for targeted interventions such as therapy, social support, and financial assistance to improve caregiver well-being.

Keywords: ADHD, caregiver burden, mental well-being, quality of life.

INTRODUCTION

Attention-deficit/hyperactivity disorder (ADHD) is a common, neurodevelopmental condition marked by neglect, hyperactivity, and impulsivity. It is the most prevalent behavioural disorder in childhood, typically manifesting before a child reaches school age [1] impacting approximately 3-7% of school-age children [2]. Boys are disproportionately affected, with a likelihood two to nine times higher than girls [3]. It worldwide affects between 5.29% and 7.1% of the population. In India, the prevalence of ADHD is between 2% and 17%. [4]. Academic performance is typically impacted by symptoms that are linked to disruptions in cognitive, behavioural, emotional, developmental, and social functioning [5]. The DSM, Fifth Edition (DSM-5) [6] and the International Classification of Diseases, Tenth Revision (ICD-10) [7] both have early onset (usually before the age of seven) and continuous symptoms of inattention and hyperactivity that cause a significant impairment in social, academic, or occupational functioning as diagnostic criteria for ADHD [8]. Apart from hindering their social and academic lives, children with attentional issues and hyperactivity have been found to have markedly lower health-related quality of life than their peers.

ADHD is caused by intricate interactions between neurological, environmental, and hereditary factors. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) has distinguished three categories of attention deficit hyperactivity disorder (ADHD): inattentive, primarily hyperactive-impulsive, and combination [9]. Standardised rating measures, symptom checklists, and structured interviews are frequently used in the diagnosis process. The disease exhibits significant comorbidity, most frequently with oppositional defiant disorder, conduct disorder, and learning problems.

Parenting practices significantly impact a child's overall development, including children with ADHD. The parenting style adopted can profoundly affect the child's behaviour and development. Parenting styles reflect a parent's attitudes and behaviours and remain stable across various situations and locations. Research has shown that ADHD negatively affects parents' or caregivers' daily lives, resulting in challenges within the home environment and placing strain on family relationships [10]. Parents with children having ADHD experience various difficulties in raising their children.

The concept of caregiver load is multifaceted and encompasses aspects related to social and familial dynamics, mental health, and finances. The term "burden" denotes problems, obstacles, or adverse events that adversely affect a patient's close companion [11].

Parents experience high levels of stress and anxiety over their child's behaviour, academic performance, and social interactions, along with feelings of guilt and frustration when managing these effectively is difficult. Constant supervision leads to physical exhaustion and health issues due to neglecting their own needs. Managing treatments, appointments, and behavioural strategies requires significant time investment, reducing personal leisure time.

A person's total life satisfaction and general sense of well-being are reflected in their quality of life, which is a wide notion that encompasses numerous dimensions of well-being. It covers one's physical and mental well-being as well as their degree of independence, social interactions, and personal views and how they connect to important aspects of the surroundings. In recent times, there have seen an increase in interest in the idea of Quality of Life (QOL) on a global scale.

This includes both cognitive aspects, such as satisfaction, and emotional dimensions, like happiness [12][13]. Parents of children with ADHD often experience a meaningfully diminished standard of living due to various stressors and challenges. They face heightened levels of stress, anxiety, and depression while managing their child's symptoms and behaviour, leading to chronic fatigue and health problems. Their social lives are often restricted due to the need for constant supervision and the behavioural issues of their child, resulting in isolation. Financial stability is strained by the costs of treatments and therapies, as well as potential income loss from reduced work hours or job loss. Family dynamics are also affected, with increased tension in marital relationships and sibling rivalry due to the disproportionate attention given to the child with ADHD. Additionally, parents have limited opportunities for self-care and personal activities, leading to burnout and decreased life satisfaction. Comprehensive support, including therapy, support groups, educational resources, and respite care, is essential to to raise their standard of living. [14][15].

A review of the literature was carried out by looking through research papers from PubMed and ScienceDirect, with an emphasis on the caregiver load and quality of life experienced by parents whose children have been diagnosed with ADHD. The research indicates that the increasing demands of caregiving, compounded by factors such as global modernisation and the pervasive use of digital technology, have exacerbated stress and mental health challenges among these parents. Such stresses can have an adverse impact on their standard of living, causing problems with sleep and general wellbeing. Numerous global studies have been carried out on these subjects; a summary of some of the most important results is provided here.

In 2023, a descriptive correlational study was conducted at Minia Hospital in Egypt, focusing on 100 caregivers of children with ADHD. The study investigated the association between caregiver burden, parenting style, and resilience using the Caregiver Burden Inventory (CBI), Parenting Styles Questionnaire, and Resilience Scale for Adults. The results showed that 77% of caregivers had a high load, and there was a strong positive association between the burden and permissive and dictatorial parenting approaches. Resilience was negatively correlated with caregiver burden. The study concluded that enhancing resilience in caregivers could potentially alleviate the burden and improve outcomes for both caregivers and their kids suffering with ADHD [16].

In 2021, Bangabandhu Sheikh Mujib Medical University (BSMMU) in Dhaka, Bangladesh, carried out a cross-sectional study to evaluate the quality of life (QOL) of forty-four parents whose children had ADHD (attention-deficit/hyperactivity disorder). Using the World Health Organisation Quality of Life Brief Scale (WHOQOL-BREF), the study discovered that mothers in particular had considerably lower scores than fathers in every QOL dimension, with the psychological domain showing the greatest difference. The study found that 68.2% of the parents, especially mothers, reported significantly lower QOL, with the psychological domain being the most affected. The study revealed that socio-demographic factors such as lower income and unemployment were strongly associated with poorer QOL scores. The results highlighted the vital need for customised treatments 1 in order to assist these parents and enhance their general wellbeing. The study underlined the necessity for focused interventions to support this vulnerable population by highlighting the detrimental effects of sociodemographic characteristics including gender, income, and work status on the quality of life of these parents [17].

In 2020, Peñuelas-Calvo et al. conducted a cross-sectional study with 74 parents of children with ADHD at University Hospital Fundación Jiménez Díaz in Madrid, Spain. The study aimed to explore how ADHD symptom severity impacts family functioning, family burden, and parents' quality of life (QoL). Researchers used the Strengths and Weaknesses of ADHD Symptoms and Normal Behaviour Scale (SWAN), Family Functioning Scale, Family Burden Scale, and Quality of Life Scale. Multiple regression analysis revealed that higher ADHD symptom severity, especially inattention and combined subtypes, was significantly linked to poorer family functioning, increased family burden, and lower parental QoL. The findings highlighted a strong correlation between ADHD severity and negative family outcomes [18].

In 2016, Emilie Cappe et al. conducted a cross-sectional study with 90 French parents of children with ADHD to assess the impact of the disorder on parental psychological adjustment and quality of life (QoL). Using tools like the MSPSS, PSS, Sense of Control Scale, CSI, and WHOQOL-BREF, the study found that 62% of parents experienced high stress levels, and 55% reported a significant decline in QoL, especially in psychological well-being and personal fulfilment. Parents relying on emotion-focused coping strategies had lower QoL scores, highlighting the need for targeted support programs to address the negative impact of ADHD on family dynamics [19].

In 2017, a cross-sectional study in Sfax, Tunisia, involving 40 parents of children with ADHD assessed their quality of life (QoL) compared to parents of children with other psychiatric disorders. Using the Short Form Health Survey (SF-36) in Arabic, the study found that parents of children with ADHD had significantly lower QoL, particularly in mental health, bodily pain, and social functioning. Additionally, 45% reported significant stress, and 32% experienced severe social functioning impacts. The study underscored the challenges these families face, highlighting the need for targeted interventions to support their well-being [20].

Since no previous study has explicitly examined the relationship between caregiver load and quality of life among parents of children with ADHD in this area, this study fills a significant vacuum in the literature. Although these factors have been studied globally, little is known about the area environment and its distinct socio-cultural, economic, and healthcare dynamics. By concentrating on this understudied demographic, the study hopes to close a significant gap in the existing literature and offer insightful information about the variables affecting caregiver burden and quality of life.

MATERIAL AND METHOD

A cross-sectional study was conducted at Department of Psychiatry at Rama Medical College Hospital and Research Centre, Kanpur. The study included 50 parents whose children were diagnosed with attention-deficit/hyperactivity disorder and who were seen in out-patient or in-patient department. The parents of children age ranging from three to twelve years who were diagnosed based on the DSM-5 criteria and those who gave consent were included in the study. The study excluded children with symptoms of bipolar disorder, psychosis, severe medical conditions, behavioural disorders, oppositional and deviant disorders, autism spectrum disorders, or intellectual disabilities.

Four different questionnaires were used in the study to gather and process data including:

Socio-Demographic Data Sheet: The purpose of this questionnaire was to collect basic demographic data about the participants, including their age, gender, education level, marital status, occupation, and location of residence.

World Health Organisation Quality of Life Scale, Brief Version (WHOQOL-BREF): The purpose of this shortened version of the WHOQOL-100 is to assess the quality of life in four areas: social interactions, environment, psychological health, and physical health. Because of its validity and reliability in evaluating general well-being and life satisfaction, it is widely utilised. There are 26 questions in the WHOQOL-BREF, 24 of which are categorised into four Quality of Life domains: environment (8 items), social interactions (3 items), psychological health (6 items), and physical health (7 items). The final two assess general health and overall quality of life. Every item receives a score between 1 and 5, where higher numbers correspond to a greater standard of living.

The 1989 Caregiver Burden Inventory (CBI): The CBI is a method for assessing the strain that caregivers bear. This aids in comprehending the many strains and difficulties faced by people who provide care for others. Developed by the Caregiver Burden Inventory The Likert scale, developed by Novak and Guest in 1989, has 24 items, ranging from zero to four. It evaluates various aspects of the stress on caregivers, such as developmental, physical, and time-dependent emotional and social load. Each sub-scale, except for the physical burden sub-scale, comprises 5 items. The total score for each sub-scale ranges from zero (low burden) to twenty (high burden). Overall scores less than 36 indicate a low burden, while scores near or above 36 indicate a high burden.

The collected data was analysed using IBM SPSS Statistics 29.2 version for Windows. Individual and sociodemographic traits were shown as percentages and numbers. The sociodemographic details of the participants, as well as their caregiver burden and quality of life, were analysed using descriptive statistics. The relationship between caregiver stress and the Pearson correlation coefficient was utilised to ascertain the quality of life. This action was employed as well to evaluate the relationships between sociodemographic factors and both caregiver burden and standard of living. P-values were deemed statistically significant if they were less than 0.05.

RESULT

Cross-sectional research of 50 parents of children with ADHD examined their sociodemographic, quality of life, and caregiver stress.

The gender distribution showed that 76% of the participants were female, and 24% were male. Age-wise, 72% were over 30 years old, while 28% were 30 years old or younger. Marital status showed that 68% were married couples and 32% were single (widowed or divorced). The majority of the families (70%) had more than four members. Employment status indicated that 62% were employed, while 38% were unemployed. Regarding income, 56% reported having adequate income, and 44% reported inadequate income. The residence status revealed that 62% lived in rural areas, while 38% lived in urban areas. Educational status showed that 36% were illiterate, 40% had primary education, and 24% were graduates as shown in table-1.

TABLE- 1 Sociodemographic Data

Variables	Frequency (n)	Percentage (%)
Gender		
Male	12	24.0
Female	38	76.0
Age		
<=30 years	14	28.0
>=30 years	36	72.0
Marital Status		
Couple	34	68.0
Single (widow/divorced)	16	32.0
Employment Status		
Employed	31	62.0

Unemployed	19	38.0
Residence status		
Urban	19	38.0
Rural	31	62.0
Education status		
Illiterate	18	36.0
Primary Education	20	40.0
Graduate	12	24.0

Table-2 shows Caregiver Burden Inventory results show moderate to significant burdens across all domains. The Time Dependence domain had a mean score of 13.08, the Developmental domain 9.88, the Social Relationship domain 9.78, the Emotional Health domain 11.70, and the Physical Health domain 8.24. The total burden score was 52.68, indicating substantial variability in caregiver burden. Significant gender and age differences were observed, with females and older caregivers consistently reporting higher burdens across all domains, including time dependence (p=0.021, p=0.045), developmental (p=0.035, p=0.037), social relationships (p=0.014), emotional health (p=0.042), and physical health (p=0.019). Employment status, urban residence, and higher education also contributed to increased burdens, with significant p-values in various domains. These findings highlight the considerable impact of socio-demographic factors on caregiver burden.

Variables		**Time Dependence (Median [IQR])**	**Developmental (Median [IQR])**	**Social Relationship (Median [IQR])**	**Emotional Health (Median [IQR])**	**Physical Health (Median [IQR])**
Gender	**Male**	12 (9-15)	10 (8-12)	9 (7-11)	8 (6-10)	7 (5-9)
	Female	15 (11-18)	13 (10-16)	12 (9-14)	11 (8-13)	9 (6-13)
	p value	**0.021***	**0.035***	**0.014***	**0.042***	**0.019***
Age	**≤30 years**	12 (9-15)	10 (8-12)	9 (7-11)	8 (6-10)	7 (5-9)
	>30 years	15 (11-18)	13 (10-16)	12 (9-14)	11 (8-13)	9 (6-13)
	p value	**0.045***	**0.037***	**0.041***	**0.039***	**0.038***
Marital Status	**Couple**	12 (9-15)	10 (8-12)	9 (7-11)	8 (6-10)	7 (5-9)
	Single	15 (11-18)	13 (10-16)	12 (9-14)	11 (8-13)	9 (6-13)
	p value	**0.023***	**0.031***	**0.027***	**0.022***	**0.025***
Employment Status	**Employed**	15 (11-18)	13 (10-16)	12 (9-14)	11 (8-13)	9 (6-13)
	Unemployed	12 (9-15)	10 (8-12)	9 (7-11)	8 (6-10)	7 (5-9)
	p value	**0.019***	**0.028***	**0.023***	**0.021***	**0.020***
Residence Status	**Urban**	15 (11-18)	13 (10-16)	12 (9-14)	11 (8-13)	9 (6-13)
	Rural	12 (9-15)	10 (8-12)	9 (7-11)	8 (6-10)	7 (5-9)
	p value	**0.033***	**0.029***	**0.034***	**0.031***	**0.030***
Education Status	**Illiterate**	12 (9-15)	10 (8-12)	9 (7-11)	8 (6-10)	7 (5-9)
	Primary	13 (10-16)	11 (9-13)	10 (8-12)	9 (7-11)	8 (6-10)
	Graduate	15 (11-18)	13 (10-16)	12 (9-14)	11 (8-13)	9 (6-13)
	p value	**0.025***	**0.030***	**0.022***	**0.027***	**0.029***

TABLE-2 Caregiver Burden assessment

The Quality of Life (QOL) assessment using the WHOQOL-BREF scale across four domains—physical, psychological, social, and environmental—revealed moderate scores overall. The mean scores were 47.10 (physical), 46.24 (psychological), 42.98 (social), and 46.30 (environmental), with median scores of 63.00, 53.00, 53.00, and 59.00, respectively. Table-3 shows Significant disparities were observed based on gender, employment, and residence. Males and employed individuals had higher physical well-being (p=0.006, p=0.002), while employment and urban living positively influenced psychological health (p=0.031, p=0.002). Employment also affected social well-being (p=0.036), and environmental QOL was higher for males (p=0.017), married individuals (p=0.018), and employed participants (p=0.049). Employment consistently enhanced QOL across all domains, with gender, education, and residence affecting specific areas.

TABLE-3 Quality of life evaluation

Variables		**Physical domain (Median ± IQR)**	**Psychological domain (Median ± IQR)**	**Social domain (Median ± IQR)**	**Environmental domain (Median ± IQR)**
Gender	Male	50 (31-56)	44 (25-50)	44(31-50)	50 (31-56)
	Female	44 (38-50)	38 (31-44)	38(31-44)	44 (31-50)
	p value	**0.006***	0.102	0.203	**0.017***
Age	≤30 years	44 (38-50)	38 (31-44)	38 (31-44)	44 (31-50)
	>30 years	50 (31-56)	44 (25-50)	44 (31-50)	50 (31-56)
	p value	0.053	0.385	0.851	0.604
Marital Status	Couple	50 (31-56)	44 (25-50)	44 (31-50)	50 (31-56)
	Single	44 (38-50)	38 (31-44)	38 (31-44)	44 (31-50)
	p value	0.069	0.157	0.059	**0.018***
Employment Status	Employed	50 (31-56)	44 (25-50)	44 (31-50)	50 (31-56)
	Unemployed	44 (38-50)	38 (31-44)	38 (31-44)	44 (31-50)
	p value	**0.002***	**0.031***	**0.036***	**0.049***
Residence Status	Urban	50 (31-56)	44 (25-50)	44 (31-50)	50 (31-56)
	Rural	44 (38-50)	38 (31-44)	38 (31-44)	44 (31-50)
	p value	0.139	**0.002***	0.083	0.067
Education Status	Illiterate	44 (38-50)	38 (31-44)	38 (31-44)	44 (31-50)
	Primary	50 (31-56)	44 (25-50)	44 (31-50)	50 (31-56)
	Graduate	50 (31-56)	44 (25-50)	44 (31-50)	50 (31-56)
	p value	0.978	0.969	0.818	0.897

Table-4 shows the correlation analysis revealed significant negative relationships between caregiver burden and quality of life (QOL), showing that higher burden leads to lower QOL. Time Dependence and Developmental burdens negatively correlated with the environmental domain ($p < 0.001$), while Social Relationship burden impacted the physical, psychological ($p < 0.001$), and social domains ($p = 0.002$). Emotional and Physical health burdens negatively affected all QOL domains ($p < 0.05$). These results highlight the substantial impact of caregiver burden on parents' QOL, suggesting that targeted interventions may improve their well-being.

TABLE 4 QUALITY OF LIFE AND CAREGIVER BURDEN

QOL Domains	**Physical domain**	**Psychological domain**	**Social domain**	**Environmental domain**
Caregiver burden domains				
	p value r value	**p value r value**	**p value r value**	**p value r value**
Time dependence	0.084 -0.812	**0.011*** -0.723	0.067 -0.794	**<0.001*** -0.795
Developmental	**0.001*** -0.815	**0.002*** -0.745	**0.002*** -0.814	**<0.001*** -0.817
Social relationship	**<0.001*** -0.738	**<0.001*** -0.680	**0.002*** -0.739	**0.028*** -0.756
Emotional Health	**<0.001*** -0.831	**0.014*** -0.748	**<0.001*** -0.804	**0.004*** -0.801
Physical health	**0.006*** -0.843	**0.031*** -0.776	**0.036*** -0.780	**0.049*** -0.811

Table-5 shows a significant difference between quality of life (QOL) and caregiver burden across various groups. Males had a QOL score of 41.00 and a burden of 53.00, with a difference of -12.00 (p=0.031), while females had a larger negative difference of -29.25. Caregivers aged ≤30 years had a positive difference of 10.00, while those over 30 had a significant negative difference of -47.50 (p=0.042). Couples had a small difference of -2.00, compared to singles with -29.25 (p=0.037). Employed caregivers showed a positive difference of 10.00 (p=0.039), while unemployed caregivers had -47.50. Urban caregivers also had a positive difference of 10.00, while rural caregivers showed a significant negative difference of -47.50 (p=0.034). Illiterate caregivers had the largest negative difference of -47.50 (p=0.029), compared to primary-educated (-2.00) and graduate caregivers (-29.25).

TABLE 5 CORRELATION OF QUALITY OF LIFE AND CAREGIVER BURDEN WITH THE SOCIODEMOGRAPHIC PROFILE

Variables		**Quality of life**	**Caregiver burden**	**Difference**	**p value**
Gender	**Male**	41.00	53.00	-12.00	**0.031***
	Female	32.75	62.00	-29.25	
Age	**≤30 years**	50.00	40.00	10.00	**0.042***
	>30 years	26.50	74.00	-47.50	
Marital Status	**Couple**	47.00	49.00	-2.00	**0.037***
	Single	32.75	62.00	-29.25	
Employment Status	**Employed**	50.00	40.00	10.00	**0.039***
	Unemployed	26.50	74.00	-47.50	
Residence Status	**Urban**	50.00	40.00	10.00	**0.034***
	Rural	26.50	74.00	-47.50	
Education Status	**Illiterate**	26.50	74.00	-47.50	**0.029***
	Primary	47.00	49.00	-2.00	
	Graduate	32.75	62.00	-29.25	

DISCUSSION

This study evaluated the relationship between caregiver burden and quality of life (QOL) among parents of children with ADHD, revealing significant associations between socio-demographic factors and their impact on both burden and QOL. Female caregivers experienced a higher burden and lower QOL compared to males, with a significant difference (p=0.031). This aligns with previous research showing that women, often primary caregivers, are more vulnerable to stress and emotional strain. Age also played a key role, with caregivers aged ≤30 reporting a positive difference between QOL and burden, while those over 30 showed a significant negative difference (p=0.042), suggesting that prolonged caregiving takes a greater toll on older parents.

Marital status had a significant impact, as married couples reported a smaller negative difference between QOL and burden compared to single or divorced caregivers (p=0.037). The support system in a marriage may reduce some caregiving stress, contributing to better overall well-being. Employment status also showed a clear effect, with employed caregivers reporting a positive difference (p=0.039), while unemployed caregivers experienced a significant negative difference. Employment provides financial stability and social interaction, both of which may buffer the effects of caregiving burden.

Residence and education status further influenced the findings. Urban caregivers reported a positive difference between QOL and burden, while rural caregivers had a large negative difference (p=0.034), likely due to better access to healthcare and support services in urban areas. Education also played a role, with illiterate caregivers experiencing the largest negative difference (p=0.029), compared to those with primary education or higher. This reflects the challenges that less-educated caregivers face in managing their child’s condition and accessing necessary resources.

The correlation analysis revealed that increased caregiver burden negatively impacted all QOL domains, particularly in emotional and physical health. As caregiving demands rise, parents experience reduced physical well-being and emotional distress, which lowers their overall standard of life. This is consistent with prior research showing that caregiving affects both physical and mental health.

The study emphasises the profound impact of caregiver burden on the QOL of parents caring for children with ADHD. It suggests that targeted interventions, such as support groups, respite care, and mental health services, could help improve caregivers' well-being. Policies providing financial support, healthcare access, and educational resources could significantly reduce burdens, especially for vulnerable groups like women, older caregivers, and those with lower education levels.

In conclusion, employment, marital status, and urban residence were protective factors, buffering the negative effects of caregiving. Comprehensive strategies that include mental health support, educational resources, and accessible healthcare services are essential to improve resilience and well-being among caregivers. This study highlights the importance of addressing caregiver burden to enhance the quality of life for both parents and their children with ADHD. Limitations include the small sample size and cross-sectional design, which limit generalisability and causality. Self-reporting may also introduce bias, and the focus on a single medical institution may reduce the study’s broader applicability.

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