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Health-related quality of life and perceived stress of informal caregivers of children and adolescents with intellectual disabilities and ADHD

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Ethical disclosures

The ethical standards committees on human experimentation at the Burdwan Medical College and Hospital in West Bengal (India) approved all procedures. Written (signed) informed consent was obtained from all enrollees.

Conflict of interest

Dr. Jana Dubey reports no conflict of interest.

Dr. Ray reports no conflict of interest.

Dr. Ghosh reports no conflict of interest.

Dr. Kumar Bhattacharyya reports no conflict of interest.

Dr. Dhor reports no conflict of interest.

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Abstract

Introduction: Informal caregivers of children and adolescents with intellectual disabilities and attention deficit/hyperactivity disorder (ADHD) face numerous challenges. However, no study has yet compared the HRQoL of the caregivers of children and adolescents with these two conditions. We aimed to compare the HRQoL and perceived stress of caregivers of children and adolescents with intellectual disabilities and ADHD.

Methods: The HRQoL and perceived stress of informal caregivers of children and adolescents with intellectual disabilities and ADHD (40 in each group) were compared using the perceived stress scale and the Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form, respectively.

Results: HRQoL was significantly worse in most dimensions in caregivers of children and adolescents with severe ADHD than in caregivers of children and adolescents with severe intellectual disabilities. However, perceived stress was similar.

Conclusion: Differences in the impact of intellectual disability and ADHD on family members’ HRQoL should be considered while developing educational programs for patients and their families.

Keywords

Attention-deficit/hyperactivity disorder; Health-Related Quality of Life; Intellectual Disability; Perceived Stress

Introduction

Primary informal caregivers are adult relatives living with a patient, in the same environment, for at least 12 months, who are involved directly in giving care to the patient and support either emotionally or financially, i.e., feel most responsible for the patient.[1,2] Efforts to fulfill the demands of the affected individuals can bring a significant level of stress for the caregivers and can affect their overall perception of their position in life in the context of the culture and value systems in which they live and with their goals, expectations, standards, and concerns, i.e., affect their health-related quality of life

(HRQoL).[3,4] HRQoL is an important indicator when evaluating the impact of chronic illnesses on patients and caregivers.[3,4]

Different studies have concluded that parents of children with various developmental disabilities experience heightened stress,[5,6] overburden and marginalization in society,[7] sense of self-blame,[8] and tiredness.[9,10]

Intellectual disability is one of the most prevalent developmental disabilities, characterized by impairments of skills manifested during the developmental period, contributing to the overall level of intelligence.[11] Those closest to the persons with intellectual disabilities and care for them bear the burn.[12,13]

Attention-deficit/hyperactivity disorder (ADHD), a common neurobehavioral disorder of childhood, is characterized by developmentally inappropriate inattention, hyperactivity, and impulsivity, often leading to serious impairments in academic performance and social adaptive behavioral functioning.[14,15] ADHD harms HRQoL and adds to the stress of parents/family members.[16,17]

This cross-sectional study aimed to assess and compare HRQoL and perceived stress of primary informal caregivers of children and adolescents with intellectual disabilities and ADHD. Both intellectual disability and ADHD affect the same age group. However, no study has yet compared the HRQoL of the caregivers of children with these two conditions.

Materials and methods

Participants

This study was conducted in the psychiatry outpatient unit of the Burdwan Medical College and Hospital in West Bengal (India). The study comprised two groups – forty caregivers of children with intellectual disabilities and forty caregivers of children with ADHD who were randomly selected from a dataset of family caregivers of children having both diseases. The caregiver was identified as an adult relative, aged 18 to 60 years, living with the patient in the same environment for at least 12 months, directly giving care, and feeling responsible for the patient's care. The inclusion criteria for the participants were children and adolescents of either sex, aged between 6 to 18 years. A consultant psychiatrist confirmed the diagnosis of intellectual disability and ADHD per DSM-IV TR criteria.[18] The study did not include illiterate caregivers or those with psychiatric disorders, comorbid medical or surgical illnesses, or substance abuse.

The ethical standards committees on human experimentation at the Burdwan Medical College and Hospital in West Bengal (India) approved all procedures. Written (signed) informed consent was obtained from all enrollees.

Instruments

Perceived stress and HRQoL of caregivers were assessed using the perceived stress scale (PSS)[19] and the Quality of Life Enjoyment and Satisfaction Questionnaire – Short Form (Q-LES-Q-SF),[20] respectively.

The PSS was developed by Cohen et al.[19] to detect perceived stress in different populations. It contains 29 questions distributed over six dimensions that include: “stress from taking care of patients” (8 items), “stress from teachers and nursing staffs” (6 items), “stress from assignments and workload” (5 items), “stress from peers and daily life” (4 items), “stress from lack of professional knowledge and skills” (3 items), and “stress from the clinical environment” (3 items).[19] Total scores ranged from 0 to 116 (the higher the score, the higher the degree of stress).[19] To assess the HRQoL of the caregivers, Q-LES-Q-SF was used.[20] The scoring of this instrument involves summing the first 14 items to yield a raw total score.[20] Higher scores indicate better HRQoL. The last two items are not included in the total score but are standalone items.[20] The raw total score ranges from 14 to 70.[20] In addition, the raw total score is transformed into a percentage maximum possible score using the following formula: (raw total score − minimum score) / (maximum possible raw score − minimum score).

The severity of ADHD was measured according to the Conners ADHD rating scale 3-parent short form.[21] It consists of a 43-item parent-report designed to assess ADHD and evaluate problem behavior in children and adolescents (ages 6 to 18). We classified the severity of ADHD symptoms into three groups according to t-score: less than 40 (low severity) (i.e., fewer concerns than are typically reported); between 40 and 64 (moderate severity) (i.e., slightly more concerns than are typically reported); and ≥65 (high severity) (i.e., much more concern than are typically reported). Children and adolescents with intellectual disabilities were classified into three groups depending on their intelligence quotient (mild, between 50 to 69; moderate, between 35 to 49; and severe, between 20 to 34).

Statistical analysis

Statistical analyses were performed in SPSS version 20.0 (SPSS, Inc., Chicago, IL). All p values are two-tailed, and we considered $p < 0.05$ significant. Following the Shapiro–Wilk test, the Kolmogorov test, and the visual examination of data, no cells deviated substantially from normality. Data were presented as a percentage, means, and standard deviations. The student’s t-test was used for continuous variables and Chi-square tests for categorical variables for comparisons between the groups. A post hoc study was performed, subdividing the population according to the degree of intellectual disability or ADHD of the children and adolescents, correcting the p-values by Bonferroni’s multiple comparisons. The relationship between the QLES-Q-SF total score and PSS total score with the caregivers’ age was assessed using Spearman’s correlation analysis.

Results

There were no significant differences in age, sex, educational level, religion, occupation, family income per month, and family type between the two groups of caregivers (Table 1). Neither the QLES-Q-SF total score ($R = 0.07$, $p = 0.55$) nor the PSS total score ($R = -0.12$, $p = 0.28$) was significantly correlated with the age of caregivers (data not shown).

Scores in the ability to get around physically without feeling dizzy or unsteady, or falling and overall life satisfaction and contentment domains (both from the Q-LES-Q-SF) were significantly lower in the caregivers of children and adolescents with ADHD than in those

caring for children and adolescents with intellectual disabilities. (Table 2). PSS's total score was similar between both groups.

When comparing caregivers of children and adolescents with mild intellectual disability and ADHD, scores in life satisfaction and contentment (from the Q-LES-Q-SF) were lower in the second one (Table 3). However, the scores were higher in leisure time activities (from the Q-LES-Q-SF) in caregivers of children and adolescents with mild ADHD (Table 3). By contrast, caregivers of children and adolescents with moderate ADHD and intellectual disability scored similarly in the QLES-Q-SF total score and its domains (Table 4). Finally, caregivers of children and adolescents with severe ADHD scored significantly lower in several domains (physical health, leisure time activities, ability to function in daily life, sexual drive/interest and performance, economic status, living, and housing situation, ability to get around physically, and hobbies), and in the QLES-Q-SF maximum percentage and total score, compared to those of children and adolescents with severe intellectual disabilities (Table 5).

There were no significant differences in the perceived stress between caregivers of children and adolescents with intellectual disabilities and ADHD (Tables 1 to 5).

Discussion

This study aimed to assess and compare the HRQoL and perceived stress of the caregivers of children and adolescents with intellectual disability and ADHD. HRQoL was significantly worse in most dimensions in caregivers of children and adolescents with severe ADHD than in caregivers of children and adolescents with severe intellectual disabilities. However, perceived stress was similar between caregivers of the two conditions.

Unlike other studies,[22,23] QLES-Q-SF and PSS total scores were not correlated with caregivers' age. For example, Upadhyaya and Havalappanavar[22] showed that parents of children with intellectual disabilities younger than 35 years suffered greater stress when compared to parents older than 35 In addition, the lower age of children with intellectual disabilities was associated with higher stress and decreased leisure time for mothers.[22]

Concerning the comparison of the domains of HRQoL and the perceived stress between caregivers of children and adolescents with intellectual disabilities and ADHD, there were statistically significant differences in the "physical" (ability to get around physically without feeling dizzy) an" overall life satisfaction and contentment " domains, which were more affected in the caregivers of ADHD patients. The differences were clearer in most of its dimensions in caregivers of children and adolescents with severe ADHD (highest t-score of the Conners ADHD rating scale 3-parent short form) compared to those caring for children and adolescentes with severe intellectual disabilities. There is a real dearth of studies to compare our results in this aspect. However, we can say that poorer HRQoL among caregivers of children and adolescents with ADHD, especially those with more severe disease, might be due to inattention, which makes them difficult to control, and hyperactivity, which forces caregivers to remain busy all the time throughout the day. In addition to impulsivity, which causes poor peer group relationships, breaks social integrity,

and may cause financial loss. These factors probably impose more responsibility, extreme alertness, huge mental pressure, and immense physical and mental fatigue on caregivers leading to overall poorer HRQoL of caregivers of ADHD than caregivers with children and adolescents with intellectual disabilities in which low intelligence is the only accountable issue, and that may not be a very important issue, particularly in a rural scenario like ours. In a rural scenario, the future educational perspective is probably less important because most people earn their daily lives as unskilled workers where education has little role.

Concerning perceived stress between caregivers with intellectual disabilities and ADHD as a whole, as well as comparing PSS scores separately according to severity, we did not find significant differences.

In closing, caregiving for intellectual disability and ADHD poses significant impairment in HRQoL and increases perceived stress among caregivers. However, the difference is there according to the severity of the illness. Further studies from different sectors are needed to unveil the intriguing association between caregiver stress and HRQoL in children and adolescents with intellectual disabilities and ADHD. Differences in the impact of intellectual disability and ADHD on family members' HRQoL should be considered while developing educational programs for patients and their families.

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Table 1

Comparison of demographic characteristics between caregivers of children and adolescents with intellectual disabilities and ADHD.

		Intellectual disabilities	ADHD		*p*-value
Demographics					
Age in years		34.4 ± 8.5	32.2 ± 5.9	1.417 (78)	0.161
Sex	Men	8 (20.0%)	7 (17.5%)	0.082 (1)	1.00
	Women	32 (80%)	33 (82.5%)		
Religion	Hindu	16 (40%)	19 (47.5%)		
	Muslim	24 (60%)	21 (52.5%)	0.457 (1)	0.652
Educational level	Illiterate	16 (40%)	13 (32.5%)		
	Up to primary education	10 (25%)	12 (30.0%)		
	More than primary education	14 (35%)	15 (37.5%)	0.527 (2)	0.768
Occupation	Unemployed	4 (10%)	5 (12.5%)		
	Unskilled worker	30 (75%)	24 (60.0%)		
	Skilled / semi-skilled worker	6 (15%)	11 (27.5%)	2.242 (2)	0.325
Family income per month in US dollars	<20.8$	17 (42.5%)	12 (30/%)		
	20.8–62.4$	18 (45%)	22 (55%)	1.353 (2)	0.508
	>62.4$	5 (12.5%)	6 (15%)		
Family type	Joint	27 (67.5%)	22 (55%)		
	Nuclear	13 (32.5%)	18 (45%)	1.317 (1)	0.359

Mean values ± SD are given for age. The Chi-square test was used for proportions.

Table 2

Comparison of Q-LES-Q-SF and perceived stress between caregivers of children and adolescents with intellectual disabilities and ADHD.

	Intellectual disabilities (N = 40)	**ADHD (N = 40)**	**t (df)**	***p*-value**
Q-LES-Q-SF dimensions				
Physical health (Q1)	2.7 ± 0.6	2.5 ± 0.9	6.70 (78)	0.32
Mood (Q2)	2.0 ± 0.7	1.9 ± 0.8	3.29 (78)	1.00
Work (Q3)	2.7 ± 0.7	2.5 ± 0.9	3.55 (78)	0.32
Household activities (Q4)	2.8 ± 0.6	2.6 ± 0.8	4.93 (78)	0.1
Social relationships (Q5)	2.1 ± 0.7	1.9 ± 0.8	2.80 (78)	0.17
Family relationships (Q6)	2.58 ± 0.9	2.2 ± 0.9	0.09 (78)	0.09
Leisure time activities (Q7)	2.3 ± 0.4	2.2 ± 0.9	18.75 (78)	0.76
Ability to function in daily life (Q8)	2.6 ± 0.7	2.4 ± 0.9	1.55 (78)	0.22
Sexual drive, interest, and/or performance (Q9)	2.4 ± 0.6	2.1 ± 0.8	0.01 (78)	0.05
Economic status (Q10)	2.6 ± 0.7	2.5 ± 0.9	1.04 (78)	0.68
Living/housing situation (Q11)	2.6 ± 0.7	2.4 ± 1.0	5.74 (78)	0.35
Ability to get around physically without feeling dizzy or unsteady, or falling (Q12)	2.7 ± 0.7	2.3 ± 0.8	1.08 (78)	0.01
Your vision to do work/hobbies (Q13)	2.4 ± 0.6	2.3 ± 0.9	8.56 (78)	0.37
Overall sense of well-being (Q14)	1.9 ± 0.6	1.7 ± 0.7	4.89 (78)	0.30
Overall life satisfaction and contentment during the past week	2.5 ± 1.0	2.0 ± 0.7	10.14 (78)	0.01
Satisfaction with medication*	–	–	–	–
Q-LES-Q-SF total score	34.2 ± 7.4	31.7 ± 10.5	5.88 (78)	0.21
Q-LES-Q-SF maximum percentage	36.1 ± 13.2	31.6 ± 18.7	5.79 (78)	0.22
Perceived stress total score	15.7 ± 6.1	15.7 ± 4.7	1.65 (78)	0.95

Mean values ± SD are given.

*Nobody was taking medication.

Table 3

Comparison of Q-LES-Q-SF and perceived stress between caregivers of children and adolescents with mild intellectual disabilities and mild ADHD.

	Mild intellectual disabilities N = 13	**Mild ADHD N = 12**	**t (df)**	***p*-value**	***p*-value Bonferroni**
Q-LES-Q-SF dimensions					
Physical health (Q1)	3.2 ± 0.6	3.5 ± 0.5	−1.19 (23)	0.25	0.75
Mood (Q2)	2.6 ± 0.5	2.7 ± 0.4	−0.69 (23)	0.49	1.00
Work (Q3)	3.1 ± 0.8	3.2 ± 0.4	−0.68 (23)	0.50	1.00
Household activities (Q4)	3.1 ± 0.7	3.2 ± 0.4	−0.41 (23)	0.69	1.00
Social relationships (Q5)	2.5 ± 0.5	2.7 ± 0.6	−0.55 (23)	0.59	1.00
Family relationships (Q6)	3.5 ± 0.5	3.1 ± 0.8	1.71 (23)	0.10	0.3
Leisure time activities (Q7)	2.5 ± 0.5	3.2 ± 0.6	−3.12 (23)	0.01	0.03
Ability to function in daily life (Q8)	3.2 ± 0.7	3.2 ± 0.4	−0.08 (23)	0.94	1.00
Sexual drive, interest, and/or performance (Q9)	2.8 ± 0.4	2.8 ± 0.8	−0.24 (23)	0.81	1.00
Economic status (Q10)	2.9 ± 0.9	3.3 ± 0.5	−1.44 (23)	0.16	0.48
Living/housing situation (Q11)	3.2 ± 0.6	3.3 ± 0.5	−0.46 (23)	0.65	1.00
Ability to get around physically without feeling dizzy or unsteady, or falling (Q12)	3.2 ± 0.7	3.2 ± 0.4	0.27 (23)	0.79	1.00
Your vision to do work/hobbies (Q13)	2.8 ± 0.7	3.2 ± 0.4	−1.69 (23)	0.11	0.33
Overall sense of well-being (Q14)	2.4 ± 0.5	2.4 ± 0.5	−0.16 (23)	0.88	1.00
Overall life satisfaction and contentment during the past week	3.5 ± 0.5	2.4 ± 0.5	4.24 (23)	<0.001	<0.001
Satisfaction with medication*	–	–	–	–	–
Q-LES-Q-SF total score	41.5 ± 6.1	43.3 ± 5.6	−0.96 (23)	0.35	1.00
Q-LES-Q-SF maximum percentage	48.5 ± 10.8	52.4 ± 10.0	−0.95 (23)	0.35	1.00
Perceived stress total score	10.4 ± 3.5	10.7 ± 2.7	−0.29 (23)	0.77	1.00

Mean values ± SD are given.

*Nobody was taking medication.

Table 4

Comparison of Q-LES-Q-SF and perceived stress between caregivers of children and adolescents with moderate intellectual disabilities and moderate ADHD.

	Moderate intellectual disabilities N = 18	**Moderate ADHD N = 17**	**t (df)**	***p*-value**	***p*-value Bonferroni**
Q-LES-Q-SF dimensions					
Physical health (Q1)	2.6 ± 0.5	2.5 ± 0.5	0.48 (33)	0.64	1.00
Mood (Q2)	1.7 ± 0.5	1.9 ± 0.7	−1.15 (33)	0.26	0.78
Work (Q3)	2.7 ± 0.5	2.7 ± 0.6	−0.09 (33)	0.93	1.00
Household activities (Q4)	2.8 ± 0.4	2.6 ± 0.6	1.09 (33)	0.28	0.84
Social relationships (Q5)	2.1 ± 0.5	1.8 ± 0.6	1.56 (33)	0.13	0.39
Family relationships (Q6)	2.2 ± 0.6	2.3 ± 0.5	−0.37 (33)	0.71	1.00
Leisure time activities (Q7)	2.2 ± 0.4	2.1 ± 0.6	0.59 (33)	0.56	1.00
Ability to function in daily life (Q8)	2.6 ± 0.5	2.4 ± 0.7	0.96 (33)	0.34	1.00
Sexual drive, interest, and/or performance (Q9)	2.3 ± 0.6	2.0 ± 0.3	1.71 (33)	0.09	0.27
Economic status (Q10)	2.7 ± 0.7	2.6 ± 0.6	0.09 (33)	0.93	1.00
Living/housing situation (Q11)	2.3 ± 0.6	2.6 ± 0.5	−1.36 (33)	0.18	0.54
Ability to get around physically without feeling dizzy or unsteady, or falling (Q12)	2.8 ± 0.6	2.3 ± 0.6	2.31 (33)	0.02	0.06
Your vision to do work/hobbies (Q13)	2.4 ± 0.5	2.3 ± 0.7	0.74 (33)	0.47	1.00
Overall sense of well-being (Q14)	1.7 ± 0.5	1.6 ± 0.6	0.41 (33)	0.68	1.00
Overall life satisfaction and contentment during the past week	2.4 ± 0.7	2.0 ± 0.6	1.99 (33)	0.05	0.15
Satisfaction with medication *	–	–	–	–	–
Q-LES-Q-SF total score	33.1 ± 5.1	31.9 ± 5.3	0.70 (33)	0.48	1.00
Q-LES-Q-SF maximum percentage	34.1 ± 8.9	31.9 ± 9.3	0.70 (33)	0.48	1.00
Perceived stress total score	16.2 ± 4.1	16.4 ± 3.2	−0.29 (23)	0.88	1.00

Mean values ± SD are given.

* Nobody was taking medication.

Table 5

Comparison of Q-LES-Q-SF and perceived stress between caregivers of children and adolescents with severe intellectual disabilities and severe ADHD.

	Severe intellectual disabilities N = 9	**Severe ADHD N = 11**	**t (df)**	***p*-value**	***p*-value Bonferroni**
Q-LES-Q-SF dimensions					
Physical health (Q1)	2.2 ± 0.4	1.5 ± 0.5	3.09 (18)	0.01	0.03
Mood (Q2)	1.4 ± 0.5	1.1 ± 0.3	1.89 (18)	0.08	0.24
Work (Q3)	2.1 ± 0.6	1.4 ± 0.5	2.61 (18)	0.02	0.06
Household activities (Q4)	2.2 ± 0.4	1.7 ± 0.5	2.42 (18)	0.03	0.09
Social relationships (Q5)	1.4 ± 0.5	1.1 ± 0.3	1.89 (18)	0.07	0.21
Family relationships (Q6)	1.9 ± 0.6	1.2 ± 0.4	3.14 (18)	0.61	1.00
Leisure time activities (Q7)	2.0 ± 0.0	1.3 ± 0.5	4.65 (18)	0.01	0.03
Ability to function in daily life (Q8)	1.9 ± 0.3	1.5 ± 0.5	1.71 (18)	0.11	0.33
Sexual drive, interest, and/or performance (Q9)	2.0 ± 0.5	1.4 ± 0.5	2.82 (18)	0.01	0.03
Economic status (Q10)	2.1 ± 0.3	1.5 ± 0.5	2.80 (18)	0.01	0.03
Living/housing situation (Q11)	2.2 ± 0.4	1.2 ± 0.4	5.49 (18)	<0.001	<0.001
Ability to get around physically without feeling dizzy or unsteady or falling (Q12)	2.0 ± 0.0	1.4 ± 0.5	3.77 (18)	0.001	0.003
Your vision to do work/hobbies (Q13)	2.0 ± 0.0	1.4 ± 0.5	3.76 (18)	0.001	0.003
Overall sense of well-being (Q14)	1.6 ± 0.5	1.2 ± 0.4	1.79 (18)	0.09	0.27
Overall life satisfaction and contentment during the past week	1.4 ± 0.5	1.5 ± 0.5	−0.43 (18)	0.67	1.00
Satisfaction with medication*	–	–	–	–	–
Q-LES-Q-SF total score	26.6 ± 3.5	18.7 ± 2.0	6.33 (18)	<0.001	<0.001
Q-LES-Q-SF maximum percentage	22.3 ± 6.2	8.5 ± 3.5	6.27 (18)	<0.001	<0.001
Perceived stress total score	22.6 ± 5.2	19.9 ± 3.3	1.39 (18)	0.18	0.54

Mean values ± SD are given.

*Nobody was taking medication.