ORIGINAL ARTICLE

PARENTAL CAREGIVER BURDEN FOR CHILDREN WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER AT TERTIARY CARE HOSPITAL IN HYDERABAD

JAHANGIR LIAQUAT [1], KAZI HUMAYOUN [2], SYED QALB-I-HYDER NAQVI [3], MUKHTAR AHMED ABRO [4], TOUSEEF AHMED [5], DARYA KHAN LAGHARI [6]

[1]Department of Medicine, Suleman Roshan Medical College Tando Adam, Sindh, Pakistan
[2,3]Department of Psychiatry, Sir C.J Institute of Psychiatry & Behavioural Sciences, Hyderabad, Pakistan
[4]Department of Medicine, Peoples University Of Medical & Health Sciences For Women, Shaheed Benzir Abad (Nawabshah), Pakistan
[5]Department of Paediatrics, Liaquat University of Medical Health Sciences, Pakistan
[6]Department of Psychiatry, Suleman Roshan Medical College Tando Adam, Pakistan

CORRESPONDENCE: **DR. SYED QALB-I-HYDER NAQVI** E-mail: drkalbhyder@gmail.com

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ABSTRACT

OBJECTIVE
To determine the level of burden among care giver parents of children with attention deficit hyperactivity disorder (ADHD).

STUDY DESIGN
A Cross-Sectional Study.

PLACE AND DURATION OF STUDY
The study was conducted in the outpatient department (Clinics) of Sir Cowasjee Jehangir Institute of Psychiatry and Behavioural Sciences, Hyderabad. The study duration was 6 months from 1st November 2021 to 30th April 2022.

SUBJECT AND METHOD
Three hundred seventy nine children diagnosed with ADHD (6 to 12 years) for a 6 months' duration with and without Psychiatric co-morbidity reported in the OPD with all subtypes recruited. Caregiver parents of ADHD children, both male and female (18-60 years) were also recruited and burden was assessed on Burden Assessment Scale. The cases of ADHD children with Adverse General Medical Conditions, History of head injury, and those who denied/withdrew consent were excluded. The data were analysed by using SPSS-version-22 (PASW).

RESULTS
The mean age of enrolled children was 9.50 years (SD=2.32), gender distribution was 283 males (74.6%) and 96 females (25.32%). The parents' ages ranged from 18 to 60 years, with a mean age of 38 years (SD= 6.5). Most caregivers, n=251 (66.22%) were females and n=62 (16.35%) were university graduates. Females n=108 (52.42%) have a higher burden of caregiving (X2 (1, n=108)=38.4234, p=0.00001) than males n=98 (47.57%). However, higher education had a significant positive correlation with the burden of care (rs=1, p=0.00).

CONCLUSION
The burden of caregiving was discovered among n = 206 (54.35%) of caregiver parents of ADHD children. Single parenting and higher education were associated with a considerably higher burden of care. Being married protects against stress.

KEYWORDS:
ADHD Children, Caregiver Parents, Caregiver Burden.

INTRODUCTION

Attention deficit hyperactivity disorder is among the most prevalent complex neuro-behavioural disorders that's frequently diagnosed in childhood and 30%–70% of cases persist into adulthood in which parental caregiving is extremely stressful.[1-2] Diagnosis of ADHD from the DSM-IV, is evident by pervasive and impairing symptoms of inattention, hyperactivity, and impulsivity,[3] in contrast with World Health Organization (WHO) refers to the disorder by a different name, hyperkinetic disorder (HD).[4] ADHD/HD, by any title, represents one of the chiefly and extensively researched medical conditions.[5] The reported prevalence of ADHD/HD was 5.29% (95% CI=5.01-5.56), with considerable differences between studies.[6] Dropout from school, parenting stress, interpersonal difficulties, depression, employment failure, and drug addiction are all serious consequences of ADHD.[7] Caregiver burden is a negative psychological condition that caretakers experience because of the demands of caring for someone who is ill or disabled.[8] ADHD affects not only the life of children, but continuously affects the life of the entire family.[9] Previous research has found a link between caring for ADHD patients and caregiver burden.[10-11] In Oman, caregivers of substance dependence children with ADHD were observed to bear the heaviest burden.[10] Caregivers' burden is associated with variables such as symptom severity, comorbidities, and a lack of social support.[11] According to a review of the literature, there is limited research on the burden of caregivers of children with mental illness, especially in parents with ADHD children, particularly in Sindh Pakistan. This study determines the key socio-demographic variable influencing the intensity of burden on parents as caregivers of children with ADHD in Sindh, Pakistan.

SUBJECTS AND METHODS

Participants

A descriptive Cross Sectional Study was conducted in the OPD of child psychiatry at Sir Cowasjee Jehangir Institute of Psychiatry and Behavioural Sciences (SCJIPBS) Hyderabad. The duration of study was from 1st November 2021 to 30th April 2022 (6 months) after approval from Ethical Review Committee of SCJIPBS. The Sample size was 379 calculated using WHO sample size calculator by taking 43.8% prevalence of burden in caregivers of children diagnosed with ADHD and presenting at OPD with a level of significance of 5% and a precision (d) of 5%.[12] Non-probability consecutive sampling was done. Inclusion criteria were children of ADHD with and without psychiatric co-morbidity reported in the OPD with all

subtypes, with at least 6 month's duration of symptoms, either gender, age range from 6 to 12 years. Parents of ADHD children, both male and female (18-60 years) accompany their children at OPD of CJIP&BS were recruited in the study. Exclusion criteria, children with adverse general medical conditions, children with head injury and who deny/withdraw consent were excluded.

Instruments

After diagnosis of a child with ADHD on DSM-IV,[13] Vanderbilt ADHD rating scale was used to rate the disorder severity.

Vanderbilt ADHD Diagnostic Parent Rating Scale

The VADPRS[14] diagnostic rating scale, for children from 6 to 12 years, includes the 18 DSM-IV ADHD symptoms rated on a 4-point Likert scale that indicates how frequently each ADHD symptom occurs (0 = never, 1 = occasionally (once a week or less), 2 = often (3 to 4 time a week), 3 = very often (most of the day).

Burden assessment scale

The Burden Assessment Scale (BAS)[15] is a four point Likert type scale where (1=not at all, 2 =little, 3=some, then 4=a lot) a sum score for total burden ranging from 19 (no burden) to 76 (severe burden).

Procedure

After written informed consent was obtained from eligible participants, cases of ADHD were diagnosed based on DSM-IV[13] severity and type was assessed on Vanderbilt ADHD Diagnostic Parent Rating Scale[14] and the burden of parents was assessed on Burden assessment scale.[15] Data were collected on semi structure Performa by collecting socio-demographic variables from the study participants/parents. The data were analysed by using SPSS-version-22 (PASW), frequency and percentages were computed for categorical variables like gender, schooling of children, gender of parents, residence of participants, educational level of parent, parent's burden. Mean standard deviation was computed for numerical variables like age. Post stratification chi-square test for categorical variables and Spearman correlation coefficient measures the strength of association between two variables was applied and $P \leqslant 0.05$ was taken as significant.

RESULTS

A total of 379 children with ADHD were enrolled during the 6 months period. The median age of the patients was 10 years, with an interquartile range (6-12) years. The gender distribution was 283 (74.6%) male and 96 (25.32%) female. 182 (48.02%) children attended school and 197 (51.97%) did not (Table 1). n=186 (49.07%) of the cases are from rural areas and n=193 (50.92%) of cases are from urban areas (Table 1). The age of the parents ranged from 18 to 60 years, with a mean of 38 years and a standard deviation (SD) of ± 6.5 years. Females held the most representation of the caregivers' population n=251 (66.22%) then male counterpart n=128 (33.7%), while female participants n=62 (16.35%) were university graduates. More than half of the caregiver's females n=152 (60.55%) were not working and 47.5% of the caregivers had an income of less than 50000 Pakistani rupees monthly. In the family, the presence of someone assisting with child-care with parents was found in 54.5% of caregivers. Presence of other comorbid psychiatric illness in children with ADHD was around (53.03%).

According to the Burden Assessment Scale, moderate and severe burden were found in n=206 (54.35%) of the participants, of which n=108 were female (52.42%) and n=98 were males (47.57%) respectively. There was a significant relationship between gender and burden of care, which is higher in female p=0.00001 (Table 2). In contrast, the total number of male participants was 128 (33.77%), of which 76.56% were burdened, and female participants were n=251 (66.22%), of which 43.02% were burdened. In relation to caregivers who live in urban areas (n=193) and rural areas (n=186), the burden of care is more or less evenly distributed (53.88%) and (54.83%) respectively. Regarding marital status of caregivers n=296 (78.10%) were married and n=164 (55.40%) had no burden. Meanwhile, n=83 (21.89%) were divorced / widowed, and had a significantly higher burden of caregiving n=74 (89.15%) X^2 (1, n=83)=51.88, p=0.00001. In breakdown by education level of caregivers, n=157 (41.42%) were educated up to the secondary level. However, higher education had a significant positive correlation with the burden of care (rs=1, p=0.00), as the higher the education of the carer, the greater was the burden of care.

Table 1
Socio-demographic Variables of the Children with ADHD and Parents (N=379)

Socio-demographic variables		n	Percentage
Mean Age in years Median		9.50 years (s.d.=2.32) 10	
Gender of Children with ADHD			
	Male	283	74.6%
	Female	96	25.32%
Schooling of children with ADHD			
	Attended	182	48.02%
	Non Attended	197	51.97%
Gender of Parents			
	Male	128	33.7%
	Female	251	66.22%
Residence of Participants			
	Urban	193	50.92%
	Rural	186	49.07%
Education level of Parents			
	Not formally educated	34	8.97%
	Primary Education	126	33.24%
	Secondary education	157	41.42%
	College/University	62	16.35%
Burden			
	Present	206	54.34%
	Absent	173	45.64%

Table 2
Chi-square association with Burden and other variables of Parents of the Children with ADHD

	Burden		Total	Chi-Square	p-value
	Present	Absent			
Gender of Parents					
Male	98 (47.57%)	30 (17.34%)	128	38.4234	0.00001
Female	108 (52.42%)	143 (82.65%)	251		
Total	206 (54.34%)	173 (45.64%)			
Residence of Parents					
Urban	104 (53.88%)	89 (46.11%)	193	0.0347	0.852
Rural	102 (54.83%)	84 (45.16%)	186		
Martial status					
Married	132(44.59%)	164 (55.40%)	296	51.88	0.00001
Divorced/Widowed	74 (89.15%)	9 (10.84%)	83		
				Spearman's Rho	
Education					
Not formally educated	18 (52.94)	16 (47.05%)	34	r = 1	0.00
Primary education	68 (53.96%)	58 (46.03%)	126		
Secondary education	85 (54.14%)	72 (45.85%)	157		
University	35 (56.45%)	27 (43.54%)	62		

DISCUSSION

Caring for children with mental illnesses, particularly ADHD, is a burden for caregivers, especially parents. However, compared to other mental illnesses, researchers have paid little or no attention to this assessment. ADHD is a common childhood disorder that affects school-aged children, and this study was conducted in Pakistan to estimate the caregiver burden on parents. According to literature, prevalence varies by gender, 5.3% in girls and 5.3% in boys.[9] In our study, only parents were reported in contrast with other studies in which 15 fathers, 104 mothers, 2 grandmothers, and 1 grandfather were reported.[10] In a study by Chen Jih-Yuan et al, more than half of the participants (59%) were employed, half of the mothers stayed at home, 16.4% were labourers, and 12.3% were business owners[10] in contrast with our results caregiver females n=152 (60.55%) were not working and (47.5%) of the caregivers had an income of less than 50000 Pakistani rupees per month. Meanwhile, in other studies, 32% of families reported annual family incomes of less than US $12,000, while only 15.4% reported incomes of more than US $30,000.[10] Participants from ADHD children's families were much more likely to have their job task changed frequently, or they were terminated, and they noted poorer performance at work place.[11] ADHD places a significant economic burden on patients and their families due to the expense of medical treatment and work loss.[16] The annual average direct cost per ADHD client was $1,574, compared to $541 for matched controls.[16] The findings highlight the importance of interventions aimed at reducing the expensive, poorly functioning outcomes in families with ADHD children.

In the family, the presence of someone assisting with child care with parents was found in 54.5% of caregivers. Orly Klein et al reached the conclusion that support groups can provide basic and meaningful opportunities by repositioning people from different positions of burden, isolation, and social cut-off to positive, active association through an affective and efficient dynamic process called 'solidarity-as-care.[17] The average burden for caregiving mothers was 40.43±1.38,[18] and the average intensity of the illness subtypes and parenting burden were found to have a significant relationship.[18] The correlation coefficients for the impulsive, inattentive, and combined subtypes were 0.36, 0.29, and 0.29, respectively.[17] The age of the mother, the presence of ADHD in the child's brother, family member collaboration in care-giving, and the child's birth position could all have a significant impact on caregiver burden.[18] Meanwhile, in our study n=251 mothers who participated, 43.02% had a burden and 56.97% had no burden of care, whereas n=128 fathers who participated, 76.56% had a greater burden, and 23.43% had no burden of care, which was statistically significant at 0.00001. As a result, our study found that the male partner has a higher caregiver burden than the female partner. Despite using ADHD pharmaco therapy, parents of children/adolescents with ADHD experienced stresses relating to work, leisure interaction, home life, and parental worry/stress.[19] An improved comprehension of the clinical symptoms and treatment modulation, which is most commonly linked with aspects of caregiver burden, may support in ADHD management and ease caregiver burden.[19] This study also has several limitations, such that it was conducted in a hospital and included only parents who reported bringing their child to the hospital. Most ADHD caregiving parents in the community are unassessed. Further research must consider including sample size and community-based longitudinal studies, which will make the findings generalisable.

CONCLUSION

The burden of caregiving was found in n = 206 (54.35%) of caregiver parents of ADHD children. Being a male, single parenting and higher education were associated with a considerably higher burden of care. Being married, on the other hand, protected against stress.

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UNDERTAKING FORM

Sr.#	Author Name	Affiliation of Author	Contribution	Signature
1	Dr.Jahangir Liaquat	Assistant Professor of Medicine at Salman Roohen Medical College Tandoadam	Provide statistical analysis	
2	Dr.Kazi Humayoun	Senior Psychiatrist Sir CJP&BS Hyderabad	Collect data	
3	Dr.Syed Qalb-i-Hyder Naqvi	Assistant Professor & Consultant Psychiatrist Sir CJP&BS and LUMHS Hyderabad	Prepare the manuscript	
4	Dr.Mukhtar Ahemd Abro	Assistant Professor of Medicine at PUM&HS Nawabshah	Collect data	
5	Dr.Touseef Ahmed	Senior Registrar of Department Peads LUMHS Hyderabad	Conceptualizing the project	
6	Dr.Darya Khan Laghari	Assistant Professor of Psychiatry at Salman Roohen Medical College Tandoadam	Abstract writing	