Available online at **www.ijmrhs.com**

ISSN No: 2319-5886

International Journal of Medical Research & Health Sciences, 2020, 9(11): 10-17

Assessment of Burden on Caregivers of Children with Attention Deficit-Hyperactivity Disorder in Al-Madinah, Saudi Arabia

Zainab Jameel Alnakhli[1*], Sarah Almutari[1] and Sami Abdo Radman Al-Dubai[1,2]

[1]Joint Program of Family Medicine Post Graduate Studies, Al-Madinah, Saudi Arabia

[2]Saudi Board of Preventive Medicine Post Graduate Studies, Ministry of Health, Al-Madinah, Saudi Arabia

**Corresponding e-mail: Zainab.jameel1993@gmail.com*

ABSTRACT

Background and objectives: *Caregivers of children experiencing mental health challenges reporting negative physical and emotional effects due to the lack of recognition and support. This study aimed to explore the burden on caregivers of children with Attention deficit hyperactivity disorder (ADHD) in Medina.* ***Subjects and methods:*** *A cross-sectional study was conducted in the child psychiatric, developmental and behavioural clinics at Maternity and the children hospital (MMCH) and child psychiatric clinic at AlAmal hospital for mental health in Medina among 80 caregivers. The validated Arabic version of ZBI scale was distributed to 80 participants. T test and ANOVA test were performed to assess the association between sociodemographic variables and ZBI scale.* ***Results:*** *The age of participants ranged between 20 and 60 years. Females represent most of them (66.2%). Moderate to severe and severe burden on caregivers of children with ADHD were observed among 43.8% and 18.8% of the participants, respectively. Gender of the caregivers was significantly associated with burden of care giving as score of ZBI was significantly higher in females compared to males (47.3 ± 16.5 versus 39.3 ± 16.8), p=0.045.* ***Conclusion:*** *Burden on caregivers of children with ADHD in Medina was very high prevalent, particularly among female caregivers.*

Keywords: Attention deficit hyperactivity disorder, Burden, Care givers, Mental health

INTRODUCTION

Attention deficit hyperactive disorder (ADHD) is one of the most common neuro-developmental disorders of childhood [1]. It is initially diagnosed in childhood and frequently continues to adulthood [1]. It is estimated that ADHD affecting 1.3-16% of children in Arab countries [2].

ADHD may cause serious consequences, such as school failure, family stress, relationship difficulties depression, job failure, substance abuse [3]. Caregiver burden is a negative psychological state induced among caregivers due to demands of providing care to a person with an illness or a disability [4]. ADHD has impact not only to the child's life, but it can influence the whole family life [5].

Previous studies showed significant relationship between caring of ADHD patients and caregivers' burden [6-8]. In Oman, the burden among caregivers of drug native children with ADHD found to be predominant [6]. Caregivers burden associated with some variables like, symptoms severity, co- morbidities and poor social support [7].

A review of literature showed that there are no sufficient researches concerning about burden on caregivers of child with ADHD mainly in Saudi Arabia. This study aimed to assess the level of burden on caregivers of children with ADHD in Medina, KSA and to determine the main demographic factors affecting the degree of their burden.

MATERIALS AND METHODS

This cross-sectional study was conducted among 80 caregivers of children with ADHD who have follow up in the child psychiatric, developmental and behavioral clinics under Ministry of Health in AL-Madinah Al-Monawrra. Caregivers of patients with ADHD who aged 17 years and older were excluded. A self-administered and electronic questionnaire

was used in this study [6]. It included three parts. The first part included the sociodemographic data of the caregivers such as age, gender, marital status, educational level, employment status and income. The second part included the sociodemographic data of the child such as gender and duration since diagnosis of ADHD. The third part included the validated Arabic version of the Zarit Burden Interview (ZBI) scale to assess the caregiver's burden. It contains 22 questions and each item is rated on a Likert-type scale of 0 (never) to 4 (nearly always) with a total score ranging from 0 to 88 [9-12].The severity of burden was classified according to the total score into: 0-20, no or little burden; 21-40, mild to moderate burden; 41-60, moderate to severe burden and 61-88 severe burden [6]. The Cronbach alpha was 0.80 for the Arabic version and 0.92 for the English version [6,11].

Data were entered and analyzed using SPSS version 25 (IBM Corp., Armonk, NY, USA). Percentage and frequency were obtained for the categorical variables and mean ± standard deviation for the continuous variables. Test of normality was conducted for the ZBI total scale and it showed normal distribution. T test and ANOVA test were performed to assess the association between the sociodemographic variables and the ZBI scale.

Ethical approval of the study was obtained from institutional review board in Al Medina (reference num IRB 293). Participants confidentiality and anonymity were assured. Agreement was obtained by signed consents from all participants.

RESULTS

Age of the participants ranged between 20 and 60 years with a mean of 39 years and standard deviation (SD) of ± 6.6 years. Females represent most of them (66.2%), 60% were mothers of ADHD children and 60% had four children or more. Majority of them (85%) were currently married and 37.5% were university graduated. More than half of them (58.7%) were not working and 47.5% had an income of less than 5000 SR/month.

The presence of somebody helping in care of children was observed among 52.5% of the caregivers. Most of them (69%) were parents of the children (Table 1). Age of the ADHD children ranged between 4 and 16 years with a mean ± SD of 9.4 ± 2.7 years. Most of them (72.5%) were males. Duration since diagnosis was one year or more among majority of them (87.5%). History of diagnosis with cognitive, psychiatric or medical disorders other than ADHD was found among 43.8% of the children. Majority of them (86.2%) followed a management; mainly medical only (33.7%), followed by both medical and behavioral (28.7%). History of having other children in the family with ADHD was reported among 15% of children (Table 2). Moderate to severe and sever burden on caregivers of children with ADHD were observed among 43.8% and 18.8% of the participants, respectively. From Table 3, it is realized that ZBI score was significantly higher in females compared to males (47.3 ± 16.5 *versus* 39.3 ± 16.8), p=0.045. Other sociodemographic factors (age, relationship to the affected child, marital status, educational level, income and number of children) were not significantly associated with burden on caregivers of ADHD children. It is realized from Table 4 that presence of anyone helping caregivers of children with ADHD was not associated with burden on them. None of the studied factors of the ADHD child was significantly associated with burden on caregivers (Table 5).

Table 1 Socio-demographic characteristics of the caregivers of ADHD children (n=80)

Gender	n	Percentage (%)
Male	27	33.8%
Female	53	66.2%
Relationship to the affected child		
Mother	48	60%
Father	24	30%
Others	8	10%
Marital status		
Married	68	85%
Divorced/widowed	6	7.5%
Single	6	7.5%
Educational level		

Below secondary school	21	26.3%
Secondary school/diploma	29	36.2%
University	30	37.5%
Employment status		
Working	29	36.3%
Not working	47	58.7%
Retired	4	5%
Income (SR/month)		
<5000	38	47.5%
5000-10000	20	25%
>10000	22	27.5%
Number of children		
<4	32	40%
≥ 4	48	60%

Table 2 Demographic and clinical characteristics of children with ADHD (n=80)

Gender	n	Percentage (%)
Male	58	72.5%
Female	22	27.5%
Duration since diagnosis of ADHD		
<one year	10	12.5%
≥ one year	70	87.5%
History of diagnosis with cognitive, psychiatric or medical disorders other than ADHD		
Yes	35	43.8%
Psychiatric disorders	17	21.3%
Medical disorders	18	22.5%
No	45	56.3%
Following management		
Yes	69	86.2%
Behavioral only	19	23.8%
Medical only	27	33.7%
Both	23	28.7%
No	11	13.8%
History of having other children with ADHD		
No	68	85%
Yes	12	15%

Table 3 Association between socio-demographic characteristics of caregivers of ADHD children and burden on them

	The Zarit Burden Interview (ZBI) Mean ± SD	p-value
Gender		

Male	39.3 ± 16.8	0.045
Female	47.3 ± 16.5	
Age (years) (Correlation coefficient)		
r	-0.064	0.573
Relationship to the affected child		
Mother	47.4 ± 17.3	0.187
Father	39.9 ± 15.8	
Others	41.9 ± 16.4	
Marital status		
Married	44.3 ± 16.8	0.419
Divorced/widowed	52.7 ± 17.5	
Single	40.3 ± 18.8	
Educational level		
Below secondary school	43.6 ± 18.3	0.531
Secondary school/ diploma	42.5 ± 18.5	
University	47.3 ± 14.4	
Employment status		
Working	40.6 ± 16.8	0.269
Not working	46.6 ± 17.4	
Retired	49.8 ± 7.4	
Income (SR/month)		
<5000	42.8 ± 17.8	0.637
5000-10000	47.1 ± 16.8	
>10000	45.5 ± 15.9	
Number of children		
<4	45.1 ± 15.6	0.848
≥ 4	44.3 ± 18.0	

Table 4 Association between presence of anyone helping caregivers of children with ADHD and burden on them

	The Zarit Burden Interview (ZBI)	**p-value**
	Mean ± SD	
History of presence of anyone helping in children with ADHD care		
Yes	42.9 ± 16.9	0.333
No	46.6 ± 17.1	
Persons who helping in ADHD children care (n=42)		
Father/mother	42.7 ± 17.2	0.625
Housemaid/relatives	43.2 ± 16.7	
No	46.6 ± 17.1	

Table 5 Association between demographic characteristics of children with ADHD and burden among their caregivers (n=80)

	The Zarit Burden Interview (ZBI)	p-value
	Mean ± SD	
Gender		
Male	43.7 ± 15.6	0.424
Female	47.1 ± 20.2	
Age (years) (Correlation coefficient)		
	-0.056	0.622
Duration since diagnosis of ADHD		
<one year	43.1 ± 15.7	0.765
≥one year	44.8 ± 17.2	
History of diagnosis with cognitive, psychiatric or medical disorders other than ADHD		
Yes	47.0 ± 15.7	0.264
Psychiatric disorders	47.5 ± 16.2	
Medical disorders	46.6 ± 15.5	
No	42.7 ± 17.8	
Following management		
Yes	44.1 ± 17.2	0.54
Behavioral only	42.1 ± 14.5	
Medical only	41.6 ± 19.4	
Both	48.8 ± 16.2	
No	47.5 ± 15.9	
History of having other children with ADHD		
No	44.1 ± 17.2	0.502
Yes	47.7 ± 15.7	

DISCUSSION

The burden of care of child with ADHD on caregivers, mainly parents has received little attention in research compared to other aspects of the disorder [13]. In addition, a recent study carried out in Saudi Arabia revealed that ADHD is not uncommon disorder among primary school children as it affected 5% of them; its prevalence was 5.3% in girls and 4.7% in boys [14].Therefore, we intended to carry out this study to assess the burden on caregivers of children with attention deficit hyperactivity disorder in Al- Madinah Al-Munawara, Saudi Arabia. In the present study, only 10% of caregivers (90% parents) had no or little burden whereas moderate to severe and severe burden were observed among 43.8% and 18.8% of them, respectively. These figures are very high if compared to those reported in Oman where 66% of the caregivers had no or little burden [6]. However, in Nigeria, using the same tool used in the present study, the prevalence of sever caregivers burden was 24.6%, moderate to severe burden was 36.2%, mild to moderate burden was 31.9% and prevalence of little or no burden was 7.3% [7]. These figures are comparable to what has been detected in the present study. Additionally, many studies carried out elsewhere confirmed the same high level of burden on caregivers of ADHD children and adolescents [15-18]. However, they used different tools to assess burden on caregivers and some of these studies used tools to assess stress, coping strategies and quality of life. Several studies have concluded that stress of caregivers of children with developmental disorders, including ADHD result in disruptive behavior among them [9,19,20]. Additionally, Cussen, et al. observed that the majority of caregivers of children with ADHD had difficulties with their social life, relationships within the family and their occupation [21]. Therefore

many studies indicated that caregivers of children with ADHD were more likely to report more severe burden than their counterparts [10,22-25].

In accordance with others [7,10,26,27], the caregivers of children with ADHD in the present study were mostly females. This is quite expected in Saudi community where females are the usual caretakers of the children. In the current study, although majority of the children with ADHD (86.2%) followed a management; mainly medical or both medical and behavioral therapy, this was not associated with burden on caregivers. In a similar study carried out in Oman [6], the severity of burden on caregivers was lower than reported in this study, although the children in their study were not medicated. This finding could raise a question regarding the effectiveness of management of cases in the present study. In Europe, parents of ADHD children on medication experienced less challenges throughout the day [10]. Fridman, et al. in a study carried out in ten European countries revealed that caregivers of children and adolescents with ADHD experienced burden despite adherence to pharmacotherapy [9]. In the present study, female caregivers of ADHD children were more likely to have severe burden of care giving compared to males. Other similar studies carried out in Nigeria [7], revealed no difference in burden based on gender of the caregiver. This could be explained by the fact that in Saudi community, care giving is mostly done by women which reflects the socio-cultural roles women are playing in the community. Although not significant, severe care giving burden was more reported among not working participants than working caregivers. This could be explained by being not busy by work and have all of their time in caring.

CONCLUSION

This study has some few limitations as it is limited to caregivers of children with ADHD who have follow up in child psychiatric, developmental and behavioral clinics in AL-Madinah Al-Munawara, this generalizability of results is questionable. Also, the relatively small sample size did not allow us to find statistically significant findings in many occasions. The cross-sectional design of the study is considered another limitation as it allows testing the association and not proving causality between dependent and independent variables. However, the study has offered valuable information on an important subject that is under-researched in Saudi Arabia.

DECLARATIONS

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Conflicts of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

REFERENCES

[1] Catherine, T. Golden, et al. “Assessment of prevalence of attention deficit hyperactivity disorder among schoolchildren in selected schools.” Indian Journal of Psychiatry, Vol. 61, No. 3, 2019, pp. 232-37.

[2] Alhraiwil, Najla J., et al. “Systematic review of the epidemiology of attention deficit hyperactivity disorder in Arab countries.” Neurosciences, Vol. 20, No. 2, 2015, p. 137.

[3] Usami, Masahide. “Functional consequences of attention-deficit hyperactivity disorder on children and their families.” Psychiatry and Clinical Neurosciences, Vol. 70, No. 8, 2016, pp. 303-17.

[4] Mosley, Philip E., Rebecca Moodie, and Nadeeka Dissanayaka. “Caregiver burden in Parkinson disease: A critical review of recent literature.” Journal of Geriatric Psychiatry and Neurology, Vol. 30, No. 5, 2017, pp. 235-52.

[5] Muñoz-Silva, Alicia, Rocio Lago-Urbano, and Manuel Sanchez-Garcia. “Family impact and parenting styles in families of children with ADHD.” Journal of Child and Family Studies, Vol. 26, No. 10, 2017, pp. 2810-23.

[6] Al-Balushi, Naser, et al. “Predictors of burden of care among caregivers of drug-naive children and adolescents with ADHD: A cross-sectional correlative study from Muscat, Oman.” Journal of Attention Disorders, Vol. 23, No. 5, 2019, pp. 517-26.

[7] Adeosun, Increase Ibukun, et al. "The burden on caregivers of children with attention-deficit hyperactivity disorder in Lagos Nigeria: Prevalence and correlates." Journal of Education, Society and Behavioural Science, Vol. 22, No. 1, 2017, pp. 1-7.

[8] Breaux, Rosanna P., and Elizabeth A. Harvey. "A longitudinal study of the relation between family functioning and preschool ADHD symptoms." Journal of Clinical Child and Adolescent Psychology, Vol. 48, No. 5, 2019, pp. 749-64.

[9] Fridman, Moshe, et al. "Factors associated with caregiver burden among pharmacotherapy-treated children/adolescents with ADHD in the caregiver perspective on pediatric ADHD survey in Europe." Neuropsychiatric Disease and Treatment, Vol. 13, 2017, pp. 273-86.

[10] Coghill, David, et al. "Impact of attention-deficit/hyperactivity disorder on the patient and family: results from a European survey." Child and Adolescent Psychiatry and Mental Health, Vol. 2, No. 1, 2008, p. 31.

[11] Yu, Yu, et al. "A comparison of psychometric properties of two common measures of caregiving burden: The family burden interview schedule (FBIS-24) and the Zarit caregiver burden interview (ZBI-22)." Health and Quality of Life Outcomes, Vol. 18, 2020, pp. 1-9.

[12] Hagell, Peter, et al. "Assessment of burden among family caregivers of people with Parkinson's disease using the Zarit Burden Interview." Journal of Pain and Symptom Management, Vol. 53, No. 2, 2017, pp. 272-8.

[13] Wolraich, Mark L., et al. "Clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents." Pediatrics, Vol. 144, No. 4, 2019, p. e20192528.

[14] Al Zaben, Faten N., et al. "Prevalence of attention deficit hyperactivity disorder and comorbid psychiatric and behavioral problems among primary school students in western Saudi Arabia." Saudi Medical Journal, Vol. 39, No. 1, 2018, pp. 52-8.

[15] Theule, Jennifer, et al. "Parenting stress in families of children with ADHD: A meta-analysis." Journal of Emotional and Behavioral Disorders, Vol. 21, No. 1, 2013, pp. 3-17.

[16] Moen, Oyfrid Larsen, Birgitta Hedelin, and Marie Louise Hall-Lord. "Family functioning, psychological distress, and well-being in parents with a child having ADHD." SAGE Open, Vol. 6, No. 1, 2016.

[17] Mofokeng, Meisie, and Anna E. van der Wath. "Challenges experienced by parents living with a child with attention deficit hyperactivity disorder." Journal of Child and Adolescent Mental Health, Vol. 29, No. 2, 2017, pp. 137-45.

[18] Cadman, Tim, et al. "Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition into adolescence and adulthood in the United Kingdom." Journal of the American Academy of Child and Adolescent Psychiatry, Vol. 51, No. 9, 2012, pp. 879-88.

[19] Barroso, Nicole E., et al. "Parenting stress through the lens of different clinical groups: A systematic review and meta-analysis." Journal of Abnormal Child Psychology, Vol. 46, No. 3, 2018, pp. 449-61.

[20] Ahmad, Shaikh I., and Stephen P. Hinshaw. "Attention-deficit/hyperactivity disorder, trait impulsivity, and externalizing behavior in a longitudinal sample." Journal of Abnormal Child Psychology, Vol. 54, No. 6, 2017, pp. 1077-89.

[21] Cussen, Alexandra, et al. "Relationship between symptoms of attention-deficit/hyperactivity disorder and family functioning: A community-based study." European Journal of Pediatrics, Vol. 171, No. 2, 2012, pp. 271-80.

[22] Chen, Vincent Chin-Hung, et al. "Symptoms of attention deficit hyperactivity disorder and quality of life of mothers of school-aged children: The roles of child, mother, and family variables." The Kaohsiung Journal of Medical Sciences, Vol. 30, No. 12, 2014, pp. 631-8.

[23] Kim, Yeni, et al. "Parental quality of life and depressive mood following methylphenidate treatment of children with attention-deficit hyperactivity disorder." Psychiatry and Clinical Neurosciences, Vol. 68, No. 7, 2014, pp. 506-14.

[24] Flood, Emuella, et al. "The Caregiver Perspective on Paediatric ADHD (CAPPA) survey: Understanding sociodemographic and clinical characteristics, treatment use and impact of ADHD in Europe." Journal of Affective Disorders, Vol. 200, 2016, pp. 222-34.

[25] van der Kolk, Annemarie, et al. "Association between quality of life and treatment response in children with attention deficit hyperactivity disorder and their parents." The Journal of Mental Health Policy and Economics, Vol. 17, No. 3, 2014, pp. 119-29.

[26] Mirza, Hassan, et al. "School dropout and associated factors among Omani children with attention-deficit hyperactivity disorder: A cross-sectional study." Journal of Developmental and Behavioral Pediatrics, Vol. 39, No. 2, 2018, pp. 109-15.

[27] Sittironnarit, Gobhathai, Weerapat Emprasertsuk, and Kamonnet Wannasewok. "Quality of life and subjective burden of primary dementia caregivers in Bangkok, Thailand." Asian Journal of Psychiatry, Vol. 48, 2020, p. 101913.