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Relationship between Sociodemographic Factors and Caregiver Burden Among Mothers of Elementary School Students with ADHD Symptoms in Surabaya : A Cross-sectional Study

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ABSTRACT

Objective: Attention-Deficit/Hyperactivity Disorder (ADHD) is a prevalent neurodevelopmental disorder among elementary school pupils that comes out in impulsivity, hyperactivity, and inattentiveness. Keeping an eye on children with ADHD may be burdensome for their mothers. This study aimed to perform the assessment of mothers' burden in caregiving their children with ADHD symptoms who are enrolled as students at Elementary Schools in Surabaya and to reveal its relation with sociodemographic factors. **Method:** This cross-sectional study was purposively set at two elementary schools in Surabaya within a period of three months. Out of 324 total participants that partook in this study, 36 mothers were eligible as the samples to fill out sociodemographic and Zarit Burden Interview questionnaires. Afterwards, the data underwent quantitative content analysis. **Result:** Minimum burden to no burden at all were majorly experienced among mothers (63,9%) whilst the rest went through minimum to moderate burden (36,1%). Sociodemographic factors that were all set as variables in this study, which consisted of age (p = 0,723), education (p = 0,722), occupation (p = 0,399), marital status (p = 0,458), and income (p = 0,969) did not show significant relationship with mothers' burden. **Conclusion:** Mothers endured burden mainly in minimum to no-burden-at-all level with the results having no significant correlation to sociodemographic factors.

Keywords: caregiver burden; attention deficit/hyperactivity disorder; children; children well-being

INTRODUCTION

Attention Deficit/Hyperactivity Disorder (ADHD) counts as one of most prevailing neurodevelopmental disorders among elementary school pupils (1). It is characterized by its three major group of symptoms which are inattention, hyperactivity, and impulsivity attached within their daily activities taking place both at school and home (1,2). ADHD symptoms are primarily spotted in children before the age of 12. (3)

Albeit there have been no precise factors that can fully ensure the cause of ADHD to date, genetics and environmental involvement are still considered as convincing enough to play part (4). The risk of ADHD is greater in boys compared to girls (5). ADHD is evinced in 3-5% of kids and teenagers across the world (6). The rate of Indonesian children aged under 18 who were affected according data recorded in 2007 was nearly 20% (7). It happened to keep on elevating year by year among 2,4% of those who receive formal education in elementary level (8).

Aside from disrupting children's daily activities, ADHD also adds burden to their parents who constantly watch over them.

As the caregiving tasks keep going over time, a lot of aspects are affected adversely including caregivers' both physical and mental condition and socioeconomic status (9,10). Obstacles and needs should be properly comprehended in order to battle any kind of hardships obtained from caregiving children with ADHD (11).

Caretakers of children with ADHD in Lagos, Nigeria endured burden in mild (31,9%), moderate (36,2%), and severe level (26,4%) with merely 7,3% troubled with no burden (12). Severity of children with ADHD's behaviours were shown to be in relation with greater caregiver burden levels (13).

It is revealed that children with ADHD rely more on their mothers rather than the fathers (12), even though mothers tend to have higher emotional vulnerability (14). Being in charge of children with ADHD may bring guilt, mortification, desperation, and anxiety when things are getting out of hand which later on will intensively diminish mothers' health, fright, and quality of life (15, 16). As a serious consequence, mothers cannot fully cover up their children's needs due to unoptimized quality of care they provide (17).

Several studies have been conducted to investigate relationship between sociodemographic elements influencing levels of burden of ADHD children caregiver (18,19). However, there has been no similar studies taking place in Surabaya, Indonesia as of this day. Hence, the idea of this study arose in the aim of assessing caregiver burden among mothers of elementary school students with ADHD symptoms in Surabaya and analyzing the correlation between the burden levels and sociodemographic factors (income, occupation, education, age, and marital status) in hopes to amplify the awareness of ADHD, to lift up mothers' burden, and to enhance the quality of care provided by mothers in looking after their children with ADHD.

METHOD

This cross-sectional study was purposively set at two state elementary schools in Surabaya, East Java Province, Indonesia within a period of December 2022-March 2023. Instruments used in this study were in the form of hard copies questionnaires and manually filled by each participant themselves. Sociodemographic data analyzed in this study comprised both mothers' (education, age, occupation, income, and marital status) and pupils' (gender, age, and grade) data. Detection of ADHD symptoms was performed among 3rd-5th graders from both institutions with the usage of Skala Penilaian Perilaku Anak Hiperaktif

Indonesia (SPPAHI), one of instruments frequently utilized for assessing ADHD symptoms in Indonesia that consists of 35 questions, filled out by their mothers who were eligible according the mapped criteria of this study (20). 324 total participants were sieved into only 36 mothers of children whose SPPAHI score surpassed 30.

Then, these 36 mothers were directed to answer 22 questions of Zarit Burden Interview based on what they had been feeling received from caregiving their children with ADHD symptoms. The questionnaires had been through validity and reliability checks (20,22). Mothers were finally classified into burden levels ranging from minimum burden to no burden at all (score 0-21), minimum to moderate burden (score 21-40), moderate to high burden (score 41-60), and severe burden (score >60) groups according to the results. Analyses were operated on SPSS 25.0 using univariate and bivariate Chi-Square analyses. P value < 0,05 was required to statistically show significant correlation. This study was ethically legalized by Ethical Committee of Faculty of Medicine, Universitas Airlangga (Ref: No.64/EC/KEPK/FKUA/2023) and Surabaya Department of Education Ref: No.070/2023/436.7.1/2023).

RESULT

Sociodemographic Data of The Children and The Mothers Sociodemographic data of the pupils and their mothers are tabulated in Table 1 down below.

TABLE 1: Sociodemographic Data of The Elementary School Children with ADHD and Their Mothers in Surabaya, Indonesia 2023.

Children's Data	Category	Frequency (n)	Percentage (%)
Gender	Boys	19	52,8
Genuer	Girls	17	47,2
	8	1	2,8
Age	9	7	19,4
	10	12	33,3
	11	14	38,9
	12	2	5,6
ADHD Subtype	Inattentive	28	77,8
	Hyperactive/Impulsive	2	5,6
	Combined	6	16,7
Mothers' Data	Category	Frequency (n)	Percentage (%)
	25-35	9	25
Λαο	36-45	18	50
Age (yrs)	45-55	8	22,2
	> 55	1	2,8
	Elementary school or not formally	2	5,6%
	educated	3	8,3%
Education	Middle school	3 17	47,2%
	High school	14	38,9%
	Academy/University	14	30,7%
Occupation	Housewife	24	66,7
	Civil servants	1	2,8
	Private	8	22,2
	Miscellaneous	3	8,3
Marital Status	Married	28	77,8
mai itai status	Divorced	8	22,2
	< 1.500.000	15	41,7
Income	1.500.000 - 2.500.000	9	25
(IDR)	2.500.000 - 3.500.000	7	19,4
	> 3.500.000,00	5	13,9

Girls with ADHD symptoms were less in number (47,2%) compared to boys (52%). Majority of pupils involved in this study were 11 years old by nearly 40%. Inattentive type was revealed to be the most prevalent type (80%) among the other two, which were combine type (16,7%) and hyperactive/impulsive type (5,6%). Most mothers were high school graduates with merely two mothers who did not received formal education or only made it to elementary level. A mother is identified as a worker in governmental sector (2,8%). Housewives dominated among all by 66,7%. 77,8 of them remained married, whereas the other 22,2% had gone through separation. 41,7% of mothers earned less than IDR 1.500.000. The group with the higher income than the rest consisted of up to 14% of mothers. The mean income was between IDR 1.500.000 to IDR 2.500.000.

Mothers' Burden as Caregivers

Table 2 below shows the numbers of mothers grouped into each category of burden based on the results of Zarit Burden Interview questionnaire they had filled out.

TABLE 2: numbers of mothers grouped into each category of burden based on the results of Zarit Burden Interview questionnaire they had filled out.

Burden Level	Frequency (n)	Percentage (%)
Minimum to no burden at all	23	63,9
Minimum to moderate	13	36,1
Moderate to high	0	0
Severe	0	0
Total	36	100

23 mothers out of 36 endured least to no burden (63,9%), whilst the rest were placed in minimum to moderate level (36,1%). No mothers were screened for experiencing moderate to high burden nor severe burden.

Analyses on Relationship between Sociodemographic Factors and Mothers' Burden

Analyses were run with Chi-Square test to investigate whether sociodemographic factors in this study played significant part in caregiver burden that mothers experienced. The results unveiled that education, age, occupation, marital status, and income statistically did not all show significant relationships with mothers' burden as depicted in Table 3 below.

TABLE 3: Cross-Tabs between Sociodemographic Factors and Burden among Mothers of Elementary School Students with ADHD Symptoms in Surabaya, 2023.

		Mothers' Burden Level		
	Variables	Minimum to no burden at all (n (%))	Minimum to Moderate (n (%))	P
Age	25-35	5 (13,9)	4 (11,4)	
1180	35-45	11 (30,6)	17 (7)	
	45-55	6 (16,7)	2 (5,6)	0,723
	55-65	1 (2,8)	0 (0)	
Education	Elementary School	2 (5,6)	0 (0)	0,722
	Middle School	2 (5,6)	1 (2,8)	
	High School	10 (27,8)	7 (19,4)	
	Academy/University	9 (25)	5 (13,9)	
Occupation	Housewives	17 (47,2)	7 (19,4)	0,399
	Civil servants	1 (2,8)	0 (0)	
	Private	4 (11,1)	4 (11,1)	
	Miscellaneous	1 (2,8)	2 (5,6)	
Marital status	Married	17 (47,2)	11 (30,6)	0,458
	Divorced	6 (16,7)	2 (5,6)	
Income (IDR)	< 1.500.000	10 (27,8)	5 (13,9)	0,969
	1.500.001 - 2.500.000	6 (16,7)	3 (8,3)	
	2.500.001 - 3.500.000	4 (11,1)	3 (8,3)	
	> 3.500.000	3 (8,3)	2 (5,6)	

Based on the analyses output, no sociodemographic variables in this study were significantly associated with mothers' burden shown by each variable's p value exceeding 0,05.

DISCUSSION

This study showed that ADHD symptoms were exhibited more in male pupils. This revelation was agreeably supported by the former prevalence of ADHD in the United States presenting that boys outnumbered girls (5). Another research performed in Surabaya also came up with similar output (22). The pupils in this study were 8 to 12 years of age, which was in line with the guidance of ADHD diagnosis in DSM-5 pointing out that ADHD symptoms in children were supposed to be observed before the age of 12 (3).

The majority of the students in this study were categorized into inattentive type of ADHD. This has relevance with a study in Massachusetts, United States declaring that this type was found more in girls (23).

Inattention tends to put difficulties into children's effort to commence tasks they are meant to do and to bring themselves to a focus without any distractions (24). This also means that inattention may get in the way of the children with ADHD's studying method (25). Furthermore, children with ADHD are prone to weak persistence and demotivation in comparison to others without ADHD (26). This brings a consequence on much more time cost for them to reach completions (27).

Symptoms of ADHD may persist until a child strikes their adulthood phase and carry distressing impacts into their later lives in the shape of uncontrollably impulsive acts, unsatisfactory performance at work, horrendous social life, anxiety, and depression (28). Thereby, parents and tutors of children with ADHD symptoms should be in the front line harmoniously as their best support providers to not solely prevent the worse to occur in the future but also to encourage them to live up to their potentials with any positive ways possible.

This can begin through ADHD awareness uplift among parents and tutors and early screening carried out on students applying to not only inclusive schools but as well as mainstream schools based on the evidence that ADHD has been still underdiagnosed due to poor understanding on ADHD coupled with its stigmatization that still exist among society (29).

Burden in light level was carried by most of mothers involved in this study. This finding aligned with a prior study conducted in Iran (30). On the other hand, a finding in Lagos, Nigeria showed greater burden level. Another distinguished result came from a research conducted in Spain (14) which had lighter burden compared to this study (14). The variety of these outputs likely occur due to accessibility of mental health providers being unequally spread all over the world.

This study aimed to analyse whether mothers' sociodemographic data might significantly give a hint to the burden they had from keeping an eye on children with ADHD symptoms. The outcome came with no significant relationship between mothers' age, education, occupation, marital status, and income in the present study with the assessed burden. A bunch of former findings declared that age added a significant role in envisaging burden endured by caretakers of children who suffered long-term illnesses, both psychologically and physically (31,32,33). On the contrary, some discoveries highlighted caregivers' age being notably responsible in elevating the burden predisposition (17,34). This might be reasonable as the older caregivers are, the more vulnerable they are to exhaustion which later on will progressively diminish the quality of supports and adversely drive the burden to raise up (35). As in case for the education background, the finding in this study was consistent with a study in Iran performed on mothers looking after of their children with cerebral palsy (36). In contrast, a study in South Africa found that higher education history brought a significant influence in reducing caregiver burden (37). One's education background may determine their capability to overcome the burden they go through (38). The same as what this study revealed, prior discoveries presented occupation were not in relation with perceived burden level (30,37). A study in New York City was found to contradict this study pointing that burden was experienced higher among married couples (39). Burden may derive from pressure and distress mothers experienced from taking care of children with special needs (36). Consequently, they do not get the chance to have sufficient privacy and intimacy for themselves and their significant others (40). Lastly, disassociation between income and caregiver burden in this study mirrored some findings available (39,41), although they were all against other researches (30,37,42). Income may as well possess an important thing to do with needs that mothers as caregivers of children with ADHD symptoms have to fulfil (30).

LIMITATIONS

Further studies are expected to include more mothers whose children will have been positively screened with ADHD symptoms in hope for wider representability. Indirect interviews done in this study might contribute biases for the participant could have made their responses up to conceal the truth. Therefore, in-depth talks in person and supervisions may be preferrable as a way for the better.

CONCLUSION

In conclusion, most of mothers of elementary school students with ADHD symptoms in Surabaya endured burden in minimum to no-burden-at-all level with the results having no significant correlation to every sociodemographic factor in this study. A synergic collaboration should be carried out involving parents and tutors of children with ADHD symptoms hand in hand with supportive government through education department and mental health professionals to continuously voice the awareness of ADHD and its impact on the children themselves and their parents in the community, combat the stigma, and embolden us all that help is an openness away whenever they need it.

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CONFLICT OF INTEREST

The authors declared there to be no conflict of interest in this study.

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AUTHOR CONTRIBUTION

YS carried out the idea of this study and revision. NPN, ARHA, and RDAJH contribute to the design of the study, interpreted the results, and arrangement of the manuscript.

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