


Differences In Caregiver Burden Of Child Patients With Attention Deficit Hyperactivity Disorder And With Autism Spectrum Disorder At the West Java Provincial Mental Hospital and Grha Atma Main Clinic

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Article Info	ABSTRACT
<p>Keywords: ADHD, ASD, caregiver, caregiver burden.</p>	<p>Caregivers are individuals who provide assistance to those unable to carry out daily activities due to illness. They play a crucial role in offering support and aid to patients. Caregiver burden represents the pressure experienced by caregivers while attending to patients, encompassing physical, psychological, social, and financial strains. This research aims to explore whether there are differences in caregiver burden between caregivers of children with Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) at the Mental Health Hospital in West Java Province and Grha Atma Primary Clinic. Additionally, the study seeks to determine which caregiver burden is more substantial. This was a cross-sectional analytical study utilized purposive sampling, with 70 respondents, including 35 caregivers of ADHD patients and 35 caregivers of ASD patients. Primary data collection involved sociodemographic questionnaires to assess caregiver characteristics and the Zarith Burden Interview (ZBI) in Indonesian, consisting of 22 questions to measure caregiver burden. Univariate and bivariate analyzes were employed, and the results, presented in narrative and tabular form, revealed a significant difference in caregiver burden between ADHD and ASD caregivers. Overall, the caregiver burden for ASD (42.34) was found to be higher compared to ADHD caregivers (28.66). Based on these findings, the study recommends healthcare professionals at the Mental Health Hospital in West Java Province and Grha Atma Primary Clinic to provide counseling on workload management to prevent caregivers from experiencing excessive burdens.</p>
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INTRODUCTION

Caregiver is a person who provides assistance to people who have disorders or problems in carrying out their daily activities due to the illness they suffer from. Because of this, *caregivers* need the ability to balance their dual roles as caregivers for patients and as themselves who

carry out their activities.^{1,2} Children with special needs or ABK are children who have limitations in terms of physical, mental, thinking abilities, and abilities in socialize.³

Currently, the average Indonesian person knows that medical personnel are the ones who handle and provide full care to patients for 24 hours. However, in fact, according to research, it is the family who cares for and takes care of sick patients.¹ One of the disorders in children that requires the role of parents as *caregivers* is child patients with *Attention Deficit Hyperactivity Disorder* and *Autism Spectrum Disorder*.^{4,5} With Thus, this review aims to differentiate the burden experienced by *caregivers of Attention Deficit Hyperactivity Disorder* and *Autism Spectrum Disorder* patients at the West Java Provincial Mental Hospital and Grha Atma Main Clinic.

MATERIALS AND METHODS

This study uses an analytical research type with a *cross-sectional design*. The study was conducted at the West Java Provincial Mental Hospital and the Grha Atma Main Clinic with the subjects used being data *from caregivers* of children with ADHD and ASD who had met the research criteria. The number of samples in this study was 70 people taken using the *purposive sampling method*. The data in the study were taken using primary data, namely sociodemographic questionnaires and *Zarith Burden Interviews*. The study has carried out an ethical permit with letter number 15292/KH.07.02.01/RSJ.

RESULTS AND DISCUSSION

This research was conducted in West Java Provincial Mental Hospital and Grha Atma Main Clinic with a total sample of 70 that have met the research criteria. For patient data attached in table 1.

Patient	ADHD		ASD	
	N	%	N	%
Gender				
Man	31	88.6%	26	74.3%
Woman	4	11.4%	9	25.7%
Age				

Table 1. Patient data

2	1	2.9%	0	0%
3	2	5.7%	1	2.9%
4	0	0%	4	11.4%
5	1	2.9%	4	11.4%
6	2	5.7%	2	5.7%
7	8	22.9%	4	8.6%
8	7	20%	4	8.6%
9	4	11.4%	6	17.1%

10	8	20% 7 20%
11	3	8.6% 5 14.3%

Table 1 shows data on ADHD and ASD patients based on gender, the largest number is male, namely 31 people (88.6%) for ADHD and 26 people (74.3%) for ASD. Based on age, the largest number of ADHD patients are patients aged 7 and 10 years, namely 8 people (20%), in ASD patients the largest number of patients are aged 10 years, namely 7 people (20%).

The results of the study based on gender are based on the epidemiology of both disorders. According to research conducted by Diana PT, it is more common in ADHD patients in boys than girls. ⁶ Several research results state that boys have a greater risk of autism than girls, this is due to the genetic process of autism. ⁷ Other research results state that male gender, both ADHD and ASD patients, have more severe symptoms than girls, so this can affect the burden experienced by *caregivers*. ^{8,9}

The results of the study based on the age of the patients showed that the highest age for children was 7 and 10 years. ADHD and 10 years in ASD children, in detecting abnormalities in this case due to the lateness of the child's parents. ^{10,11}

	N	%	N	%
Gender				
Man	4	11.4%	10	28.6%
Woman	31	88.6%	25	71.4%
Age				
< 30 years	10	28.6%	4	11.4%
31 – 40 years	17	48.6%	20	57.1%
41 – 50 years	8	22.9%	8	22.9%
> 50 years	0	0%	3	8.6%
Gender				
Man	4	11.4%	10	28.6%
Woman	31	88.6%	25	71.4%
Age				
< 30 years	10	28.6%	4	11.4%
31 – 40 years	17	48.6%	20	57.1%
41 – 50 years	8	22.9%	8	22.9%
> 50 years	0	0%	3	8.6%
Gender				
Man	4	11.4%	10	28.6%
Woman	31	88.6%	25	71.4%
Age				

< 30 years	10	28.6%	4	11.4%
31 – 40 years	17	48.6%	20	57.1%
41 – 50 years	8	22.9%	8	22.9%
> 50 years	0	0%	3	8.6%

The Role of ADHD Caregivers		ASD	
N	%	N	%
Caregiver	0	0	0%
Introduction	0	0	0%
Babysitter & delivery person	35	35	100%

In Table 2. Shows The role of caregivers for both child patients with ADHD and ASD as a whole is caregivers and escorts with 35 people (100%). This is because most of the patients met act as parents of patients. There is research that states that caregivers Caregiver Most children with special needs are parents as caregiving and accompanying

In Table 2. Shows The role of *caregivers* for both child patients with ADHD and ASD as a whole is caregivers and escorts with 35 people (100%). This is because most of the patients met act as parents of patients. There is research that states that *caregivers Caregiver*

Caregiver Data	ADHD		ASD	
Marital status				
Marry	32	91.4%	34	97.1%
Not married yet	0	0%	0	0%
Widow/Widower	3	8.6%	1	2.9%
Last education				
SD	3	8.6%	0	0%
JUNIOR HIGH SCHOOL	3	8%	2	5.7%
High School/Vocational School	16	45.7%	19	54.3%
Bachelor	13	37.1%	14	40%
No school	0	0%	0	0%
Employment Status				
Government employees	4	11.4%	3	8.6%
Private sector employee	5	14.3%	3	8.6%
Self-employed	2	5.7%	4	11.4%
Retired	0	0%	0	0%
Housewife	22	62.9%	21	60%
Other	2	5.7%	4	11.4%
Patient Relations				
Parent	35	100%	35	100%
Siblings	0	0%	0	0%
Other	0	0%	0	0%
Long Care				

< 1 year	0	0%	0	0%
12 years old	0	0%	0	0%
> 2 years	35	100%	35	100%
Income	5		6	
< Rp. 1,000,000	19	14.3%	21	17.1%
Rp. 1,000,000 – Rp. 3,000,000	11	54.3%	8	60%
> Rp. 3,000,000		31.4%		22.9%
<i>Caregiver</i>				
Heavy load	2	5.7%	7	20%

Most children with special needs are parents as *caregiving* and *accompaning*.

Table 3. Characteristics of ADHD and ASD *caregivers*

Medium – heavy load	2	5.7%	10	28.6%
Light – medium load	17	48.6%	13	37.1%
Minimum load/no load	14	40%	5	14.3%

In Table 3. It is obtained patient *caregiver* characteristics results ADHD and ASD do not have any differences. Based on gender, the most are women, namely ADHD 31 people (88.6%) and ASD 25 people (71.4%). This is due to the stigma and culture in Indonesia which believes that women are the ones who take care of family members, whether healthy or sick, optimally. ¹² Based on age, the most *caregivers* are 30-40 years old, namely 17 people (48.6%) in ADHD and 20 people (57.1%) in ASD. This age is a productive age and many people at that age do many activities so that it will interfere with *the caregiver's time* and cause stress or burden. ¹⁰ Based on marital status, the most are married, namely 32 people (91.4%) in ADHD *caregivers* and 34 (97.1%) in ASD *caregivers*. This is in accordance with research conducted by Sisca MR et al. which stated that *caregivers* with married status have a higher burden of care due to the responsibilities and conditions of the *caregiver's family*. ¹³

Based on the last education, the most were high school/vocational school, namely 16 people (45.7%) in ADHD *caregivers* and 19 people (54.3%) in ASD *caregivers*. The education and knowledge of *caregivers* will influence information regarding disorders in patient. Based on the most jobs, *caregivers* are housewives, namely 22 people (62.9%) ADHD *caregivers* and 21 people (60%) ASD *caregivers*. *Caregivers* who do not work or only act as housewives do not have other activities other than caring for and nurturing patients, so this will cause a feeling of boredom and stress. ⁸

Based on the relationship with the patient, the overall *caregiver of* ADHD and ASD is the parent. This is because the majority of *caregivers* of children with special needs are parents who have full responsibility for the condition or circumstances experienced by their children. ¹¹ Based on the length of care, both *caregivers* overall have cared for patients > 2 years. This is because all respondents have cared for patients since they were small or since birth. Other studies state that the longer the time of caring for patients, the higher the likelihood of a heavy burden experienced. ¹² Based on family income, both ADHD and ASD *caregivers* are at most IDR 1,000,000 - IDR 3,000,000. This income according to the West

Java UMR is included in the low category. Research conducted by Yolla N et al. states that low economic conditions will affect a person in obtaining information related to the patient's illness, in addition it can have an impact on service costs health that needs to be done.^{2,12}

caregiver burden, the most are light-moderate burdens, namely 17 people (48.6%) in ADHD *caregivers* and 13 people (37.1%) in ASD *caregivers*. However, when viewed from the heavy burden, the most caregivers are ASD caregivers, namely 7 out of 35 respondents (20%), while ADHD *caregivers* are 2 out of 35 respondents (5.7%). This result is due to the complexity of ASD symptoms which are more severe than ADHD symptoms.^{5,9,10}

Table 4. Differences in *caregiver* burden

Burden	Group	N	Mean
Physical load	ADHD	35	30.46
	ASD	35	40.54
Psychological burden	ADHD	35	6.20
	ASD	35	9.37
Social burden	ADHD	35	28.31
	ASD	35	42.69
Financial burden	ADHD	35	32.43
	ASD	35	38.57
Total load	ADHD	35	28.66
	ASD	35	42.34

From table 4. shows the results of the physical burden of ASD *caregivers* (40.54) is heavier compared to ADHD *caregivers* (30.46), the psychological burden of ASD *caregivers* (9.37) is heavier compared to ADHD *caregivers* (6.20), the social burden of ASD *caregivers* (42.69) is heavier, the financial burden of ASD *caregivers* (38.57) is heavier compared to ADHD *caregivers* (32.43). compared to ADHD *caregivers* (28.31), the total burden of *caregivers*

ASD (42.34) was more severe compared to ADHD *caregivers* (28.66).

The physical burden of ASD *caregivers* is heavier than ADHD *caregivers* because ASD symptoms are hyperactive and even tend to be aggressive, often commit self-harm, and experience mood swings that often cause *caregivers* to need intensive supervision.⁷ This will increase the need for physical assistance from *caregivers* so that the dependence of ASD patients is what makes *caregivers* unable to be far from ASD patients.^{8,11}

The psychological burden of ASD *caregivers* is heavier than ADHD *caregivers* because ASD symptoms include difficulty in communicating and socializing, resulting in ASD *caregivers* having difficulty understanding the patient's wishes and because of this challenge in communicating, it causes *stress*.¹⁴ It can also be seen from other symptoms of ASD patients, namely they tend to be aggressive, often commit acts of self-harm, and experience frequent mood swings, this can result in tension and emotional feelings in *caregivers* when with patients.¹¹

The social burden of ASD *caregivers* is heavier than ADHD *caregivers* because compared to their peers, ASD children are usually left behind in the development of

communication, social skills and cognition. In addition, there are also dysfunctional behaviors that appear, such as repetitive activities and behaviors that have no purpose. Characteristically, it can usually be clearly seen from these symptoms that the patient has ASD, in contrast to ADHD which is like a normal child.^{9,12}

The financial burden of ASD *caregivers* is heavier than ADHD *caregivers* because children with ASD require intensive and special interventions, such as applied behavioral therapy (ABA). This therapy requires a lot of money. When compared to therapy for ADHD, it does not require the same level of special and intensive care as for ASD. Therapy for ADHD can focus on behavioral management and approach strategies that can be applied.¹⁵

In terms of total burden, the results showed that the burden of ASD *caregivers* was heavier than that of ADHD *caregivers*. These results are in accordance with research conducted by Gabra & Hashem in Egypt which stated that the burden of ASD *caregivers* was heavier than that of ADHD *caregivers*.⁹ This is due to the complexity of ASD symptoms and behaviors such as difficulty in communicating, challenges in interacting or socializing, and the presence of repetitive and obsessive actions.

CONCLUSION

There is a significant difference between the burden of *caregivers* of children with *Attention Deficit Hyperactivity* (ADHD) and *Autism Spectrum Disorder* (ASD). In terms of physical burden, *caregivers* of ASD (40.54) are heavier than *caregivers* of ADHD (30.46). In terms of psychological burden, *caregivers* of children with ASD (9.37) are heavier than *caregivers* of ADHD (6.20). In terms of social burden, *caregivers* of children with ASD (42.69) are heavier than *caregivers* of ADHD (28.31). In terms of financial burden, *caregivers* of children with ASD (38.57) are heavier than *caregivers* of ADHD (32.43). In total, the burden of *caregivers* of children with ASD (42.34) is heavier than *caregivers* of ADHD (28.66).

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