

Differences in Caregivers' Burden in Caring for Children with Intellectual Disabilities who Attend Formal and Non-Formal Education

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Abstract

Background: Children with Intellectual Disabilities (ID) or mental disorders caused by genetic disorders have a higher risk of morbidity and mortality than normal individuals. Long dependence causes the caregiver burden to increase. **Objective:** To measure the difference in caregiver burden on ID children attending formal and non-formal education. **Method:** The type of research used is observational analytic with a cross-sectional approach. The number of samples was 85 respondents, with 55 parents with children in formal education and 30 having non-formal education. The research instrument used the ZBI (Zarit Burden Interview) questionnaire. Statistical data were analyzed using the Mann-Whitney U Test. **Results:** A total of 42 (76.4%) respondents with ID children attending formal education has no burden, while 28 (93.3%) respondents with non-formal education ID children considered it moderate. **Conclusion:** The Mann-Whitney U Test shows a significant value of < 0.000 or < 0.05 , which states that there is a significant difference between the burden of caregivers for ID children and formal and non-formal education. For future research, we recommend that the classification of formal and non-formal education be explained in more detail by involving inclusive education and home-schooling.

Keywords: burden, caregiver, intellectual disability



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INTRODUCTION

Intellectual disability (ID) is a mental disorder based on genetic diseases that impact cognitive function disabilities and limitations in adaptive development (1). Children with ID have a higher risk of morbidity and mortality than normal individuals (2). Physical problems such as obesity, cancer, thyroid dysfunction, epilepsy, and dental and oral issues are often reported as the main problems in ID children (3).

UNICEF says 10 to 25% of people in the world have disabilities. Meanwhile, in Indonesia, the prevalence of children with ID reaches 14.2% of the total population. Based on data from the Social Service Department, the number of people with ID in Jember Regency reached 1,929. The Indonesian Ministry of Health recorded 4000 new ID cases undergoing outpatient therapy (4). Data from a preliminary study showed that around 100 ID children attended formal education in Sekolah Luar Biasa (SLB) C, Jember Regency.

The lack of ability to fulfill the basic human needs and be involved in the social environment is considered difficult for ID children, so it becomes a burden for the family, especially the caregivers (5). Children with ID are highly dependent and need long-term protection and assistance. The burden on caregivers has a negative impact on physical, social, financial, emotional, and family relationships (6,7). Physical effects include improvement and declining health levels because they have to take care of ID children daily to meet their needs.

The challenges and needs of daily care are the main reasons for the greatest stress on the elderly. Parents need time to adapt so that although there are still parents who reject their children, in the end, they can accept children with special needs (8,9). In a study by Desriyani (2019), it is stated that parents of ID children who attend school have a burden in the light category (10). On the other hand, Suresh's research (2022) said that the load is heavier on caregivers who raise ID children who do not have formal education (11).

Differences in caregiver burden are closely related to IQ (Intellectual Quotient) status and individual behavior (12). Lack of IQ

is one of the causes of children suffering from ID. Apart from IQ, the chronology of the causes of ID is due to genetic factors. Chromosomal abnormalities often cause ID and are associated with other physical abnormalities (13,14). Based on this background, the authors are interested in examining these differences.

OBJECTIVE

This study was conducted to measure the difference in caregivers' burden for ID children who attend formal and non-formal education.

METHODS

Design

This study uses an observational analytic research design using a cross-sectional approach.

Sample size and sampling technique

The population in this study were parents of students who had formal non-formal education. The sampling technique used is total sampling. Respondents in this study were 55 parents who had ID children with proper education and 30 with non-formal ID children. This research was carried out at SLB-C Jember and in the community from June to July 2021.

The inclusion criteria in this study were parents who had ID children who went to school and parents who had ID children who did not go to school and lived with ID children. In contrast, the exclusion criteria were parents who had ID children with chronic metabolic disease (DM) and heart disorders and were not present at the time of the study.

Research instrument and data collection

We used a questionnaire as a caregiver burden research instrument. The Zarit Burden Interview (ZBI) questionnaire consists of 22 questions. It has been tested for validity and reliability with the value of the person product-moment correlation test (0.88) and the Cronbach Alfa test (0.91). The assessment score is 0-4, with the lowest score of 0 and the highest being 88, related to personal pressure and pressure that requires a caregiver pattern in raising ID children. Each answer choice has a

score of never=0, rarely=1, sometimes=2, often=3, and always=4.

Data analysis

The collected data is selected for completeness (screening process) and then entered into SPSS version 25 for analysis (coding and entry process). The characteristics of the respondents are shown in the frequency and percentage tables. While the difference in load was analyzed using the Mann-Whitney U Test.

Ethical Consideration

This study received ethical approval from the Ethics Commission of the Faculty of Nursing, Jember State University, East Java Province, with the number 114/UN25.1.14./KEPK/2021.

RESULTS

Characteristic of respondent

Table 1. Characteristic of respondent

Variables	Children Education		Total
	Formal	Non-Formal	
	N (%)	N (%)	
Sex			
Male	21 (38.2)	12 (63.0)	33 (38.8)
Female	34 (61.8)	18 (37.0)	52 (61.2)
Age			
26-45 yo	40 (72.7)	25 (83.3)	65 (76.5)
46-65 yo	15 (27.3)	5 (16.7)	20 (23.5)
Burden level			
No	42 (76.4)	0 (0.0)	42 (76.4)

Table 2 Differences in Caregiver Burden

Variable	Formal Education		Non-Formal Education		p
	Mean±SD	Min-Max	Mean±SD	Min-Max	
Burden level	16.8 ± 11.6	3-44	48.6 ± 6.00	34-63	0.000

DISCUSSION

Identification of caregiver burden in caring ID children with Formal Education

Based on the results of the research that has been carried out, it can be seen that the burden of caregivers for ID children who are formally educated, out of 55 respondents in SLB-C Jember Regency does not experience the burden with a majority of 42 respondents (76.4%). This is in line with previous research,

Mild	10 (18.2)	1 (3.3)	11 (12.9)
Moderate	3 (5.5)	28 (93.3)	30 (35.3)
Severe	0 (0.0)	1 (3.3)	1 (1.2)

Based on the table above, it can be concluded that the characteristics of respondents with ID children with formal education are 55, with the majority of women 34 (61.8%) and men 21 (38.2%). Meanwhile, the respondents with non-formal education were 30, the majority of whom were women, 18 (37.0%), with the age range of respondents being 26-45 years. Based on the scoring results, the burden of caregivers is classified into the categories of has no burden, mild, moderate, and severe. It can be seen that respondents with formally educated ID children do not predominantly consider the burden of raising ID children, with the majority of respondents 42 (76.4%). On the other hand, respondents who have non-formal education ID children have a caregiver burden in the moderate category 28 (93.3%).

Differences in Caregiver Burden

Statistical analysis using the Mann-Whitney test showed a significant difference in burden status between caregivers of ID children who attended formal and non-formal education ($p = 0.000 < 0.05$). The difference in mean and SD in the two groups of respondents can be seen in Table 2 below.

which stated that parents who send their children to special schools tend to feel that there is no burden (15). One of the reasons is because parents have a good perception of the treatment given by the school to formal education ID children.

Formal education is generally found in schools through a predetermined curriculum learning process (16). In formal education in Indonesia, there are still many discriminations

or other terms “bullying” against children who are considered different from the others (17). The helplessness of children with ID is often used as a differentiator from children given the predicate “normal.” It is undeniable that many Indonesians still assume that children with ID cannot compete with “normal” children (18). In addition, it is rare to be ostracized from friends because students who study at SLB, on average, have almost the same characteristics. This can increase parents' perception of confidence to meet all kinds of demands in ID childcare.

Law number 20 of 2003, article 32 states that special education is education for students who have difficulty participating in the learning process due to physical, emotional, mental, and social disorders and have the potential for superior intelligence and talent (19). Through the ministry of education and culture, the Indonesian government classifies special education in SLB-A, SLB-B, SLB-C, SLB-D, SLB-E, and SLB-G. The classification is based on groups of students with different special needs. SLB-A is an SLB specifically for blind people. Blindness is a condition of a person experiencing obstacles and limitations in his sense of sight. The teachers at SLB-A teach students in a method understood by the blind. The teacher teaches with braille letters and writing, object models, embossed letters, and sound recordings (20).

This study has the same results as the theory of Poetry in Hadi Kosasih (2016), which states that parental acceptance is better after ID children attend formal education. Formal schools are proven to improve the basic skills of ID children, especially in carrying out daily activities (21).

Identification of caregiver burden in caring ID children with non-Formal education

Based on the research results, it can be seen that the burden of non-formal ID children caregivers from 30 respondents in the community is in the moderate burden category, namely 28 (93.3%). According to researchers, caregivers' burden for non-formal ID children is categorized as moderate due to the limitations of ID children and the low ability to carry out daily activities.

These results align with Oti-Boadi's research (2017), which shows that parents with non-formal ID children have a caregiver burden categorized as a heavy burden (22). The study by Prasa (2012) explained that the source of stress for parents with non-formal ID children is the loss of hope when previously, parents had certain expectations if their child was born normal. The mismatch between expectations and reality makes parents with non-formal ID children need more time to accept the child's situation. Parents who have not been able to take their children's condition tend to feel stressed in caring for children with non-formal ID. The lower the parental acceptance of non-formal ID children, the higher the perceived parenting stress (23).

The problems most often arise from the experiences experienced by caregivers in raising ID children, especially to become independent children. The child's lack of ability to fulfill personal hygiene, lack of attention from children when trained on independence by caregivers, and children's speaking problems are unclear (24). This can be a burden for caregivers raising ID children. Mace and Rabins in Retnaningsih (2016) state that raising ID children can have social and financial impacts on families who care for them because of the disability conditions of ID children, thus becoming a burden for the care of ID children (25). Therefore, the caregiver will need support from family members.

Analysis of Differences in Caregivers' Burden in Caring for Children with Intellectual Disabilities who Attend Formal And Non-Formal Education

In this study, the results showed differences in caregivers' burden on raising ID children who attended formal and non-formal education. We concluded that parents as caregivers of ID children with proper education have no burden, while parents who take care of non-formal ID children are more burdened.

According to research by Jenaro (2020), non-formal ID caregivers cause anger, stress, and depression in parents (26). The impact of depression on parents of children with disabilities will affect the role of parents in parenting, inhibit assistance for children, and

reduce support for children to minimize these disorders or disorders (27). The burden of caregivers for ID children with formal education felt no burden because they received assistance at school in developing the potential of ID children (28).

According to the researcher's assumption, caregivers have differences in the burden of raising ID children who attend formal and non-formal education. Parents who raise children with non-formal ID feel burdened by this because of the characteristics of the parents, the aspects of the child, lack of self-control, and lack of social support.

Conclusion

Based on the results of research and discussions that have been carried out regarding the differences in the burden of caregivers in raising ID children who attend formal education in SLB-C and non-formal, the authors draw the following conclusions:

1. Most caregivers' burdens for DI children who attend formal education are not burdensome.
2. Most of the non-formal DI childcare burdens fall into the heavy burden category.
3. There is a significant difference between the burden of caregivers raising DI children who attend formal education in SLB-C and non-formal, with a value of $0.000 < 0.05$

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