



DESCRIPTION OF STRESS ON PARENTS IN CARING FOR CHILDREN WITH INTELLECTUAL DISABILITIES

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ABSTRACT

Children with intellectual disabilities have limitations in cognitive functions and adaptive behavior. This makes parents who have children with intellectual disabilities face many problems like social isolation, community stigma, loss of hope, and unrealistic expectations regarding children's conditions. This research aims to determine the stress on parents in caring for children with intellectual disabilities. This research uses quantitative descriptive methods. The sampling strategy used total sampling and obtained sample 74 of parents who had children with intellectual disabilities without comorbidities and whose children attend at the SLB Negeri Cileunyi. Data were collected using the parenting stress scale questionnaire. Data analysis was conducted using univariate analysis with cross-tabulation. The results of this research are that the majority of parents of children with intellectual disabilities experience low levels of parenting stress. Based on the characteristics of respondents, higher levels of parenting stress were experienced by mothers aged between 45-65 years, with secondary education, not working, and with a monthly family income below the minimum wage. Meanwhile, based on children's characteristics, parents who have higher levels of parenting stress have daughters aged between 12-21 years with moderate intellectual disabilities.

Keywords: child with intellectual disabilities; parents; parenting stress

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INTRODUCTION

The presence of children with healthy optimal growth and development conditions is the desire of all parents. However, in reality, there are various problems or disorders in child development. Child development includes physical, behavioral, and cognitive development. Developmental disorders that occur in children make children experience limitations or disabilities. According to the Ministry of Health in 2018, the overall prevalence of disability incidence in children aged 5-17 years in Indonesia reached 3.3%, of which 2.8% was the incidence of disability in West Java Province (Ministry of Health RI, 2018). The most common disability found in children is intellectual disability. Intellectual disability also known as tunagrahita is a developmental disorder characterized by a decrease in cognitive or intellectual function and adaptive behavior that occurs before the child reaches the age of 18 years (American Association on Intellectual and Developmental Disabilities, 2010). In this condition, mental development is stalled or incomplete, characterized by skill limitations during development that impact all intellectual levels such as cognitive, language, psychomotor, and social, characterized by IQ scores below 70, indicating significant deficits

in intellectual functioning (International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10), 2019).

The condition of limited intellectual function and adaptive behavior that occurs in children with intellectual disabilities has an impact on children's limited ability to communicate, solve problems, carry out daily activities, and have significant delays in both academic and non-academic learning (Afifah, 2021). The limitations that children with intellectual disabilities have to make children need help from others and cause high dependence of children on their parents (Mardiawati, 2019). Parents are responsible and play a role in raising, caring for, and educating children. However, when parents are faced with the presence of children who have limitations and lifelong dependence, the responsibilities of parents become heavier. The limitations of children with intellectual disabilities also make parents experience difficult situations. The high dependence of children on their parents in carrying out daily activities and children's behavioral problems cause parents to feel high physical fatigue (Ramadhany, Larasati, and Soleha, 2017). In addition, the condition of the child's disability also creates a psychological burden on parents related to feelings of disappointment and guilt about the child's condition, negative stigma from society, loss of hope and unrealistic expectations of the child, lack of family support and feelings of pessimism about the child's future, and the high financial burden that makes parents experience stress.

Stress is a condition that occurs due to changes in the internal and external environment of an individual that is perceived as a threat (Zaini, 2019). Stress begins with an imbalance that occurs between the demands and resources of the individual. Stress that is prone to be experienced by parents is stress in the parenting process. Parents of children with disabilities report higher levels of stress and lower levels of quality of life compared to parents of normal children (Dizdarevic et al., 2022). In addition, when compared to parents of normal children, parents of children with intellectual disabilities suffer from higher levels of depression, stress, and anxiety. This is caused by behavioral problems in children with intellectual disabilities (Eddy, 2013). Parenting stress felt by parents of children with developmental disabilities is influenced by marital satisfaction, social support, family income, conflict with spouse, and severity and type of disability (Ali Nathwani et al., 2021). Parenting stress felt by parents can disrupt the parenting process and have various negative impacts on individuals, family functions, and children with intellectual disabilities. The impact of parenting stress leads to depressive parents, conflicts with spouses, overreactions to children's behavior to violence against children which can hurt child development (Neece, Green, and Baker, 2012). Negative parenting can also hurt children's social relationships with peers, compliance with parents, and emotional well-being (Aisha and Aska, 2022).

Although children with intellectual disabilities have limitations in intellectual functioning and delays in the learning process, children with intellectual disabilities must also receive rights that are commensurate with normal children in general. One of the rights that children with intellectual disabilities must receive is the right to education. There are two education systems for children with disabilities in Indonesia: integration schools or inclusive schools and segregation schools or special schools (SLB). Integration schools, also known as inclusive education, is an education system that allows all students with special needs, including students with disabilities, to participate in class education together with general students (Directorate of Primary Schools, 2021). Meanwhile, special schools (SLB) are schools that provide special education to students who experience physical, mental, social, and emotional disorders or have special potential and talents. Special schools are classified according to the type of disability, which consists of SLB A for the blind, SLB B for the deaf, SLB C for the

tunagrahita, SLB D for the tunadaksa, SLB E for the tunalaras, and SLB G for multiple disabilities (Suharsiwi, 2017).

It is recorded that the number of children with intellectual disabilities in Indonesia who are studying in special schools (SLB), both public and private, in the 2020/2021 school year is 80,837 children out of a total of 144,621 children with special needs with 14,991 children being SLB students in West Java Province (Pusdatin Kemendikbud, 2021). Bandung Regency has the third highest number of special schools in West Java after Bogor City and Bandung City. One of the special schools in Bandung Regency is SLB Negeri Cileunyi. SLB Negeri Cileunyi is one of the public special schools in Bandung Regency with the largest number of students, namely 235 students consisting of 145 male students and 90 female students with 68 study groups, where the most common type of disability in this special school is intellectual disability.

Parents' feelings of stress in caring for children with intellectual disabilities were also identified in the parents of SLB Negeri Cileunyi students. Researchers conducted interviews with several parents of children with intellectual disabilities who actively attended the school and from the results of the interviews obtained the results that parents felt sad and did not accept when they first heard that their children were diagnosed with barriers in intelligence. Parents said that while caring for their children, they felt afraid when they had to go out with their children and meet with many people because they were worried that their children would disturb others or do things out of control. Parents also said that their child was not accepted as well as normal children in the community. Some family members also still cannot accept the child's condition which is not like normal children in general. Parents are worried about their child's future condition when the child will have to be independent in socializing in the community. This is because the child always obeys the orders of others or his friends even though the order can endanger him.

Parents also find it difficult to understand what their child wants so they have to guess many times and this makes the child angry. When children get angry or have tantrums, parents also say that they must have unlimited patience to deal with children and it is not easy to control their emotions when they see children's tantrums. One parent said that sometimes they feel sad and futile in caring for a child with intellectual disabilities and question why there is no development or progress from their child even though they have been cared for wholeheartedly. In interviews, parents said that although it was difficult, they tried to accept their child's condition and considered that their child was a child of heaven who would be a field of reward for parents who cared for them wholeheartedly.

Many previous studies have compared parenting stress in parents of children with intellectual disabilities who have comorbidities with parents of children who have other developmental disorders and the various factors that cause high and low levels of parenting stress in parents. However, each region with different populations certainly has its characteristics related to parenting stress. In addition, research with a focus on issues related to parenting stress experienced by parents of children with intellectual disabilities without comorbidities based on parental characteristics (gender, age, latest education, occupation, and income) and child characteristics (child's gender, child's age, and level of disability) has not been carried out by previous studies. Based on the literature review results and the phenomena found in SLB Negeri Cileunyi, the problem of parenting stress is a serious problem that must be addressed due to the various negative impacts caused by stress in the parenting process. Therefore, this study aims to see the description of the stress experienced by parents in caring for children

with intellectual disabilities without comorbidities at SLB Negeri Cileunyi by looking at the factors that cause parenting stress on the characteristics of parents including gender, age of parents, latest education, occupation, and family income as well as the characteristics of children including the sex of the child, the age of the child, and the level of the child's disability.

METHOD

This research is quantitative descriptive research. The population in this study were parents of children with intellectual disabilities in SLB Negeri Cileunyi. The sample determination was carried out using the total sampling technique and obtained a sample of 74 parents who had children with intellectual disabilities without comorbidities and actively attended school at SLB Negeri Cileunyi. The variable in this study is a single variable, namely parenting stress experienced by parents of children with intellectual disabilities without comorbidities in SLB Negeri Cileunyi. Data were collected directly using a respondent demographic data questionnaire, a child data questionnaire, and the Parenting Stress Scale Questionnaire adapted to Indonesian by Kumalasari (2022) into a parenting stress scale questionnaire with 15 question items consisting of positive and negative aspects in parenting process. The instrument has been tested for validity and reliability with a validity test value of 0.7 and Cronbach Alpha of 0.828. Data were analyzed using univariate analysis and cross-tabulation between parenting stress variables and factors causing parenting stress from the parent domain and child domain which were then described in three categories of parenting stress, namely low, moderate, and high parenting stress. This study has obtained ethical permission from the Research Ethics Committee of 'Aisyiyah University Bandung with No. 699/KEP.01/UNISA-BANDUNG/1/2024. Research respondents have been explained the research to be carried out and signed informed consent in advance as a form of agreement to participate in the study.

RESULTS

Table 1.
Respondent Characteristics (n=74)

Respondent Characteristics	f	%
Gender		
Female	61	82.4
Male	13	17.6
Age		
Early Adulthood (21-35 tahun)	8	10.8
Middle Adulthood (36-45 tahun)	30	40.5
Late Adulthood (46-65 tahun)	33	44.6
Old Age (>65 tahun)	3	4.1
Educational Background		
Elementary Education (SD/MI)	3	4.1
Middle Education (SMP/SLTP/MTS/SMA/SLTA/MA/SMK)	57	77.0
High Education (Diploma/Sarjana/Magister/Doktor)	14	18.9
Occupation		
Work	23	31.1
Doesn't work	51	68.9
Family Income		
≤Regional Minimum Wage (≤Rp.3.492.465)	49	66.2
≥Regional Minimum Wage (≥Rp.3.492.465)	25	33.8

Table 1 shows the characteristics of the respondents and it was found that female respondents or mothers participated more in this study. The majority of respondents were in the late adult

age range of 46-65 years old, with the majority of respondents having a middle education background (SMP/SLTP/MTS/SMA/SLTA/MA/SMK). The majority of respondents were unemployed and had a monthly family income below the average minimum wage.

Table 2.
Child Characteristics

Child Characteristics	f	%
Gender		
Female	22	29.7
Male	52	70.3
Age		
Preschool	2	2.7
School Age	25	33.8
Adolescent	47	63.5
Level of Intellectual Disability		
Mild	36	48.6
Moderate	24	32.4
Severe	13	17.6
Profound	1	1.4

Table 2 shows the characteristics of the children. The majority of children with intellectual disabilities who actively attend school at SLB Negeri Cileunyi are male, with the age of the children being in the adolescent age range (12-21 years). The types of intellectual disabilities suffered by children are mostly mild level of intellectual disabilities and there is only one child who suffers from profound intellectual disabilities.

Table 3.
Level of Parenting Stress

Level of Parenting Stress	f	%
Low	65	87.8
Moderate	9	12.2
High	0	0

Table 3 shows the level of stress experienced by respondents in caring for children with intellectual disabilities during the past month. The majority of respondents experienced low levels of parenting stress and there were no respondents who experienced high levels of parenting stress during the past month.

Table 4 shows that the highest number of respondents for both fathers and mothers experienced low levels of parenting stress. Meanwhile, the mother experienced the most moderate level of parenting stress. The majority of respondents who experienced low and moderate levels of parenting stress were in late adulthood, namely the range of 46-65 years. All respondents who experienced moderate levels of parenting stress had a history of middle education (SMP/SLTP/MTS/SMA/SLTA/MA/ SMK). Almost all respondents who worked or did not work experienced low levels of parenting stress. However, respondents who did not work and had a family income per month below the minimum wage experienced more moderate levels of parenting stress.

Table 4.
Cross-tabulation of Respondents' Characteristics and Level of Parenting Stress

Respondent Characteristic	Level of Parenting Stress			
	Low		Moderate	
	f	%	f	%
Gender				
Female	53	56.9	8	13.1
Male	12	92.3	1	7.7
Age				
Early Adulthood	7	87.5	1	12.5
Middle Adulthood	27	90	3	10
Late Adulthood	28	84.8	5	15.2
Old Age	3	100	0	0
Pendidikan Terakhir				
Elementary Education	3	100	0	0
Middle Education	48	84.2	9	15.8
High Education	14	100	0	0
Occupation				
Work	20	87	3	13
Doesn't Work	45	88.2	6	11.8
Family Income				
≤Regional Minimum Wage	42	85.7	7	14.3
≥Regional Minimum Wage	23	92	2	8

Table 5.
Cross-tabulation Child Characteristics and Level of Parenting Stress

Child Characteristics	Level of Parenting Stress			
	Low		Moderate	
	f	%	f	%
Gender				
Female	16	72.7	6	27.3
Male	49	94.2	3	5.8
Age				
Preschool	1	50	1	50
School Age	23	92	2	8
Adolescent	41	87.2	6	12.8
Level of Intellectual Disability				
Mild	34	94.4	2	5.6
Moderate	20	83.3	4	16.7
Severe	10	76.9	3	23.1
Profound	1	100	0	0

Table 5 shows that the majority of respondents who have children with intellectual disabilities who are female experience higher levels of parenting stress compared to respondents who have children with intellectual disabilities who are male. Higher levels of parenting stress were also experienced by respondents who had children with intellectual disabilities aged adolescents (12-21 years). In addition, respondents who have children with intellectual disabilities with moderate disabilities experience higher levels of parenting stress than other levels of disabilities.

DISCUSSION

Respondents' Level of Parenting Stress

Parents who have children with intellectual disabilities will generally experience difficulties in the parenting process (Maysa & Khairiyah, 2019). This is because children with intellectual disabilities require different supervision from other children and there are many problems experienced by parents such as children's behavioral and emotional problems, children's independence, concerns about the child's future, social stigma in society, as well as high parenting and financial burdens (Norhidayah et al., 2013). Therefore, parents who have children with intellectual disabilities are at higher risk of experiencing stress in the process of raising children.

The findings of the research showed that as many as 65 (87.8%) parents of children with intellectual disabilities at the SLB Negeri Cileunyi experienced low levels of parenting stress and as many as 9 (12.2%) parents experienced moderate levels of parenting stress and no parents were found who experienced high level of parenting stress. The low level of parenting stress experienced by parents of children with intellectual disabilities at the SLB Negeri Cileunyi is influenced by the program held by the school. The program is a parenting meet which is held 4 times a year. Parenting meet is a meeting program between parents and teachers to discuss student progress, learning plans, and activities that will be held every 3 months. Apart from that, in the parenting meet there were also entertainment activities, namely outbound activities which were attended by all students, parents, and teachers who taught children with intellectual disabilities at the SLB Negeri Cileunyi. This activity strengthens the close relationship between parents and students and creates a sense of togetherness and support for each other. Social support influences the level of parenting stress. Support and social networks can help reduce stress and have a positive influence on an individual's ability to cope and adapt (Ramadhany et al., 2017). The programs implemented by schools influence the level of parenting stress experienced by parents because parents can share thoughts and feelings about parenting, as well as communicate with each other and provide solutions regarding the problems or conditions of children with intellectual disabilities to lighten the burden on parents.

This finding is in accordance with the opinion of Lutfianawati et al. (2019) & Marlina et al. (2021) who state that the majority of parents who have children with intellectual disabilities experience low levels of parenting stress. Low levels of parenting stress can be influenced by the social support that parents receive. This is in line with research by Yi (2007) which states that parents who receive high social support feel lower parenting stress compared to parents who receive low social support. Apart from that, the low level of parenting stress is also due to parents receiving the positive consequences of parenting (happiness, joy, and love) which are greater than the negative consequences of parenting (cost, time, and energy). However, the results of this study are not in line with research by Yilmaz (2020) & Hemati Alamdarloo & Majidi (2022) which states that parents of children with intellectual disabilities have high parenting stress. Researchers believe that various other factors differentiate the research findings, such as the characteristics of parents and the characteristics of children with intellectual disabilities.

Level of Parenting Stress Based on Respondent Characteristics

In the research, the majority of female respondents experienced higher levels of parenting stress compared to male respondents. This finding is in line with research by Pisula & Kossakowska (2010) which states that mothers experience higher levels of stress than fathers, one of which is the stress of parenting. Women as mothers are considered to have the skills

and attitudes to educate and care for children so the responsibility for educating and caring for children falls on the mother (Safitri & Hapsari, 2013). The large role of mothers in the process of raising children makes mothers more vulnerable to problems that occur in children, causing parenting stress (Mawardah & Hidayati, 2012). Most parents who are in late adulthood (45-65 years) experience higher parenting stress than parents of younger ages. This finding is in line with research by Ramadhany et al. (2017) which states that as parents age, physical strength decreases, while the burden of caregiving remains the same, which can cause caregiving stress. However, this is not in line with the opinion of Plant & Sanders (2007) who state that as parents get older they can reduce parenting stress because parents already have a more mature psychology and have a lot of experience in the process of raising children.

Parents with a middle educational background experience higher parenting stress compared to parents with a higher educational background. This is because parents with a higher educational background generally have more knowledge regarding child care. This finding is in line with the opinion of Aldosari & Pufpaff (2014) who stated that parents with a higher educational background experience less parenting stress. This is because parents with higher education know effective coping strategies in dealing with the behavior of children with intellectual disabilities. Meanwhile, parents with a lower educational background tend to have limited knowledge regarding children's growth and development which influences the decision-making in dealing with behavioral problems in children with intellectual disabilities (Ramadhany et al., 2017). Parents who do not work and have a monthly family income below the minimum wage mostly have higher levels of parenting stress compared to working parents with a monthly income above the minimum wage. This finding is in line with the opinion of Fucà et al. (2022) which states that unemployment is related to parenting stress (Fucà et al., 2022). Parents who do not work experience higher levels of parenting stress. This is caused by personal factors such as life limitations due to the demands of raising children. On the other hand, Hassall et al. (2005) stated that working parents experienced higher levels of parenting stress compared to non-working parents because parents found it difficult to balance childcare responsibilities and work so that childcare time became divided. Meanwhile, high demands and low levels of income cause difficulties in caring for and meeting children's needs, giving rise to psychosocial burdens and conflicts between partners which have the potential to cause parenting stress in parents (Aldosari & Pufpaff, 2014).

Level of Parenting Stress Based on Child Characteristics

Parents who have female children with intellectual disabilities experience higher levels of parenting stress compared to parents who have male children with intellectual disabilities. This finding is in line with research by Sabih & Sajid (2008) which states that parents who have male children experience lower levels of parenting stress compared to parents who have female children. This is because parents who have daughters become more worried about their children's future. As girls get older, there are more things to pay attention to, such as sexual problems related to menarche experienced by girls, which will cause parents to need to spend a lot of time and pay more attention, which can cause parenting stress for parents (Sabih & Sajid, 2008). However, this finding is not in line with the opinion of Hidangmayum & Khadi (2012) who stated that parents who have sons experience higher levels of parenting stress compared to parents who have daughters. This is related to behavioral problems in boys. Higher levels of parenting stress are experienced by parents who have adolescent children with intellectual disabilities. This finding is in line with research by Sabih & Sajid (2008) which states that parents with young children experience lower levels of parenting stress. On the other hand, the older the child, the higher the level of parenting stress felt by parents. This is because as children get older, parents develop a more realistic view regarding

their child's future. In addition, as children get older, parenting demands and behavioral problems in children with intellectual disabilities also increase, so this can contribute to high parenting stress and low parental well-being.

The majority of parents of children with moderate intellectual disabilities experience higher levels of parenting stress. The level of intellectual disability influences parenting stress. This finding is in line with research by Ali Nathwani et al. (2021) which states that the severity and type of disability has a significant relationship with parenting stress. This is because the more severe the level of disability experienced by children, the more intensive care and care they need from parents and this has an impact on the burden of care felt by parents and the time parents spend helping children (Ramadhany et al., 2017). Although there are parents who have children with intellectual disabilities at higher levels such as severe and profound, research results show that these parents experience low levels of parenting stress. In this case, there are factors other than the child's level of incompetence or disability due to the high level of parenting stress, other factors are the child's behavior or the child's temperament.

CONCLUSION

The research results showed that the parenting stress experienced by parents of children with intellectual disabilities without comorbidities at the SLB Negeri Cileunyi was mostly in the low level parenting stress category. Based on the characteristics of the respondents, higher levels of parenting stress were experienced by respondents who were female, in late adulthood ranging from 45-65 years, had secondary education, did not work, and had a monthly family income below the minimum wage. Meanwhile, based on children's characteristics, the results showed that higher levels of parenting stress occurred in parents who had children with intellectual disabilities who were female, aged between 12-21 years, and who had moderate levels of intellectual disability. Suggestions for the school, program preventive measures in the form of parenting meetings that create bonding between parents and students still need to be carried out to provide support for each other. Nurses can act as educators by providing counseling about the child's growth and development process and strategies that can be used to overcome problems in caring for children with intellectual disabilities. Apart from that, nurses can also provide information about stress management techniques that parents can use when experiencing stress so that it does not hurt the child. It is recommended that future research use a larger sample size and conduct further research on the influence of social support on the stress of caregivers of children with intellectual disabilities. In addition, research on parenting stress experienced by parents of children with intellectual disabilities can be carried out using qualitative methods with interview techniques to obtain more accurate information and describe the actual situation felt by each parent in caring for children with intellectual disabilities.

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