



Original Research

THE RELATIONSHIP BETWEEN ACCEPTANCE AND CAREGIVING BURDEN IN PARENTS OF CHILDREN WITH INTELLECTUAL DISABILITIES

Yeni Fitria*^{ORCID}, Ni Made Galuh Widiyantari^{ORCID}, Erti Ikhtiarini Dewi^{ORCID}, Enggal Hadi Kurniyawan^{ORCID}

Faculty of Nursing, University of Jember, Jember, Indonesia

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CORRESPONDING AUTHOR

Yeni Fitria
yeni.fitria@unej.ac.id
Faculty of Nursing,
University of Jember, Jember,
Indonesia

ABSTRACT

Introduction: Parents of children with intellectual disabilities often deal with complex emotional and psychological challenges. This can affect parents' acceptance of their child's condition. Parental acceptance plays an important role in determining the ability to manage caregiving burden, which will have an impact on childcare. This study aims to analyze the relationship between acceptance and caregiving burden in parents of children with intellectual disabilities.

Method: This study used a cross-sectional design with total sampling technique involving 74 respondents. Inclusion criteria were biological parents who live together and care for children with intellectual disabilities at SLB-C TPA Jember and SLB Negeri Jember. Data was collected using the Parental Acceptation-Rejection Questionnaire (PARQ) and Zarit Burden Interview (ZBI) and analyzed using Kendall's Tau-C correlation test.

Results: The results showed that most respondents 68 (91.9%) had a high acceptance, while 42 (56.8%) experienced a mild burden. The p-value = 0.005 and the coefficient correlation $r = -0.298$, shows that there is negative relationship with a weak correlation between parental acceptance and caregiving burden in parents of children with intellectual disabilities.

Conclusions: This study found that there is relationship between parental acceptance and the caregiving burden. The higher the parental acceptance, the lower the caregiving burden. Parents who can accept their children with intellectual disabilities tend to be more ready to deal challenges and are able to perform their parenting role with an adaptive attitude. Parental acceptance can reduce the perception of caregiving burden. The findings highlight that parents should increase their acceptance to children with intellectual disabilities to deal with parenting challenges more easily.

Keyword: caregiving burden; mentally retarded children; parental acceptance

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1. INTRODUCTION

Parent wants their children to be healthy and without any deficiencies. However, in reality not all children who are born have normal development or experience disability (Kusnadi et al., 2022). Disabilities suffered by children can

be physical or mental disabilities. Children with intellectual disabilities have limitations that affect intellectual functioning that are different from other children with disabilities which have an impact on children's failure to adapt to their

environment so that they often require special care, treatment, or other support services that have been planned and specialized for the long term or during their lives (Chen et al., 2020; Lubis et al., 2023; Mestre et al., 2024). Research conducted by Syaputri & Afriza (2022), states that great challenges are often experienced by parents when caring for children with intellectual disabilities. These challenges include managing inappropriate child behavior, the inability of children to undergo activities independently, long-term care costs, and work restrictions (Bonyani et al., 2023).

According to the (United Nations Children's Fund), the prevalence of children with intellectual disabilities in the world in 2021 is around 28.9 million children aged 0-4 years and around 207.4 million children aged 5-17 years. In Indonesia, according to Risesdas in 2018, children aged 7-15 years were 3.3% with intellectual disabilities. According to Fitria et al (2019), children with intellectual disabilities in children is around 1-3% or equal to 6.6 million people. Meanwhile, according to (Survei Kesehatan Indonesia (SKI) in 2023, children with intellectual disabilities aged 5-17 years have a prevalence of around 1.0%. Based on the prevalence above, cases of children with intellectual disabilities are still classified as mild cases. However, parents who care for children with intellectual disabilities still feel the impact physically and psychologically (Fitria et al., 2019).

The birth of children with intellectual disabilities can cause parents to feel helpless, frustrated, and hopeless (Hemati Alamdarloo & Majidi, 2022; Jandrić & Kurtović, 2021). Thus, caring for children with intellectual disabilities requires more patience. This indicates that parents find it difficult to accept all conditions of their children when things are not in line with expectations (Sesa & Yarni, 2022). According to Munisa et al (2022), the first reaction of parents when they find out their child has intellectual disabilities includes feelings of shame, disbelief, surprise, and anger. After this response, the lack of parental acceptance has an impact on parental neglect of children as a form of refusal to have children with intellectual disabilities (Sesa & Yarni, 2022). In a study conducted by Dewi & Wibowo (2022), it was found that around 59.6% of parents, especially mothers, could not accept their child's condition. This is due to the factor of not understanding the condition of children with intellectual disabilities. Parental rejection is influenced by several factors such as community

stigma and parental coping mechanisms. Low parental acceptance will make parents when caring for children with intellectual disabilities feel worried about the child's future and fulfillment of the child's more complex needs (Niara et al., 2024).

Parental acceptance plays a role in the care of children with intellectual disabilities. An accepting attitude helps parents see their children with intellectual disabilities not as a burden or a tiresome responsibility, but as a unique and valuable individual who needs to be given the same support, love and attention as other normal children (Putri & Sairatu, 2023). Parents who accept children with intellectual disabilities will be aware of the demands that are in accordance with the child's abilities. Thus, parents have expectations that are easier to achieve which will help parents adjust while caring for children with intellectual disabilities which can further minimize stress in caring for children (Fitria et al., 2019). Parents with good acceptance will focus on solving problems, so that parents will find it easier to face challenges in caring for children with intellectual disabilities, which in turn allows parents to get a good quality of life (Ariyanti, 2021). In Hidayatullah & Hidayati (2021) research, parents who can accept children with intellectual disabilities mean that these parents do not have emotional burdens so that they can adapt to situations that are sometimes unpredictable when caring for children with intellectual disabilities.

There are many factors that can trigger the caregiving burden experienced by parents of children with intellectual disabilities. Parental acceptance is one of the key factors that can help reduce the caregiving burden among parents of children with intellectual disabilities. In essence, parental acceptance requires time and a lengthy process, beginning with denial and gradually progressing to the stage of accepting the child as a gift from God that should be appreciated and cherished. Therefore, the researcher is interested in conducting a study on the relationship between parental acceptance and caregiving burden among parents of children with intellectual disabilities.

2. MATERIALS AND METHODS

2.1 Design

This research design is quantitative correlational with a cross-sectional approach. Researchers will analyze the relationship between parental

acceptance and caregiving burden in parents of children with intellectual disabilities. The research variables are taken at the same time.

2.2 Population and sampling

The research was conducted at the SLB-C TPA Jember and SLB Negeri Jember. The population size in this study was 87 parents. The research sample was obtained using a purposive sampling technique, resulting in a sample of 74 parents who care for children with intellectual disabilities. The Inclusion criteria were biological parents of children with intellectual disabilities from SLB-C TPA Jember and SLB Negeri Jember from grade I elementary school and XII high school and live in the same house. Exclusion criteria were parents who cared for severely children with intellectual disabilities, had multiple diagnoses, and did not live in the same house.

2.3 Variable

The independent variable in this study is parental acceptance, and the dependent variable is caregiving burden in parents with children with intellectual disabilities

2.4 Instrument

The instrument used to measure parental acceptance uses the Parental Acceptance-Rejection Questionnaire (PARQ) based on Rohner's theory (2012) and has been translated into Indonesian and modified by Nur Maulany (2015) and has 22 items, with a validity test result of 0,264-0,634 and a reliability of 0,857. Indicators on the instrument include warmth or affection, hostility or aggression, indifference or neglect, and rejection. The scoring in the warmth or affection dimension begins with Always (score 4), Sometimes (score 3), Rarely (score 2), and Never (score 1). Meanwhile, the scoring in the dimensions of hostility or aggression, indifference or neglect, and rejection are scored in reverse, namely Always (score 1), Sometimes (score 2), Rarely (score 3), and Never (score 4). Interpretation of parental acceptance is high with a score ≥ 66 and low acceptance with a score of < 44 .

The instrument used to measure the burden of caregiving uses the Zarit Burden Interview (ZBI) instrument which has been translated into Indonesian by Andriani (2019) and has 22 items, with a face validity test showing that 22 statements are valid and a reliability of 0,804.

Indicators on the instrument include physical burden, emotional burden, economic burden, social burden, and the relationship between parents and children. The scoring consists of never (score 0), rarely (score 1), sometimes (score 2), often (score 3), always (score 4). The interpretation of caregiving burden is categorized into four levels and the score range is from 0 to 88, with the burden levels as follows; no burden (0-20), mild burden (21-40), moderate burden (41-60), and heavy burden (61-88).

2.5 Procedure

First, the researcher completed the administrative permissions process. Then the researcher selected respondents according to the inclusion and exclusion criteria. Respondents were given a consent form that included their rights, a letter of consent to participate, and an explanation of the study. The researcher gave informed consent to sign the willingness to be a respondent form. Data collected by distributing the Parental Acceptation-Rejection Questionnaire (PARQ) and Zarit Burden Interview (ZBI) questionnaires directly by the respondents. The researcher waited and accompanied the respondent when filling in to ensure that all questionnaire items were filled in and assist respondents if they have difficulty understanding the questionnaire. Data collection was carried out on February 10 to March 10, 2025.

2.6 Analysis

Data analysis conducted in this study using univariate analysis to describe the frequency distribution and percentage of all characteristics on each research variable and bivariate analysis to analyze the relationship between parental acceptance and caregiving burden by using Kendall's tau-C correlation test. Kendall's tau-C correlation test is suitable for analyzing the strength and direction of associations between two ordinal variables, especially when the data are not normally distributed and may contain ties. This non-parametric test provides a more accurate measure of correlation in ranked data.

2.7 Ethical Clearance

Researchers conducted ethical testing on the health research ethics committee (KEPK) of the Faculty of Nursing, University of Jember with number 023/UN25.1.14/KEPK/2025.

Tabel 1. Distribution of Characteristics Respondents Based on Age (n=74)

Respondent Characteristics	Median	Minimal-Maksimal
Age of Parents	42	31-63
Age of Child	13	6-24

Tabel 2. Distribution of Characteristics of Parent Respondents Based on Role, Education Level, Occupation, Income, Marital Status, total Number of Children, and Level of Children with intellectual disabilities (n=74)

Respondent Characteristics	f(%)
Role	
a. Father	23 (31.1)
b. Mother	51 (68.9)
Total	74 (100)
Parent Education Level	
a. Not in School	1 (1.4)
b. Elementary	6 (8.1)
c. Junior High School	11 (14.9)
d. Senior High School	32 (43.2)
e. College	24 (32.4)
Total	74 (100)
Occupation	
a. Not Working/Housewife	39 (52.7)
b. PNS	3 (4.1)
c. Private employee	4 (5.4)
d. Wiraswasta	18 (24.3)
e. Other	10 (13.5)
Total	74 (100)
Income	
a. ≤ 2.838.642 (MRW,2025)	58 (78.4)
b. > 2.838.642 (MRW,2025)	16 (21.6)
Total	74 (100)
Marital Status	
a. Married	71 (95.9)
b. Widow/Widower	3 (4.1)
Total	74 (100)
Number of Children	
a. 1	29 (39.2)
b. 2	30 (40.5)
c. 3	13 (17.6)
d. 4	2 (2.7)
Total	74 (100)
Level of Children with intellectual disabilities	
a. Mild	39 (52.7)
b. Moderate	35 (47.3)
Total	74 (100)

Tabel 3. Distribution of Acceptance in Parents of Children with intellectual disabilities(n=74)

Categories Variabel	Frekuensi	Percentage (%)
Medium Acceptance	6	8.1
High Acceptance	68	91.9
Total	74	100

Tabel 4. Distribution of Caregiving Burden Categories in Parents of Children with intellectual disabilities(n=74)

Categories Variabel	Frequency (f)	Percentage (%)
No Burden	26	35.1
Mild Burden	42	56.8
Moderate Burden	6	8.1
Total	74	100

Tabel 5. The Correlation between Parental Acceptance and Caregiving Burden Categories in Parents of Children with intellectual disabilities (n = 74)

Variabel		Caregiving Burden								<i>r</i>	p-value
		No Burden		Mild Burden		Moderate Burden		Total			
		f	%	f	%	f	%	f	%		
Parental Acceptance	Moderate	0	0	0	0	6	8.1	6	8.1	-0.298	0.005
	High	26	38.2	42	61.8	0	0	68	91.9		
	Total	26	35.1	42	56.8	6	8.1	74	100		

3. RESULTS

Based on the characteristics of respondents in Table 1, it was found that the median age of parents was 42 years with a minimum age of 31 years and a maximum age of 63 years. Meanwhile, the median age of children was 13 years with a minimum age of 6 years and a maximum age of 24 years.

Based on the characteristics of the respondents in Table 2, it was found that most of the respondents who played a dominant role in caring for children were mothers, namely 51 respondents (68.9%). A total of 32 respondents (43.2%) had a high school education. More than half of the respondents, namely 39 respondents (52.7%), were unemployed or housewives. A total of 58 respondents (78.4%) had an income of \leq Minimum Regional Wage (MRW). Most respondents were married, namely 71 respondents (95.9%). Most respondents, namely 30 respondents (40.5%), had two children. Most respondents, namely 39 respondents (52.7%), had children with mild children with intellectual disabilities.

Based on Table 3, it was found that most respondents were in the high acceptance category, namely 68 respondents (91.9%), while only 6 respondents (8.1%) were in the moderate acceptance category. Based on Table 4, it was found that most respondents had a mild burden, with 42 respondents (56.8%), 26 respondents (35.1%) had no burden, and 6 respondents (8.1%) had a moderate burden. Based on Table 5, the analysis results show a p-value = 0.005 and a correlation value $r = -0.298$, which means there is a negative relationship between parental acceptance and the burden of care on parents of children with children with intellectual disabilities.

4. DISCUSSION

The results showed that most respondents in this study were in the high acceptance category, 68 respondents (91.9%). High acceptance is

characterized by the behavior of accepting the presence of children unconditionally where it is shown by sensitivity to children's interests, expressions of affection, care, and having a happy relationship with children (Firmawati & Ayu, 2022; Negara & Rismawan, 2020). Acceptance in the high category is influenced by a sense of gratitude and social support received by parents. This is in line with the findings of Alyya & Hidayat (2024), that a high level of gratitude will make parents tend to have a high acceptance of the shortcomings of children with intellectual disabilities. This makes parents of children with intellectual disabilities no longer feel burdened by unrealistic expectations or expectations. In addition, the social support found in the study is also influential. Social support from family and other parents who both have children with intellectual disabilities or peer groups have a positive impact on acceptance because with the same background they can share their parenting experiences and strengthen each other in various conditions which ultimately allows parents to adapt well emotionally and socially (Chakraborti et al., 2021)

The results of the PARQ study indicate that most parents of children with intellectual disabilities have close and positive relationships with their children. In terms of warmth, most parents (86.5%) give their full attention and openly express their affection, as well as supporting their children in expressing their thoughts and feelings. This indicates a high level of emotional involvement through verbal and physical expressions such as hugging or giving praise. On the hostility/aggression indicator, most parents (77%) never say hurtful things or hurt their children's feelings, indicating good emotional management skills in parenting. The indifference indicator also shows positive results, with most parents (68.8%) always paying attention to their children and being responsive to their needs, reflecting high levels of care both physically and psychologically. On

the rejection indicator, nearly all respondents (93.2%) did not show a rejecting or unwilling attitude toward their children, meaning they continue to accept and love their children despite their limitations. Overall, these results indicate a positive emotional bond between parents and children with intellectual disabilities, characterized by strong love, attention, and acceptance.

Based on the findings in this study, it was found that the majority of respondents were mild burden category, 42 respondents (56.8%), moderate burden as many as 6 respondents (8.1%). These results are in line with the findings of Ariyanti (2021), that most respondents had a mild category burden as many as 38 respondents (50%). Parents in the mild burden category feel fatigue or stress occasionally, but can still carry out their roles and responsibilities relatively well. Based on research, the role of parents also influences. The results showed that mothers have a higher burden than fathers. This is because mothers have a large responsibility in caring for, raising children, and spending more time with children so that they have a relatively higher burden of care compared to fathers (Herrero et al., 2024). Thus, non-working parents have a significantly milder psychological burden than working parents.

The results of the study using the Zarit Burden Interview (ZBI) instrument show that the burden on parents in caring for children with intellectual disabilities varies across five aspects. In terms of physical burden, some respondents felt that their children were very dependent on their parents (23%), always expected attention (32.4%), and often asked for more help than was needed (25.7%). In terms of emotional burden, 24.3% of respondents felt worried about the child's future, particularly regarding the uncertainty of the child's future in terms of independence and social acceptance. In terms of economic burden, nearly half of the respondents (47.3%) stated that they were able to cover the child's needs without significant difficulty. In terms of social burden, most respondents did not feel disrupted in their personal and social lives, as indicated by 82.4% not feeling their social life was disrupted, 78.4% not feeling uncomfortable when friends visited, and 67.6% still having personal freedom. Meanwhile, regarding the parent-child relationship indicator, 47.3% of parents felt they needed to do more for their children, and 60.8% felt capable of performing parenting tasks more effectively. This indicates parental acceptance and commitment to

continue providing optimal care for children with intellectual disabilities.

Based on the results of the Kendall's tau-C correlation test, there is a significant relationship between parental acceptance and caregiving burden in parents of children with intellectual disabilities. The correlation coefficient value indicates a negative relationship direction with weak strength. This can be interpreted that the higher the acceptance, the lower the caregiving burden felt by parents of children with intellectual disabilities. Consistent with the findings of Ariyanti (2021), which states that parental acceptance makes parents continue to strive to do the best for their children. In addition, acceptance has also been shown to make parents more empathetic and patient in caring for children (Valentia et al., 2020). Research conducted by Pratiwi et al (2022), shows that parental acceptance helps parents understand children better and helps parents focus on children's potential and strengths, not on the limitations that children have.

Based on the results of this study, it was found that most parents of children with intellectual disabilities were mostly in high acceptance with mild burden, 42 respondents (61.8%). Then, a small proportion were in moderate acceptance with moderate care burden as many as 6 respondents (8,1%). Parents with low levels of acceptance tend to feel excessively worried or afraid about their children's future and face challenges in providing their more complex needs (Niara et al., 2024). In addition, parents with low acceptance face difficulties in responding appropriately to children and fail to build strong relationships with children (Valentia et al., 2020). In contrast, parents with high acceptance tend to view challenge as something that can be faced, so they focus on finding solutions and trying to adapt to existing conditions, rather than avoiding or blaming the situation (Singh & Lohumi, 2023). Additionally, parents with high level of acceptance can view their children's conditions objectively, enabling them to better recognize their children's strengths and limitations (Fitria et al., 2019). Therefore, it can be concluded that the more parents are able to accept their children's conditions, the milder the burden they feel in parenting. Acceptance makes parents more sincere and helps them understand that children with intellectual disabilities are still valuable although they have limitations.

5. CONCLUSION

Most parents of children with intellectual disabilities included in the high acceptance category and a small percentage included in the moderate acceptance category. Most parents of children with intellectual disabilities experience a mild caregiving burden. In addition, there is a significant relationship between parental acceptance and the caregiving burden on parents with children with intellectual disabilities. To minimize the caregiving burden, parents should increase their acceptance of their children so that they can more easily cope with the challenges of caregiving and not set expectations that are too high and beyond their children's abilities.

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Conflict of Interest

The authors declare no conflict of interest, financial or otherwise.

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