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Strengthening Families: How Family Support Shapes the Quality of Life for Children with Intellectual Disabilities

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ABSTRAK
Anak berkebutuhan khusus adalah anak yang berisiko mengalami penyakit kronis, gangguan perkembangan, gangguan emosional, abnormalitas, atau disabilitas fisik, dan membutuhkan layanan kesehatan lebih banyak daripada anak pada umumnya. Dukungan keluarga dibutuhkan sebagai pendukung dan untuk membantu meningkatkan kualitas hidup anak-anak ini agar mereka tetap dapat menjalankan aktivitas dengan kemampuan yang didukung oleh keluarga. Jenis penelitian kuantitatif ini menggunakan pendekatan cross-sectional. Populasi dalam penelitian ini adalah seluruh orang tua yang memiliki anak berkebutuhan khusus di PNS Negeri Kabupaten Mesuji dengan sampel sebanyak 84 responden menggunakan teknik total sampling. Penelitian ini dilakukan pada bulan Desember 2022 di SLB Negeri Kabupaten Mesuji. Hasil penelitian menunjukkan tidak ada hubungan yang signifikan antara dimensi dukungan keluarga dan kualitas hidup anak berkebutuhan khusus. Dukungan keluarga dalam bentuk pemberian informasi dan dukungan sosial harus menjadi dukungan prioritas yang diberikan kepada keluarga dengan anak berkebutuhan khusus.

Kata kunci: Dukungan keluarga, kualitas hidup, disabilitas intelektual

ABSTRACT

Children with special needs are children who are at risk of experiencing chronic diseases, developmental disorders, emotional disorders, abnormalities or physical disabilities and require more health services than children in general. Family support is needed as a supporter and to help the quality of life of these children to continue to be able to carry out their activities with their abilities supported by the family. This type of quantitative research uses a cross-sectional approach. The population in this study were all parents who have children with special needs at the Mesuji Regency State Special School with a sample of 84 respondents using a total sampling technique. This study was conducted in December 2022 at the Mesuji Regency State Special School. The results of the study showed no significant relationship between the dimensions of family support and the quality of life of children with special needs. Family support in the form of providing information and social support should be a priority support given to families with children with special needs.

Keywords: Family support, quality of life, Intelectual Disability

INTRODUCTION

Based on Law No. 8 of 2016 concerning the Presentation of Disabilities, there are five categories of disabilities, namely physical, intellectual, mental, sensory, and multiple/multi. According to the results of a WHO survey, 64% of the world's population are people with disabilities. Based on 2020 census data from the Central Bureau of Statistics, the number of people with disabilities in Indonesia reached 22.5 million, or around 5 percent (Carroll, 2012). According to the 2020 SUSENAS survey conducted by BPS, people with disabilities are grouped into 8 types: difficulties or problems in seeing, walking, concentrating/memory, hearing, communicating, using hands/fingers, taking care of themselves, and behavioral/emotional disorders. In general, the most common type of disability in Indonesia is visual impairment, which is around 64% of the total number of people with disabilities, followed by people with walking and concentration/memory disorders, which are 38.3% and 29.7%, respectively. Meanwhile, the types of problems/disorders that are the least common in

Indonesia are emotional or behavioral problems, taking care of themselves, and using hands/fingers (Fajri et al., 2021). The results of the 2018 Basic Health Research show that the number of people with disabilities or children with special needs in Lampung Province reached 8,613 people with disabilities aged 7-15 years, 17,546 people with disabilities aged 18-59 years, and 2,837 people with disabilities aged ≥ 60 years. The proportion in Lampung Province is higher than the average for all provinces in Indonesia, at 0.6% of the total number of disabilities. (Balitbangkes RI, 2018).

Disability is a complex process between individuals and their environment. In general, a person is said to have a disability if he or she has difficulty performing daily tasks due to a physical, mental, or emotional condition. (Natalie A. E., 2021). Children with disabilities experience substantial difficulties in daily living, are at higher risk for poor physical health, and have a 5 to 12 times higher risk of death compared to those without Intellectual Disability (ID). (Bourke et al., 2017). There are several types of children with special needs, including retarded children, blind children, deaf children, hearing impaired children, disabled children, besides the five types of children with special needs above, there are still other types, namely: children who experience difficulties in learning (slow to digest lessons), children who experience difficulties when learning something specific, as well as children who are too intelligent, and also children who experience difficulties when communicating with other people (Nisa et al., 2018).

Children with disabilities have many difficulties in their daily lives, including not being able to walk as many as 112 (25.8%), non-verbal communication as many as 109 (25.1%), eye contact when talking is at a moderate level as many as 170 (39%), the presence of epilepsy in daily or weekly as many as 60 (13.8%), severe scoliosis symptoms with surgery 35 (8%), occasional pain 196 (45.2%). These disorders or difficulties will create dependence. Children with greater dependence to manage personal needs and limited eye contact when talking experience a poorer quality of life. The total quality of life score of children with disabilities is substantially lower when children are unable to walk, unable to communicate, have the worst level of eye contact when talking, or are completely dependent on others to manage their personal needs, compared to individuals with the highest level of functioning in each domain (Williams et al., 2021).

As the primary caregivers of children with intellectual disabilities, families face their own difficulties in providing the normal life functions expected in many cases. It is clear that families of children with intellectual disabilities experience increased levels of stress that threaten the integrity of the family structure. Families need information and support regarding the care and management of children with intellectual disabilities, professional collaboration regarding children's safety, and community involvement in the care of children and in improving their living conditions, as most families and households are headed by women, have low incomes, and need further financial support. The mother's needs, ranked from highest to lowest, are information and professional support 71.0%, community services 64.5%, explaining to others 38.7%, financial needs 22.6%, child care 16.1%, and family/social support 12.9%. The father's needs, ranked from highest to lowest, are information 71.0%, community services 64.5%, professional support 61.0%, explaining to others 45.2%, financial needs 29.0%, child care 22.6%, and family/social support 19.4%. The research aims to examine the relationship between family support and the quality of life in children with intellectual disabilities, including the domains of Informational Support, Emotional Support, Esteem Support, Instrumental Support, and Social Support.al Support, Emotional Support, Esteem Support, Instrumental Support, Social Support.

METHODS

This research was conducted in February at the Mesuji Regency State Special School for Children with Special Needs. This study used a cross-sectional design with a quantitative approach. The prevalence of students with intellectual disabilities in the 2023-2024 academic year was 84 students, consisting of 52 students from elementary schools with special needs, 19 from junior high schools with special needs, and 13 from senior high schools with special needs. The sample selection method in this study used total sampling of 84 children and their parents who were willing to be respondents in the study, excluding those who did not complete the questionnaire. Data collection used the PedsQL questionnaire and the Family Support Scale questionnaire (FSS). The statistical test used was the Spearman rank correlation test at a 95% confidence level and a significance level (α) of 0.05.icance level (α) of 0.05.

This research received ethical approval from the Ethics Committee of Aisyah University

Pringsewu (Number: 789/UAP.OT/KEP/EC/2024). Consent was obtained from all respondents, guaranteeing confidentiality and voluntary participation. Data were stored using a coding system and used solely for this research.

RESULTS

Based on table 1, most respondents are aged 8 to 12 years (65.4%). The gender of respondents is mostly female, 54 people (64.3%). The occupation of the respondents' mothers is mostly housewives, 52 people (61.9%). Most of the respondents' mothers have a high school/equivalent education, 72 people (85.8%). Most of the respondents' mothers are aged 36 - 40 years, 50 respondents (59.5%).

Table 1
Frequency Distribution of Respondent Characteristics

Category	Frequency	Percentage
Child's Age		
8 - 12 y.o	55	65,4%
13 - 15 y.o	29	34,6%
Gender of the child		
Male	30	34,6%
Female	54	65,4%
Mother's Age		
36 – 40 y.o	50	59,5%
41 – 48 y. o	34	40,5%
Maternal education		
D3 – S1	12	14,2%
SD-SMA	72	85,8%
Mother's job		
Buruh	8	9,5 %
IRT	52	61,9 %
Petani	24	28,6 %

Based on Table 2, the most common family support dimension in the insufficient category is information support at 92.8%, followed by appreciation support at 91%, and emotional support at 90.4%. The most common family support dimension in the sufficient category is social support at 23.8%.

Table 2
Frequency Distribution of Family Support

Dimension of Family Support	Category		
	Less	Enough	Good
Informational Support	78 (92,8%)	4 (4,7%)	2 (2,3%)
Emotional Support	76 (90,4%)	6 ((7,1%)	2 (2,3%)
Esteem Support	77 (91,6%)	6 (7,1%)	1 (1,1%)
Instrumental Support	71 (84,5%)	10 (11,9%)	3 (3,5%)
Social Support	62 (73,8%)	20 (23,8%)	2 (2,3%)

Based on Table 3, the quality of life dimension with the highest score was emotional function, followed by physical function, with a score not significantly different from emotional function. Social function had the lowest score.

Table 3
Dimensions of Quality of Life in Children with Intelektual Disability

Dimensions of Quality of Life	Mean Score Quality Of life
Physical Functioning	25
Emotional Functioning	25,9
Social Functioning	12
School Functioning	22

Based on Table 4, the normality test results for the family support domains indicated that Esteem Support and Social Support were not normal. The quality-of-life domains with abnormal data distributions were emotional function, social function, and school function.

Table 4
Normality Test

Variabel	P-value	Conclusion
Informational Support	0,057	Normal
Emotional Support	0,126	Normal
Esteem Support	0,002	Not normal
Instrumental Support	0,437	Normal
Social Support	0,032	Not normal
Physical Functioning	0,185	Normal
Emotional Functioning	0,001	Not normal
Social Functioning	0,039	Not normal
School Functioning	0,017	Not normal
Psychosocial Functioning	0,353	Normal

Based on Table 5, the p-value for the relationship between family support and quality of life is>0.05, indicating no significant relationship between the family support variable and the quality of life of children with special needs at the Mesuji Regency State Special Needs School.

Table 5
Analysis of the Relationship between Family Support and Children's Quality of Life

Family Support Score	Quality of Life Score	
	Spearman rho	P.value
Informational Support	-0.023	0.833
Emotional Support	-0.071	0.522
Esteem Support	-0.083	0.450
Instrumental Support	-0.087	0.434
Social Support	-0.026	0.816

The analysis per dimension of both the family support dimension and the quality of life dimension of children with ASD is shown in Table 6. The results showed that there was no relationship between quality of life and family support.

Table 6
Analysis of the Relationship between Dimensions of Family Support and Dimension of Quality of Life

Dimension of Family Support	Dimension of QoL	P-value
D. Informasional	Emotional Functioning	0.004
	Social Functioning	0.903
	School Functioning	0.704
	Physical Functioning	0,100
	Psychosocial Functioning	0,086
Emotional Support	Emotional Functioning	0,409
	Social Functioning	0,473
	School Functioning	0,321
	Physical Functioning	0,622
	Psychosocial Functioning	0,165
Esteem Support	Emotional Functioning	0,082
	Social Functioning	0,062
	School Functioning	0,150
	Physical Functioning	0,133
	Psychosocial Functioning	0,158
Instrumental Support	Emotional Functioning	0,489
	Social Functioning	0,712
	School Functioning	0,442
	Physical Functioning	0,321

	Psyicococial Functioning	0,576
Sosial Support	Emotional Functioning	0,332
	Social Functioning	0,960
	School Functioning	0,344
	Physical Functioning	0,246
	Psychosocial Functioning	0,341

DISCUSSION

Respondent Characteristics

Table 1 shows that the average child respondent with mental disability is at the age of 8-12 years. Severe intellectual disability is often identified by age 3, because children with this level of disability typically show marked developmental delays and may have associated physical abnormalities. Moderate intellectual disability may be diagnosed by age 3 to 5, because these children often show clear signs of cognitive impairment and adaptive challenges throughout childhood (Patel et al., 2020). Children with mild intellectual disabilities may not be recognized until they are between the ages of 5 and 9. This delay occurs because they often meet developmental milestones initially but then struggle with academic skills and social interactions. According to the American Psychiatric Association, the criteria for diagnosing ID include that the deficits must have originated during the developmental period, usually before age 18 (American Academy of Child and Adolescent Psychiatry, 2023).

Table 1 shows that respondents with children with intellectual disabilities are mostly women. Recent research suggests that girls with autism spectrum disorder (ASD) and intellectual disability (ID) may exhibit more severe symptoms than boys with similar diagnoses. This may lead to higher rates of under-recognition in girls, as their behavior may be more prominent or different than that typically seen in boys, contributing to higher rates of diagnosis among girls. (Saure et al., 2023). Research suggests that girls with ASD and ID often exhibit different symptom profiles than boys. For example, girls may exhibit more social difficulties and restricted repetitive behaviors when they have ID, while boys may exhibit fewer social problems without ID. These differences in symptomatology may lead to underdiagnosis in girls who do not fit the typical presentation associated with ID (Gesi et al., 2021; Saure et al., 2023).

Family Support of Children with Intellectual Disabilities

Table 2 shows that informational support is less than other supportsa. Informational support from families plays a crucial role in helping children with intellectual disabilities develop essential daily living skills, such as dressing and eating. Research indicates that various forms of family support, including informational guidance and parental training, are effective in fostering independence and adaptive behaviors in these children.

Studies have shown that family education programs designed to teach self-care skills are beneficial for individuals with intellectual disabilities. For instance, an education program focused on "Self Care Instruction to Individuals with ID" was found to be effective in helping children acquire these skills, which they could then generalize to different environments, individuals, and materials (Kurtoğlu & Cavkaytar, 2021). Another intervention highlighted how adequate information about time management for mothers of children with intellectual disabilities led to significant improvements and satisfaction in the quality of daily living activities (Arzhangi et al., 2020).

Family involvement is considered a major source of support for children with mental and developmental disabilities (Arzhangi et al., 2020). Parents are often seen as facilitators and supporters in the development of functional and adaptive skills, and they require training to effectively follow up on daily activity instruction at home (Mumpunıartı et al., 2021).

The types of skills targeted in such training often include functional life skills like making beds, self-feeding, dressing, and toileting (Machalicek et al., 2015). Practical life activities, encompassing self-care tasks such as handling clothes, buttons, and folding, have been shown to positively impact fine motor skills and overall development in children with disabilities (Winegal et al., 2018).

Dimensions of Quality of Life in Children with Intelektual Disability

Table 3 related to the dimension of quality of life shows that respondents have the lowest social function compared to other functions. The present findings challenge the general assumption that Physical Functioning and Emotional Functioning consistently demonstrate higher outcomes than Social Functioning and School Functioning among children with intellectual disabilities. Instead, the

literature reflects a more nuanced and varied pattern influenced by the level of intellectual disability and the specific functional domains examined.

Although some reports suggest that children with intellectual disabilities exhibit motor characteristics not substantially different from typically developing peers, most still experience developmental motor delays. These delays tend to be associated more with limitations in attention and comprehension than with physiological or neuromotor impairment (Válková, 2019). Conversely, other studies highlight that motor skills represent one of the most significantly affected developmental areas, with marked impairments emerging early and persisting over time (Elshani et al., 2020). Thus, physical functioning cannot be assumed to represent a consistent strength across this population.

The functional profile also appears to vary by severity of disability. In cases of mild or borderline intellectual disability, Daily Living Skills, which involve practical physical tasks such as self-care, may be relatively stronger than Socialization (Hapčová et al., 2022). However, the pattern reverses in moderate to severe intellectual disability, where Socialization scores may exceed Daily Living Skills domains (Hapčová et al., 2022). This suggests differing developmental trajectories and adaptive expectations across severity levels.

The assumption that emotional functioning is consistently higher than other domains is not supported uniformly. Emotional regulation is frequently reported as a major area of difficulty (Brown et al., 2013; Girgis et al., 2024; Noel, 2018; Rodrigues et al., 2019). Additionally, certain physical health conditions may further limit emotional development (Sterkenburg et al., 2022) . Some studies indicate that emotional and physical functioning may present similar levels of quality-of-life scores, both of which tend to be higher than social and school domains.

Consistent evidence identifies Social Functioning as one of the most impaired dimensions for children with intellectual disabilities. Many individuals demonstrate difficulties forming and maintaining interpersonal relationships as well as managing social (Jacob et al., 2022; Kajda et al., 2021). Furthermore, School Functioning remains the most affected domain, largely due to the intrinsic nature of intellectual disability, which directly impacts learning, academic skills, and classroom adaptation (Boat et al., 2015)(Patrick et al., 2020).

Overall, the findings indicate that quality-of-life outcomes across functioning domains cannot be generalized uniformly. Rather than assuming consistent strengths in physical or emotional functioning, assessments should consider severity levels, individual differences, and contextual influences. These results highlight the importance of individualized intervention approaches tailored to specific domain weaknesses, particularly in social and academic functioning.

The Correlation between Family Support and Quality of Life of Children with Intellectual Disabilities

The results of this study in accordance with those listed in table 5 show that there is no relationship between the quality of life of children with intellectual disabilities and family support. A specific study on hypertensive patients found no significant correlation between family support and quality of life, with a p-value of 0.454 indicating that the level of family support did not affect quality of life in this group (Nurchayati et al., 2019). This suggests that although family support is generally beneficial, its impact may vary depending on health conditions or context.

Many respondents in this study were diagnosed with intellectual disabilities. Children with intellectual disabilities (ID) face a variety of conditions that affect their cognitive, adaptive, and overall functioning. The primary criteria for diagnosing ID is an IQ score below 70, indicating significant deficits in reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and experiential learning. Symptoms can include failure to achieve intellectual milestones, such as sitting, crawling, or walking later than typical children, and problems learning to speak or speak clearly. Deficits in adaptive functioning hinder conformity to developmental and sociocultural standards for independence and social responsibility. These include difficulties understanding rules, navigating daily tasks, participating in family, school, and community activities (Boat et al., 2015). .

Although functional ability can influence quality of life, it was found that functional ability had a less strong relationship compared to sleep problems and community participation in children with intellectual disabilities. Poor sleep quality has a significant impact on the quality of life of children with intellectual disabilities. The study highlighted how children with high levels of daytime sleepiness generally had a lower quality of life compared to those with minimal sleep

problems and greater community participation (Jacoby et al., 2022). Factors that influence the quality of life of children with special needs are not only family support but also social support (community and school) (Molnárová Letovancová & Slaná, 2022), access to health services, psychological well-being (Ghedhaifi & Hmidi, 2024), Family Dynamics and Parental Resilience (Widyawati et al., 2023).

Table 5 shows Informational support has the highest correlation coefficient value, which is -0.023, which means that the relationship between Informational Support and the quality of life of children with special needs is most closely related compared to emotional support, esteem support, instrumental support and social support. Informational support equips patients with the knowledge they need to overcome their health challenges. Studies show that patients who receive adequate informational support experience better health outcomes, because they are more informed about their condition and treatment options. For example, studies show that informational support from friends significantly improves general health among patients, while emotional support from partners helps in coping with illness (Ellardus et al., 2022)

Family support significantly impacts children's mental health. Research shows that perceived family support is positively correlated with emotional, social, and psychological well-being. Children who feel supported by their families typically experience higher levels of happiness and lower levels of anxiety and depression. This support fosters a supportive environment, increasing emotional stability and resilience to life's challenges (An et al., 2024). Strong family support systems and parental resilience play a vital role in improving the quality of life for children with intellectual disabilities. Families with supportive environments, where parents adapt well to caregiving responsibilities and manage stress effectively, tend to have children with better outcomes (Joung, 2022; Widyawati et al., 2023)

The limitation of this study is that confounding factors were not included in the study, so that when the results were not significantly related, it was quite difficult for the researcher to explain the suspected cause.

Table 6 shows that there is a significant relationship between family information support and children's emotional function. This study highlights the importance of informational support in improving the emotional and functional outcomes of children with intellectual disabilities. Informational support, including parental training programs, has been shown to enhance parental competence in teaching daily living skills to their children (Kurtoğlu & Cavkaytar, 2021). When parents feel more capable and effective in supporting their child's learning, parental stress levels tend to decrease. A less stressful and more stable home environment—resulting from increased parental confidence—positively influences children's emotional well-being. Previous research emphasizes that parental stress and family quality of life significantly affect the emotional climate within the home (Río et al., 2020).

Access to informational support enables children with intellectual disabilities to acquire new skills, such as independent dressing or self-feeding. Mastery of these skills contributes to greater independence and a sense of achievement, which in turn strengthens self-esteem and self-confidence—key components of healthy emotional functioning. For example, self-care training programs have demonstrated effectiveness in helping children achieve functional independence, ultimately improving their quality of life (Kurtoğlu & Cavkaytar, 2021)

Emotional functioning in children with intellectual disabilities often demonstrates significant developmental delays and higher levels of emotional dysregulation (Girgis et al., 2024; Sterkenburg et al., 2022). Informational support that provides parents with strategies for emotional regulation and coping skill development can contribute to improved emotional outcomes. Parents equipped with relevant knowledge are better able to guide children in interpreting and responding to emotional situations, thereby supporting healthier emotional development.

A systematic review by (Jacob et al., 2022) highlights that interventions aimed at improving social skills often integrate emotional intelligence training and computer-based emotion regulation activities. Such programs provide structured opportunities for children to practice emotional control and social communication within supportive learning environments.

These findings underscore the role of parent-focused informational interventions as an essential component of holistic support for children with intellectual disabilities. Strengthening parental competence not only enhances the child's functional abilities but also enriches emotional well-being by fostering a more supportive home environment. Future research should examine

long-term outcomes of parental training programs and explore culturally adapted models to ensure broader applicability.

CONCLUSION

Families with children with intellectual disabilities face unique challenges that significantly impact their overall quality of life (QOL). While family support is generally beneficial, its impact can vary depending on the child's health condition. Children with disabilities have a variety of conditions that impact their cognitive, adaptive, and overall functioning. Family support in the form of providing information and social support should be a higher priority for families with children with intellectual disabilities.

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