

Proceeding Paper

THE CORRELATION BETWEEN PARENTAL SOCIAL SUPPORT AND THE QUALITY OF LIFE ON CHILDREN WITH INTELLECTUAL DISABILITY

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Abstract

Intellectual disability is the disruption of cognitive function due to intelligence levels below average. Children with disabilities tend to have a poor Quality of Life (QoL) and need special services from parents because this condition affects a person's quality of life. One aspect of QoL is social relationships. In this aspect, there is social support provided by parents. It stated that social support is the dominant factor affecting QoL. This correlation research design with a cross-sectional approach to analyzed the correlation between parental social support and the quality of life of children with intellectual disability at The Pelambuan State Special School of Banjarmasin. The population and sample in this study was 48 respondents used total sampling technique. Data were collected using a Parental Social Support questionnaire and WHOQoL-BREF Disability questionnaire with the Chi-Square test. The results showed that there were 39 respondents (92,9%) with high parental social support and high QoL. Based on the results of the statistical test using Chi-Square, p value = $0.049 < \alpha 0.05$ was indicated a significant relationship between variables. The increasing in parental social support is associated with the improvement of the QoL of children with intellectual disability. The parents can optimize the social support given to children with intellectual disability by providing love, attention, and providing the facilities needed.

Presented at The 4rd
Bengkulu International
Conference on Health (B-ICON),
Bengkulu-Indonesia,
September 24-26th, 2024

Published: December 31st, 2024 **Copyright** © 2024 by authors. ISSN: 2986-027X

Keywords : Children, Intellectual Disability, Parental Social Support, Quality of Life

INTRODUCTION

Children are the most precious treasure and the most beautiful grace for every parent entrusted by God Almighty (Nugroho, 2023). The birth of a child is a dream by every parent. Children are

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potential successors to the nation's ideals and are expected to become a quality generation (Anggeriyane, 2019). Every parent surely wants their children to grow up to be a healthy child, smart, creative, independent, and faithful (Rahayu et al., 2022). The parents' wishes or expectations are a child who has perfect nature without any shortcomings, but parents cannot afford to refuse the birth of children with special needs or children with disabilities (Rezieka et al., 2021). People with disabilities can be categorized into 5, namely: physical, intellectual, mental, sensory, and multiple disabilities (Nugroho, 2023).

One of the problems that occurs in children is intellectual disorders, such as intellectual disability. Children with disabilities are children who have limitations, physical, intellectual, mental, sensory limitations and even have more than one type of limitation. Intellectual disability is the disruption of cognitive function due to intelligence levels below average. Lack of ability to understand information and apply new skills. Intellectual disability is usually divided into 3 types, namely: learning ability disorders, mental retardation, and Down-Syndrome (Nugroho, 2023). Intellectual disability or previously called mental retardation is a developmental disorder characterized by a lack or limitation of intellectual function and adaptive behavior (Lestari et al., 2021).

The average number of children with disabilities globally is nearly 240 million, according to a recent report (United Nations Children's Emergency Fund {UNICEF}, 2021). According to 2020 running data from the Central Statistics Agency, the number of people with disabilities in Indonesia reached 22.5 million people or around five percent of the total population (Kemensos RI, 2020). Recorded that there are 180 students with disabilities at The Pelambuan State Special School of Banjarmasin (Dapodik, 2024). Dra Hj. Nurhuda's representative from the South Kalimantan Education Department revealed that the number of children with special needs in South Kalimantan reached 2,353 children (Ilham, 2018). Data on children with disabilities in Banjarmasin in 2022 was recorded at 974 people (Dinas Sosial Banjarmasin, 2022).

One to three percent of the global population has an intellectual disability or as many as 200 million people (Geukes et al., 2019). From 2019 to 2021, it has been diagnosed and observed in the United States that there was no significant change in the prevalence of intellectual disability in 2019 was 1.70%, then in 2020 the population of intellectual disability increased by 0.5% to 2.20%, and decreased in 2021 to 1.65% (Zablotsky et al., 2023). There were 38,545 children with intellectual disability in Indonesia, enrolled in a special school (Lestari et al., 2021). The number of people with intellectual disabilities in Banjarmasin was recorded at 274 people (United Nations Educational, Scientific and Cultural Organization {UNESCO}, 2019). According to Dinas Pendidikan dan Kebudayaan Provinsi Kalimantan Selatan (2023) intellectual disability was recorded in as many as 1415 people. Pelambuan State Special School of Banjarmasin has the highest number of children with intellectual disability in Banjarmasin, amounting to 48 students.

Children with disabilities tend to have a poor quality of life due to their low ability to meet basic needs independently. Therefore it requires special services from parents (Desriyani et al., 2019). The intellectual disability condition affects a person's quality of life, so they need support system, affection, and attention from the closest environment, which is the family (Juliani et al., 2023)

World Health Organization (WHO) ((1997, in Surjaningrum & Mujahadah, 2022) stated that quality of life aspects consist of physical, psychological, environmental, and social relationship health. Physical health consists of pain and feelings of discomfort, mobility, ability to carry out daily activities, energy levels and fatigue, sleep and rest, as well as dependence on medical care and work capacity. The psychological aspect includes the positive things experienced by the individual (happy, enjoying life, and having hope), and the ability to think, learn, remember, and concentrate. The social relationships aspect consists of personal relationships, social support (parents, family, closest people), and sexual activity. The environmental aspect consists of freedom, security, home environment, accessibility, opportunities for recreation, physical environment, and transportation.

Burgess & Gutstein (2007, in Surjaningrum & Mujahadah, 2022) argue that quality of life is important to know the conditions of services provided to individuals with disabilities. A person's life can be known to experience an increase that is influenced by the surrounding environment, namely family or community, through the quality of life. When a child with intellectual disability does not receive social support from his parents or family, it will affect his quality of life, in addition, the quality of life can determine how life is lived today.

Firman et al., (2023) found that social support became the dominant factor influencing quality. Research conducted by Surjaningrum & Mujahadah (2022), state that the improved quality of life of adult autistic individuals is due to social support. Social support can take the form of direct and indirect assistance. Direct assistance such as assistance when doing schoolwork and campus assignments and indirect assistance such as informing, being noticed, advised, and directed.

Social support is support given to individuals who have an emotional bond with the person, such as attention, motivation, comfort, and social support itself can be in the form of any assistance that has been received by an individual or group benefits of social support can affect individual perception, help individuals cope with pressure and can reduce the negative impact of stress on mental and physical health, thus improving various aspects of health (Moningka et al., 2022).

Based on the results of a preliminary study on Tuesday, 27 February 2024, it was found that The Pelambuan State Special School of Banjarmasin has 48 children with intellectual disability who are in elementary school from grade 1 to 6. In the interview results, 6 of 10 parents said that their children still need supervision while playing, parents also forbid children to play with neighbors, and parents say children are still undervalued in the surrounding environment. 6 of 10 children still need

help in self-care such as bathing, eating, urinating, or defecating. Based on the description above, it is known that social support has not been optimally provided by parents to children, so it can affect the quality of life of children, moreover, some children with intellectual disability are still not independent. In addition, the number of children with intellectual disability is also increasing every year, but there are still few studies that examine related to children with intellectual disability in Banjarmasin, so this is an urgency for researchers to conduct research.

MATERIALS AND METHODS

The research used a correlation research design with a cross-sectional approach to analyze between independent variables, namely parental social support and dependent variables of quality of life of children with intellectual disability. The population in the research was parents of children with intellectual disability consisting of Down syndrome children, mentally retarded children, and children with learning difficulties totaling 48 students who attend the Elementary School of The Pelambuan State Special School of Banjarmasin. The sampling method was is total sampling.

This research was conducted at The Pelambuan State Special School of Banjarmasin, West Banjarmasin District, Banjarmasin City, South Kalimantan. The research instruments used the Parental Social Support Questionnaire and the WHOQol-BREF Disability Questionnaire. The purpose of this research was to analyze the correlation between parental social support and the quality of life of children with intellectual disability at The Pelambuan State Special School of Banjarmasin. The data collection protocol was approved by the ethics committee of the University of Muhammadiyah Banjarmasin; certificate number 399/UMB/KE/VI/2024.

RESULTS AND DISCUSSION

Description of respondent characteristics

Gender

Table 1: Characteristics of Respondents Based on Gender

Gender	Frequency (f)	Percentage (%)
Female	48	100
Male	0	0
Total	48	100

Table 1 shows that all respondents in this study were female with a total of 48 respondents (100%). This may be due to the role of the mother who is more involved in taking care of and caring for the child than the role of father who works more to earn a living (Stevanny & Laksmiwati, 2022). This research is in line with a meta-analysis that revealed that women give and receive more social support than men (Tifferet, 2020).

The men are seen by cultural constructions as individuals who are more independent than women in the context of Indonesian culture. This cultural construction affects the dynamics of receiving social support in the subject so that it affects the subject in responding to the social support received and given (Fakih, 2008). Women provide more social support because women also receive a lot of social support from their surroundings. Therefore, women are more likely to accept and give social support to others compared to men. In addition, this factor is caused by culture, family structure, and individual characteristics.

Age
Table 2: Characteristics of Respondents Based on Age

Age	Frequency (f)	Percentage (%)		
25-35	8	16,7		
36-45	27	56,3		
46-55	6	12,5		
56-65	6	12,5		
65>	1	2,1		
Total	48	100		

Table 2 shows that most respondents in 36-45 years old with total of 27 respondents (56.3%). Based on the Ministry of Health of the Republic of Indonesia (2009) the age categories are as follows: 1) toddlerhood: 0-5 years, 2) childhood: 5-11 years, 3) early adolescence: 12-16 years, 4) late adolescence: 17-25, 5) early adulthood: 26-35, 6) late adulthood: 36-45, 7) early old age: 46-55, 8) late old age: 56-65, 9) senior age: >65. Most respondents in this study are in the late adult stage.

The older the mother's age, the better the child's grades, the better the social support provided and the better the role of mothers in parenting (Arlianty, 2018). The relationship between age and social support is very close. As children with intellectual disabilities age, the need for social support changes and the challenges of getting support also become more complex. With parents who are getting older, they can provide social support to children more optimally, so that the quality of life of children also increases.

Occupation

Table 3: Characteristics of Respondents Based on Occupation

Occupation	Frequency (f)	Percentage (%)		
Housewife	27	56,3		
Private Employee	16	33,3		
Civil Servant	5	10,4		
Total	48	100		

Table 3 shows that the majority of respondents work as housewives with a total of 27 respondents (56.3%). The majority of respondents from the study on parental support with the quality of life of thalassemia children in the Flamboyant Room of dr. Doris Sylvanus Palangka Raya Hospital are

housewives (Maisyarah, 2023). The high percentage for housewives may be due to most respondents being women. Mothers who do not work have a role in better parenting. The better the child's grades, the better the social support (Arlianty, 2018). Housewives spend more time with children with intellectual disabilities. So, they can provide more objective social support than working mothers. In addition, housewives can also supervise children with intellectual disabilities in their daily activities.

Univariat Analisis

Parental Social Support

Table 4: Data Distribution of Social Support

Parental Social Support	Frequency (f)	Percentage (%)		
Low	6	12,5		
High	42	87,5		
Total	48	100		

Table 4 shows that the distribution of respondents based on parental social support for the quality of life of children with intellectual disability was 42 respondents (87.5%) with high social support. In line with Maisyarah (2023) the parents as a practical and concrete source of children, who strive to provide the facilities and equipment needed by each family member. High parental support is influenced by the level of cognitive knowledge of their parents, where the higher the education of the respondents, the higher the initiative and awareness about children's health. The high level of social support from parents can take the form of care, attention, comfort, appreciation, material and non-material assistance that can be done by family, friends, friends, teachers, the environment, and the community (Laela, 2022).

Social support for parents who have children with intellectual disabilities in SLB Bangkalan Regency stated that the majority of parental support that is included in the good category mainly occurs in informational support (Stevanny & Laksmiwati, 2022). It is important to understand the role of parents in providing the necessary support so that children with special needs can grow and develop optimally. With this understanding, it is hoped that it can improve the quality of life of children with special needs and reduce the stigma and discrimination they may face (Wiyono, 2016). Family support with self-reliance on children with disabilities stated that there was family support that supported as many as 29 respondents (72.5%). One of the causative factors that causes high family support in this statement is related to high levels of education. Where the higher the level of education, the more knowledge they have. That way, the higher the family support obtained, the better the self-care ability of the disabled child (Maidartati et al., 2019).

Parents have a very complex obligation to meet their children with intellectual disability needs. The fulfillment of this need is related to the ability of parents to provide care to children with disabilities.

In caring for children with disabilities, of course, it is different from caring for other normal children (Nurasa & Mareti, 2022). The role of parents in handling children with disabilities includes building communication between families of children with disabilities, providing social support for children, providing alternative education services, and providing health services (Indahni et al., 2023). High social support will provide benefits in developing a healthy personality and make it able to create a positive personality (Witjaksono & Muhid, 2021). Complex role in providing for children with intellectual disability. As well as being material providers for children, parents also act as intermediaries for children to communicate with the surrounding environment. High levels of social support are essential in developing a healthy and positive personality in children with disabilities. A supportive environment also plays an important role, where the child is allowed to be involved in the community and feel accepted in the neighborhood.

Quality of Life of Children with Intellectual Disability

Table 5: Data Distribution of Quality of Life

Quality of Life	Frequency (f)	Percentage (%)	
Low	5	10,4	
High	43	89,6	
Total	48	100	

Table 5 shows that 43 children with intellectual disability (89.6%) have a high quality of life. In line with the research conducted by Jacinto et al., (2023) that individuals with intellectual disability get high quality of life values in the domains of Emotional Well-being and Physical Well-being.

According to Bloemeke et al., (2020) the importance of a proper assessment of QoL in pediatric age becomes even clearer in clinical groups. In these cases, evaluation of QoL in clinical practice can help optimize communication between clinicians and the child and his/her caregivers as well as recognizing physical or mental health problems from the patient and caregiver perspectives and areas of potential amelioration. Children with higher levels of QoL exhibit better adaptive skills and less challenging behaviors than children with lower QoL (Fucà et al., 2022).

According to Bihm and Poindexter (1991 in Fucà et al., 2022) results from cognitive evaluation were mirrored by findings on adaptive functioning, indicating that children with higher QoL had better adaptive skills than children with low QoL. Adaptive behavior includes the practical domain (e.g., feeding, personal care, and staying safe), social functioning (e.g., interpersonal skills, understanding and compliance with rules, and resolution of social problems), and conceptual domain (e.g., language and communication, reading and writing, and handling figures). The assessment of QoL is well-suited to conditions that have a multifaceted impact, such as genetic syndromes and neurodevelopmental disorders, including intellectual disability (Fucà et al., 2022).

Assessment of quality of life (QoL) in children is important in clinical practice. It aids communication between clinicians and children and their parents or guardians, and can also help recognize physical and mental health problems from the perspective of patients and caregivers. Children with higher levels of QoL tend to have better adaptability and behavior. The high quality of life of children with intellectual disability is inseparable from the great social support of parents and the surrounding environment. Adequate health facilities and public facilities, sufficient finances, supportive friends, and positive school programs are factors that support the quality of life of children with intellectual disability.

Bivariat Analisis

The Relationship of Parental Social Support to the Quality of Life of Children with Intellectual Disability at The Pelambuan State Special School of Banjarmasin

Table 6: Data Distribution of Social Support and Quality of Life Social Support Quality of Life of Children With Intellectual Disability

Parental Social Support	Quality of Life of Children With Intellectual Disability			Total		
	Low		High			
	f	%	f	%	f	%
Low	2	33,3	4	66,7	6	100
High	3	7,1	39	92,9	42	100
Total	5	10,4	43	89,6	48	100
Chi-Square Correlation						
	Test Re	esults = 0.0	$49 < \alpha 0$.05		
(Continge	ncy Coeffi	cient = 0	.273		

Table 6 shows that the parents' social support and also the quality of life were high in 39 respondents (92.9%). The coefficient number shows a positive correlation with a value of 0.273, there was a relationship between variables with moderate or sufficient relationship strength. Based on the results of the statistical test using Chi-Square obtained p value = $0.049 < \alpha 0.05$ was obtained which indicates a significant relationship between variables.

Surjaningrum & Mujahadah (2022) which states that social support affects improving the quality of life in adult autistic individuals. The results showed a significant positive correlation between social support and quality of life. This indicates an increase in social support followed by an improvement in the quality of life in adult autistic individuals. This factor is due to other people listening to his story and sharing the same interests and fondfondness with him. There are people who can help him complete his daily work ranging from college assignments, schoolwork, and homework, people who can provide advice and direction, and financial assistance (pocket money). This research is also

strengthened by the research conducted to Khanna et al., (2014, in Surjaningrum & Mujahadah, 2022) supportive social networks can come from family, friends, and professionals. Previous research has shown that individuals who feel they receive considerable social support from family or friends have a higher quality of life.

The parental support is the existence, willingness, and care of a person who can be trusted, appreciates, and loves us, which aims to help us overcome or face a problem in a certain situation or stressful event and make us more meaningful. Parental support is a form of comfort, attention, appreciation, or helping people to acceptance their condition. So parental support is very closely related to improving the quality of life in children. The higher the parental support, the higher the quality of life of the child (Maisyarah, 2023).

The needs of children with intellectual disability are divided into three categories are the physical needs of children with mild intellectual disability such as eating, drinking, and clothing. They also need the opportunity to exercise, play, exercise, cool down, look neat, clean, and attractive. However, children with mild intellectual disability require repetitive special exercises and instruction to meet these needs. The psychological needs of children with intellectual disability include selfesteem, security, confidence, motivation, self-actualization, and acceptance of the environment. They also want attention, appreciation, and good and thoughtful treatment. The social needs of children with intellectual disability include the desire to communicate and interact with others, to express themselves, to have feelings, desires, ideas and beliefs, even if they are less significant. They want to be recognized as a family member, recognized in front of their friends, and gain status in the group (Bellaputri et al., 2022). So, presence of parents has a positive impact on the quality of life of children with intellectual disability, with the support provided by parents, both material and nonmaterial, to children with intellectual disability is very meaningful because only the parents of children with intellectual disability are dependent. They still need the presence of their parents to do therapy, go to school, and go to other places. The higher the social support provided by parents, the higher the quality of life of children with intellectual disabilities.

CONCLUSION

The parental social support for children with intellectual disability in The Pelambuan State Special School of Banjarmasin was high parental social support with a total of 42 respondents (87.5%). Quality of life of children with intellectual disability was obtained with a high quality of life, amounting to 43 children with intellectual disability (89.6%). There was a significant relationship

between Parental Social Support to the Quality of Life of Children with Intellectual Disability at The Pelambuan State Special School of Banjarmasin.

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