



ANALYSIS OF QUALITY OF LIFE OF PARENTS WITH SPECIAL NEEDS CHILDREN IN SPECIAL ELEMENTARY SCHOOLS

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ABSTRACT

The quality of life of parents is an important thing in caring for children with special needs; it can be influenced by physical and emotional health. Health workers need to know the condition of the quality of life of parents to ensure the optimal care and intervention given. This study aims to analyze the quality of life of parents with children with special needs in special elementary schools in Banda Aceh City. The research design used is quantitative analytical with a cross-sectional design. The population in this study was 233 parents of Special Elementary School students in the Banda Aceh City area. Sampling using convenience sampling techniques, namely paying attention to inclusion and exclusion criteria. Data were collected using the World Health Organization Quality of Life questionnaire-BREF 27 (WHOQOL_BREF). Data analysis using logistic regression tests. The results showed that there was a relationship between the burden of caring for children ($P=0.004$), comorbidity ($P=0.000$), mental health depression ($P=0.000$), sleep quality ($P=0.038$), self-efficacy ($P=0.000$), education ($P=0.024$), employment ($P=0.013$), marital status ($P=0.043$) with the quality of life of parents with children with disabilities. At the same time, there was no relationship between mental health anxiety ($P=0.650$), stress ($P=0.171$), social support ($P=0.457$), family income ($P=0.129$), number of children ($P=0.218$) and gender of the child ($P=0.218$) with the quality of life of parents with children with disabilities. The most dominant variable influencing the quality of life of parents with children with disabilities is marital status. Single parents will be 5 times at risk of experiencing low quality of life compared to parents who raise their children with a complete family.

Keywords: child care; child disability; quality of life for parents

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INTRODUCTION

Disability is a group of people who have long-term physical, intellectual, mental, and/or sensory limitations (Dunn et al., 2020). An estimated 500 to 650 people worldwide live with disabilities. According to the World Health Organization (WHO), there are around 10% of children to adolescents in the world, which is around 200 million people, who have sensory, intellectual, or mental health problems, and 80 percent of them live in developing countries (Vos et al., 2017). Indonesia, which is one of the countries that contributes to the large number of disability cases, found that the number of children with special needs in Indonesia continues to increase every year (Efendi, 2018). In Indonesia, it is estimated that there are around 4.2 million children with special needs. According to the latest data, the number of children with special needs in Indonesia who are recorded as studying in special schools reached 144,621 students in the 2020/2021 academic year. Of that number, 82,326 children with special needs are in elementary school. Another 36,884 children with special needs are studying in junior high schools. Meanwhile,

25,411 children with special needs are currently studying in high school. The percentage of the population aged 10 years and over who have disabilities according to province in Indonesia, that Aceh Province is in the top five of the highest contributors to the number of people with disabilities where the percentage is 9.98% (Purnamawati et al., 2022).

The activity of caring for children with disabilities is said to have an impact on the quality of life of parents who have a role as the primary caregiver for their children (Barros et al., 2019). WHO defines quality of life as an individual's perception of their position in life in the context of the culture and value system in which he or she lives and its relationship to one's goals, expectations, standards, and concerns in life. Research conducted states that parents with children with cerebral palsy (CP), autism spectrum disorders (ASD), and speech and hearing impairments show a lower quality of life compared to parents with children without these conditions (Blasco et al., 2023). Parents of children with ASD have lower quality of life and family functioning scores compared to families with children with other types of disabilities. This occurs due to the greater parenting stress obtained from the many difficulties faced in providing care for children, such as behavioral problems, emotional control, social problems, anxiety, and depression that are commonly experienced by children with ASD (Borilli et al., 2022; Losada-Puente et al., 2022).

The physical and emotional health of the parents influences the capacity and ability to provide care to children. When parents experience a decline in quality of life, it is feared that their ability to provide care will not be optimal. Therefore, health workers need to know the condition and the quality of life of parents to ensure optimal care or interventions given to children with disabilities, as well as to avoid other problems that may arise, such as a decline in the health status of the family members and other conflicts within the family (Benjamin & Sonn, 2022; Sánchez-Núñez et al., 2020). The high number of children with special needs in Aceh is assumed to be due to the low level of quality of life of parents who have children with special needs. However, so far, no one has conducted such research in Aceh. Therefore, it is important to conduct this research to determine the level of quality of life category in parents who have children with special needs and compare it with parents who have normal children. This study aims to analyze the quality of life of parents with children with special needs in special elementary schools in Banda Aceh.

METHOD

The research design used is quantitative analytical with a cross-sectional research design. In this study, the population was 233 parents of students from all Special Elementary Schools in the Banda Aceh City area with a sampling technique of convenience sampling totaling 160 respondents. The inclusion criteria are parents who have children with special needs aged 6 to 12 years; Parents who have children who attend school in grades 1 to 6; Parents who have children with special needs who are physically and mentally healthy; Parents who have children with special needs who are willing to be research subjects. While the exclusion criteria are in the form of children with special needs not being present at school during the study, Documented data is not completely available according to the research variables. The quality of life of parents who have children with special needs and normal children includes quality of life, physical, psychological, social, and environmental, using the World Health Organization Quality of Life-BREF 27 (WHOQOL_BREF) questionnaire. The WHOQOL questionnaire measurement method uses a Likert scale with interpretation results of very high $102 < x$; high $79.3 < x \leq 102$; moderate $56.6 < x \leq 79.3$; low $33.9 < x \leq 56.6$; very low ($x \leq 33.9$). Data analysis in this study was carried out using the STATA 15.0 program. Data were

analyzed descriptively and analytically, and hypothesis testing was carried out using logistic regression.

RESULT

Table 1.
Respondent characteristics (n = 60)

Characteristics	f	%
Respondent Age	42,35	28-62
Education	7	4,38
Low	153	95,63
High		
Job		
Working	54	33,75
Not Working	106	66,25
Income		
< Rp. 3,280,327	128	80,0
≥ Rp. 3,280,327	32	20,0
Marriage		
Complete Family	155	96,88
Single Parent	5	3,13
Number of Children	2,46	1-8
≤ 2 Children	97	60,63
> 2 Children	63	39,38
Child Gender		
Boy	96	60,0
Girl	64	40,0
Child Disabilities		
Blindness	17	10,63
Deafness/speech impairment	14	8,75
Mental impairment	71	44,38
Physical impairment	22	13,75
Autism	27	16,88
Speech Delay	1	0,63
Learning Difficulties	1	0,63
Down Syndrome	6	3,75
Cerebral palsy	1	0,63
Quality of Life of Parents		
Very High	30	18,8
High	94	58,7
Medium	28	17,5
Low	8	5,0
Child Care Burden		
None	64	40,0
Light-Moderate	51	31,9
Moderate-Heavy	45	28,1
Comorbidity		
Yes	26	16,3
No	134	83,7
Mental Health – Depression		
Normal	153	95,6
Light	7	4,4
Mental Health – Anxiety		
Normal	157	98,1
Light	3	1,9
Mental Health – Stress		
Normal	150	93,7
Light	10	6,3
Sleep Quality		

Characteristics	f	%
Good	95	59,4
Bad	65	40,6
Self Efficacy		
High	133	83,1
Low	27	16,9
Social Support		
High	24	15,0
Medium	68	42,5
Low	68	42,5

Table 2.
Results of logistic test of independent variables on quality of life variables of parents with children with disabilities

Variables	OR	95% CI	p-value
Child Care Burden: Yes	1,65	0,2-3,2	0,150
Comorbidities: Yes	5,45	1,4-20,4	0,012
Mental Health-Depression: Yes	3,91	0,2-55,4	0,312
Mental Health-Anxiety: Yes	12,96	0,6-252,0	0,091
Mental Health-Stress: Yes	1,03	0,1-6,0	0,969
Sleep Quality: Poor	1,70	0,5-4,9	0,320
Self efficacy: Low	7,73	2,1-27,6	0,002
Social Support: Not High	1,72	0,7-3,9	0,198
Respondent Age	0,94	0,8-1,0	0,138
Education: Low	3,20	0,2-35,9	0,345
Occupation: Not Working	2,15	0,5-8,8	0,290
Family Income: < Rp. 3,280,327	2,88	0,5-16,8	0,240
Marital Status: Single Parent	12,99	1,1-148,3	0,039
Number of Children: >2 children	0,39	0,1-1,2	0,127
Child Gender: Female	1,09	0,3-3,1	0,864
Types of Child Disabilities	0,85	0,5-1,2	0,388
Pseudo R ²		0,3758	

The characteristics of respondents in this study showed that most parents of children with special needs in special elementary schools in Banda Aceh City had a higher education background (95.63%), and most were unemployed (66.25%). Most respondents also came from intact families (96.88%) with an income of less than Rp3,280,327 per month (80%). Most parents had two or fewer children (60.63%), with a higher proportion of boys than girls (60% versus 40%). The most common type of disability experienced by children was mental disorders (44.38%), followed by autism (16.88%) and visual impairment (10.63%). Most parents had a high quality of life (58.7%) and very high (18.8%), although 5% reported a low quality of life. In terms of the burden of caring for children, around 28.1% felt a moderate to heavy burden, while 40% did not feel a burden. Most respondents did not have comorbidities (83.7%) and were in normal mental conditions related to depression (95.6%), anxiety (98.1%), and stress (93.7%). However, sleep quality is still challenging, with 40.6% of respondents experiencing poor sleep. Even so, the majority had high self-efficacy (83.1%) and received moderate to high social support (42.5% each) (Table 1).

Several variables significantly affect the quality of life of parents who have children with disabilities. Marital status emerged as the most dominant factor, where single parents had a 12.99 times greater risk of experiencing low quality of life compared to parents from intact families ($p = 0.039$; 95% CI = 1.1–148.3). In addition, low self-efficacy also had a significant effect, with an odds ratio of 7.73 ($p = 0.002$; 95% CI = 2.1–27.6), indicating that parents' self-confidence in parenting challenges greatly determines their quality of life. Comorbidity in parents also had a significant effect, where respondents with comorbid conditions had a 5.45

times greater risk of experiencing low quality of life ($p = 0.012$; 95% CI = 1.4–20.4). Meanwhile, other variables such as anxiety, income, occupation, burden of caring for children, sleep quality, and education did not show a statistically significant relationship. These results confirm that psychosocial support, physical health conditions, and family conditions are the main determinants in maintaining the quality of life of parents with children with special needs (Table 2).

DISCUSSION

The results showed that respondents with the latest elementary and junior high school education tend to experience a higher care burden than those with high school or college education. Higher education gives parents broader insight into their child's condition, which affects their attitude toward caregiving. Previous research supports this finding, showing that education level negatively correlates with caregiver burden, where higher education is associated with a lower burden of caregiving. Employment status also affects the burden of caregiving. Unemployed parents tend to have a lighter burden because they can focus more on caring for their children without dividing their time with work. In contrast, working parents face challenges in balancing work and caregiving responsibilities, which can increase their burden. Research by Desriyani et al. (2019) supports this, showing that working caregivers have a higher burden because they have to balance work duties with caring for children. Family income also affects the burden of caregiving. The higher the income, the lower the burden felt. Gea et al. (2023) stated that caring for a child with a disability costs three times more than caring for a child without a disability. Families with lower-middle economic conditions are more vulnerable to the financial burden of caregiving compared to those in the upper-middle economic class.

The age of the child also affects the burden felt by the parents. The older the child, the greater the burden felt by the parents. This may be related to the child's sexual development and reproductive problems, as well as the parents' expectations that the child can live independently and be accepted in society. Research Prasasti & Nursasi (2023) supports this finding, showing that mothers have a higher burden on older children. The gender of the child also affects the burden of care. Parents with male children with disabilities have a higher burden than those with daughters. This is in line with research that says that mothers with sons have a high burden because sons are considered the successors of the lineage (Siburian, 2021). The type of child's disability is also a contributing factor to the burden of caregiving. Parents with children with mental disabilities, such as intellectual disabilities and autism, tend to experience a higher burden than those with children with physical or sensory disabilities. This is because children with mental disabilities require more time and effort in care. Research by Kurnia et al. (2019) supports this finding, showing that children with mental disabilities have a higher burden of caregiving.

In addition to these factors, parental adjustment and self-efficacy also affect the burden of caregiving. The data showed that 46.3% of respondents had little or no burden, indicating that parental adjustment was good. Research by Sujadi et al. (2022) supports this, showing that good adjustment and self-efficacy can reduce the burden of caregiving. The majority of parents in this study considered caring for a child with disabilities not a burden. Parents who are able to care for their children without the help of others show good self-control in parenting. Good control in caring for children with disabilities can increase parental satisfaction in parenting. The more parents are satisfied with the care they provide, the less burden they will feel. Research by Khairunnisa and Hartini (2022) supports this finding, showing that satisfaction in parenting is associated with lower burden. However, there are still respondents who have a heavy burden. Parents with a heavy burden category reported feelings of shame, worry about their child's future, disruption of social life, and feelings of being

unable to care for their child. This shows the importance of psychosocial support for parents with children with disabilities. Quality of life assessments show variations based on the type of child's disability. Parents with blind children mostly have a low quality of life. Previous studies in Jordan, Indonesia, the Netherlands, and Italy have shown that parents of children with developmental disabilities, intellectual disabilities, and autism tend to have a lower quality of life compared to other types of disabilities (Bosqui et al., 2024).

As health workers, nurses must be sensitive to the possibilities that can occur in the quality of life of parents. Good support from the surrounding environment can help parents be more positive and able to face difficulties well. Nurses can act as consultants, a place where parents can tell their problems and discuss to find solutions. In addition, it is important for nurses to provide health education about caring for children with disabilities and how to improve the health conditions of children and their parents (Nurhidayah et al., 2020; Octavia, 2020). Multivariate analysis using logistic regression test showed that marital status is the biggest factor influencing the quality of life of parents with children with disabilities. Single parents have almost 13 times greater risk of experiencing low quality of life compared to parents who raise their children in complete families. In addition, anxiety also has a significant effect, where anxious parents have almost 13 times greater risk of experiencing low quality of life compared to non-anxious parents.

These findings are in line with the literature highlighting the importance of social support and family structure in determining the quality of life of families with children with disabilities. Single parents face a higher risk of stress and psychological burden, which negatively impacts their quality of life compared to parents living in complete families (Boehm & Carter, 2019; Jansen-van Vuuren et al., 2022). In addition, anxiety experienced by parents has also been shown to significantly reduce quality of life, as high stress and psychological distress can interfere with their physical and mental well-being (Naz & Noor, 2024; Staunton et al., 2023).

CONCLUSION

There is a relationship between the burden of caring for children ($P=0.004$), comorbidity ($P=0.000$), mental health depression ($P=0.000$), sleep quality ($P=0.038$), self-efficacy ($P=0.000$), education ($P=0.024$), employment ($P=0.013$), marital status ($P=0.043$) with the quality of life of parents with children with disabilities. At the same time, there is no relationship between mental health anxiety ($P=0.650$), stress ($P=0.171$), social support ($P=0.457$), family income ($P=0.129$), number of children ($P=0.218$) and gender of the child ($P=0.218$) with the quality of life of parents with children with disabilities. The most dominant variable affecting the quality of life of parents with children with disabilities is marital status. Single parents will be 5 times at risk of experiencing low quality of life compared to parents who raise their children with a complete family.

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