



The Relationship Between Stress Levels and The Quality of life of Children with Disability

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Abstract

Introduction: Children with disabilities have physical activity, learning, and mobility limitations. Children with disabilities can affect their parents' quality of life, especially stress levels. A process of assistance is needed for the rehabilitation, care, and education of children with disabilities, as well as measuring parents' quality of life and stress levels. This study was conceived to assess the stress level of parents of children with disabilities.

Methods: This study uses a mixed method approach with a quantitative approach applying a cross-sectional research design. The research was conducted in Padang from January to October 2021, consisting of children aged 8 to 14 and their parents. The study used the DASS questionnaire, and the data was processed and tabulated using SPSS version 2.5.

Results: A total of 87 respondents (50.3%) had moderate stress, 112 respondents had very high anxiety (64.7%), and 77 respondents had very severe depression (44.5%). There is a relationship between stress levels and the quality of life (P-value 0.003). Meanwhile, the level of anxiety (P-value 0.528) and depression (P-value 0.182) were not related to the quality of life of children with disabilities.

Conclusions: Most of the respondents had moderate stress levels and severe levels of anxiety and depression. There is a relationship between stress levels and the quality of life of children with disabilities, but there is no relationship between anxiety levels and depression levels.

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Introduction

Person with disability is any person who experiences physical, intellectual, mental, and sensory limitations for an extended period and, in interacting with the environment, may encounter obstacles and difficulties in participating fully and effectively with other citizens based on equal rights.¹ This disorder generally continues and produces substantial impairment of three or more functions, including self-care, receptive and expressive language, learning, mobility, self-knowledge, capacity for independent living, and financial ability.^{2,3} Children with disabilities need exceptional long-term and interdisciplinary care for life in the form of medication and other services.^{2,3}

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Disabilities consist of intellectual, locomotor and mental disabilities.⁴ Locomotor disability is the most common type of disability in populations of all ages. Mental disability occurs mainly due to serious illness during childhood, head injuries and birth-related causes.⁵ Indonesia has Law Number 8 of 2016 concerning Persons with Disabilities which replaces Law Number 4 of 1997 relating to Persons with Disabilities which is seen as not having a human rights perspective, is more compassionate, and fulfilling the rights of persons with disabilities is still considered a social problem whose policy is fulfilling their requests, new forms of social security, social rehabilitation, social assistance, and improvement of social welfare.¹

Indonesia has 3.3% of children aged five to 17 years with disabilities.¹ Provinces with the highest proportion of children with disabilities were Central Sulawesi (7.0%), North Kalimantan, and Gorontalo (5.4% each), while the lowest ratios were in West Sulawesi, Lampung, and Jambi (1.4% each).¹ The World Health Organization (WHO) defines the quality of life as an individual's perception of their position in life in the context of the culture and value system in which they live and concerning their goals, expectations, standards, and concerns.⁷ The measurement of quality of life has the advantage of being a comparison of several management alternatives, clinical research data, assessing the benefits of a clinical intervention, screening tests in identifying children with specific difficulties and requiring medical corrective action or counseling assistance, can also be used for early recognition so that additional (Non-medical) interventions can be given, as well as predictors for estimating health care costs.⁸

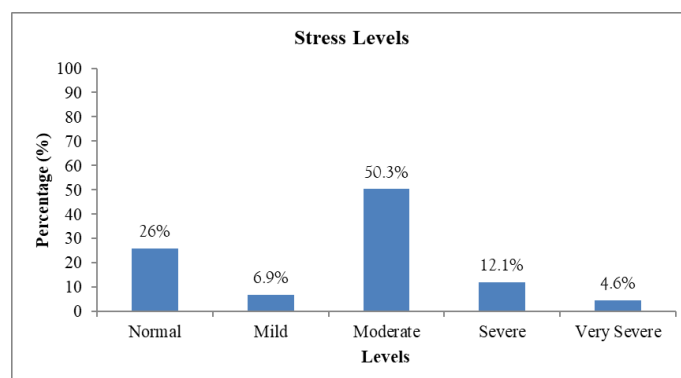
Disabilities in children can burden family members, especially the parents who care for them.³ Children with disabilities can affect their parents' quality of life, especially stress levels.³ Parents may need to spend most of their time caring for their children, especially children with severe disabilities.³ They will limit other activities and social life so that it negatively affects their quality of life.³ In the era of the COVID-19 pandemic, the handling and prevention of COVID-19 in children with disabilities were challenging to reach. Based on a rapid study by the April 2020 COVID-19 Response Network of Organizations for Persons with Disabilities, 70% of children with disabilities did not understand proper health protocols, so the education process was temporarily suspended. Therefore, a method of assessment is needed for the rehabilitation, care, and education of children with disabilities and measuring their parents' quality of life and stress levels so that children can grow and develop according to their potential by applying community-based rehabilitation models at various levels of society.

Methods

This study uses a mixed method approach with a quantitative approach applying a cross-sectional research design. The research was conducted in Padang in collaboration with the Health Department, Social Department, Education Department, Women's Empowerment and Child Protection Department, and Community Based Rehabilitation (RBM) team in West Sumatra. The research sample comprised children and their parents recruited from special schools for disabilities. The age range of children was four to 18 years. The Depression Anxiety Stress Scale (DASS) questionnaire was distributed to parents for stress assessment. The research was conducted from January until October 2021. Data were processed, tabulated descriptively, and analyzed using chi-square test in SPSS version 2.5. This research has received approval from the Research Ethics Committee of Universitas Andalas, Padang, Indonesia.

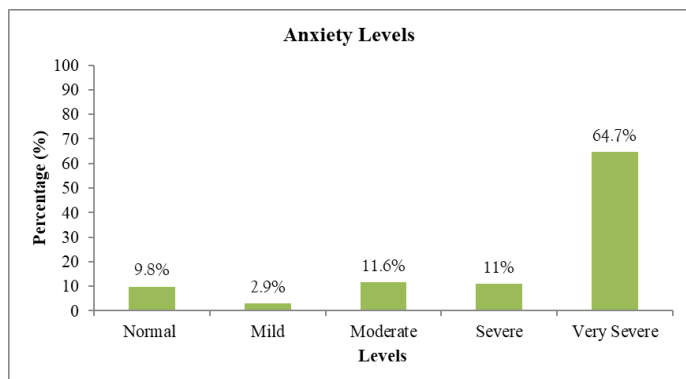
Results

Based on the study's results, Graph 1 illustrates the stress level with the highest percentage was found in 87 respondents which was moderate stress level (50.3%). In comparison, the stress level with the lowest rate was found in 8 respondents which was very severe stress level (4.6%).



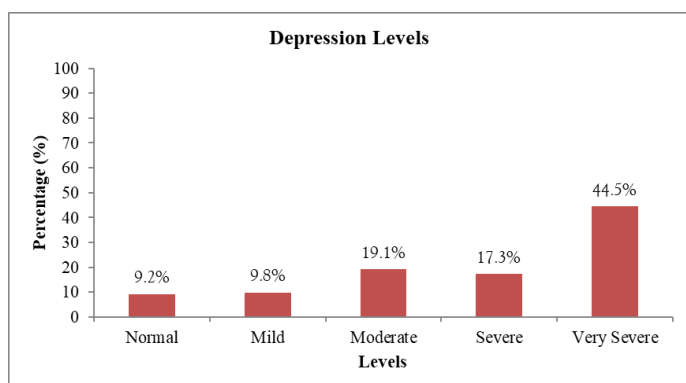
Graph 1: Stress levels respondents.

Based on Graph 2, it was found that the anxiety levels in the study respondents varied, with 112 respondents having very severe levels of anxiety (64.7%) and five respondents having mild levels of stress (2.9%).



Graph 2: Anxiety levels respondents.

Meanwhile, in Graph 3, it is found that the depression level of respondents with the highest percentage is very severe (44.5%), and the lowest rate is average (9.2%).



Graph 3: Depression levels respondents.

Research on the average quality of life was conducted in four domains related to physical, emotional, social, and school. Table 1 shows the domain of quality of life associated with the physical at 53.6, related to emotion at 56.0, related to social at 58.6, and related to school at 61.1. Overall, the average quality of life score was 57.5.

Table 1: Respondent’s average quality of life

| Quality of life domain | Average | Lowest | Highest |
|-------------------------------------|---------|--------|---------|
| Related to physical | 53.6 | 0 | 100 |
| Related to emotion | 56.0 | 0 | 100 |
| Related to social | 58.6 | 0 | 100 |
| Related to school | 61.6 | 0 | 100 |
| Average total quality of life score | 57.5 | 0 | 100 |

The results of the study regarding the quality of life domain in Table 2 show that the poorest quality of life was found in all fields, that is physical function 85%, emotional function 88.4%, social function 86.1%, school function 79.8% with a full function being 83.8%. Meanwhile, good quality of life in all domains was physical function being 15%, emotional function was 11.6%, social function was 13.9%, and school function was 20.2% with a full function of 16.2%. The highest good life is in the school function domain, with a percentage of 20.2%, and the highest lousy quality of life is in the emotional function domain, with a rate of 88.4%.

Table 2: Distribution of respondents based on quality of life.

| Domain | Quality of Life | |
|--------------------|-----------------|-------------|
| | Good N (%) | Badn N (%) |
| Physical function | 26 (15%) | 147 (85%) |
| Emotional function | 20 (11.6%) | 153 (88.4%) |
| Social function | 24 (13.9%) | 149 (86.1%) |
| School function | 35 (20.2%) | 138 (79.8%) |
| Total function | 28 (16.2%) | 145 (83.8%) |

The results showed that there was a relationship between stress levels and quality of life (p-value 0.003), there was no relationship between anxiety levels and quality of life (P-value 0.528), and there was no relationship between depression levels and quality of life (P-value 0.182) (Table 3).

Table 3: Relationship between stress, anxiety and depression levels with quality of life

| Variable | Quality of Life | | Total | P-value |
|----------------|-----------------|-----|-------|---------|
| | Good | Bad | | |
| Stress Levels | | | | |
| Very severe | 3 | 5 | 8 | 0.003 |
| Severe | 6 | 15 | 21 | |
| Moderate | 5 | 82 | 87 | |
| Mild | 4 | 8 | 12 | |
| Normal | 10 | 35 | 45 | |
| Anxiety Levels | | | | |
| Very severe | 16 | 96 | 112 | 0.528 |
| Severe | 4 | 15 | 19 | |
| Moderate | 4 | 16 | 20 | |
| Mild | 2 | 3 | 5 | |
| Normal | 2 | 15 | 17 | |

| Depression Levels | | | | |
|-------------------|---|----|----|-------|
| Very severe | 9 | 68 | 77 | 0.182 |
| Severe | 6 | 24 | 30 | |
| Moderate | 5 | 28 | 33 | |
| Mild | 6 | 11 | 17 | |
| Normal | 2 | 14 | 16 | |

Discussion

Children with disabilities have a lower quality of life than children with good development. As reported by Azaula et al, children with disabilities have a higher quality of life related to young age, high adaptive skills, low maladaptive behavior, low parental psychological pressure, and high satisfaction in educating children.⁹ Another study from India and Denmark also stated that children with disabilities at school do remarkably well and are more adapted to their circumstances so that they have a better quality of life.¹⁰

This study based on Table 1 and Table 2 shows that the highest quality of life domain is school function, which is 20.2%, and the lowest quality of life domain is emotional function, which is 88.4%. Another study by Victor et al compared whether children with intellectual disabilities and autism spectrum disorders show a lower quality of life than children with only intellectual disabilities. The study was conducted on 1,060 children with intellectual disabilities, 25% of whom had autism spectrum disorders with an age range of 4 to 21 years. Children with autism spectrum disorders show lower scores in several domains in QoL. Still, if several other variables are controlled, the scores are lower only on interpersonal, social inclusion, and material well-being.¹¹ In children with cerebral palsy, it is statistically stated that their physical quality of life is impaired. However, no clear association was found between cerebral palsy and psychosocial quality of life.¹²

Table 3 shows that there is a relationship between stress levels and quality of life (P-value 0.003), but no relationship between anxiety levels and quality of life (P-value 0.528), and no relationship between depression levels and quality of life (P-value 0.182). Our finding also resonated with a study conducted by Anja et al on 50 parents with mentally disabled children and 50 parents with non-disabled children as controls. The results showed a statistically significant difference between the perceptions of quality of life of parents of children with intellectual disabilities and parents of children without disabilities. The effect of gender and educational status on

the quality of life of parents of children with disabilities is also statistically specific. However, the interaction of gender and academic status on QoL is not related.¹³ Caring for children with disabilities is challenging for parents who require additional financial, social, emotional, and physical resources. Where the COVID-19 pandemic will affect the quality of life of parents of children with disabilities. Research on parents with disabilities compared with parents without children with disabilities as measured using the WHOQoL-BREF questionnaire.¹⁴ Where the quality of life of parents with children with disabilities is lower both in terms of physical health, psychology, social relations, and the environment.¹⁴

Mary et al researched health and rehabilitation services for children and adolescents with disabilities using the health-related quality of life (HRQoL) questionnaire.¹⁵ The results of his study showed that of 427 parents of children with disabilities aged six to 14 years, environmental barriers, behavioral difficulties, family functioning / impact, and general health had a significant relationship with quality of life.¹⁵ Sandy et al also researched the quality of life, associations, and costs of the multi-diagnosis group of children with disabilities residing in Simcoe / York. Quality of life was lower in children with disabilities and quality of life scores decreased with age.¹⁶ Child psychosocial well-being is more strongly related to child / family variables than physical well-being and health utilization costs are higher for children with disabilities.¹⁶

In children with disabilities, parents are not limited in providing care to children. Parents must also guarantee the continuity of their child's educational process. Therefore, there is a need for collaboration between parents, children, and companions so that the quality of life of children with disabilities and the stress level of parents can be improved.

Conclusions

Most of the respondents with children with disabilities had a moderate degree of stress. In general, the anxiety level in respondents is at a hefty level. Parents with depression had experienced very severe depression. All qualities of life domains had the poorest quality of life in physical, emotional, social, school, and total function. The highest good quality of life was in the school function domain, and the highest lousy quality of life was in the emotional function domain. There was a relationship between stress levels and quality of life, but no relationship between anxiety levels and quality of life.

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Conflict of Interest: None

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