

DOI: https://10.23917/fisiomu.v5i2.4257

# Description of Motor Function and Quality of Life in Down Syndrome Children

<sup>1</sup>Rena Mailani, <sup>2</sup>Bunga Anisa Abu Bakar, <sup>3</sup>Luthfiyah Nadza Hisanah

<sup>1,2,3</sup>Physiotherapy Study Program Diploma Three Program, Faculty of Health Sciences, National Development University "Veteran" Jakarta

Email: rena.mailani@upnvj.ac.id

Submition: 2024-02-03; Accepted: 2024-02-20; Published: 2024-06-01

#### **ABSTRACT**

Introduction: Down syndrome children occur due to a chromosomal abnormality in the form of an increase in one copy of the 21st chromosome to 3 chromosomes which is called trisomy 21. Down syndrome children experience physical abnormalities in the form of distinctive facial and body shapes as well as delays in motor and mental or cognitive development in the form of intellectual disability. Delays in motor development that occur in children with Down syndrome cause children's movements to be slower and daily activities tend to be done with the help of other people. Children with Down syndrome at school age are given education in special schools so that they receive an educational program that is appropriate to their development. Intellectual disability that occurs causes the educational program provided to be able to train with the aim of children being able to independently carry out their daily activities. Research Objective: to determine the description of motor function and quality of life in children with Down syndrome at the Depok Special Education Foundation. Research Method: a descriptive study with a sample size of 89 people by measuring motor function using GMFM-88 and quality of life using TACQOL. Research Results: motor function of children with Down syndrome in the delayed category with moderate to poor quality of life. Conclusion: children with Down syndrome at YPLB Depok experience delays in motor function compared to their normal age, apart from that their cognitive function has less impact on their quality of life, which is moderate to poor. A training process is needed for independence and developing the talents of children with Down syndrome.

Keywords: Down Syndrome, Gross Motor Function, Quality of Life, Physiotherapy

ISSN 2722 - 9610 E -ISSN 2722 - 9629

# INTRODUCTION

Down syndrome is a chromosomal abnormality in the form of the addition of one chromosome to chromosome 21, called trisomy 21 (Windsperger and Hoehl 2021). According to the results of Basic Health Research for 2010 - 2018, there was an increase in cases of Down syndrome in Indonesia. In 2018, physical disability between 0 - 59 months was 0.41%, while disability due to Down syndrome was up to 0.21% of the total number, namely 57,361 children.

Down syndrome children have both physical and mental or cognitive disorders. Physical

abnormalities in the form of narrow eyes, wide foreheads, flat noses, small mouths, short hands and feet are shared by all children with Down syndrome, so they are called children of a thousand faces (Maclennan 2020). Abnormalities in internal organs also occur in the form of failure to close heart valves, abnormalities in the liver, abnormalities in respiratory organs, abnormalities in the brain in the form of intellectual disability and others (Windsperger and Hoehl 2021). Risk factors for Down syndrome include maternal age over 30 during pregnancy, and exposure to chemicals, drugs and alcohol (Varshney et al. 2022).

Down syndrome children are born with low postural tone so that when they are born the baby does not cry much or cries in a low voice. Apart from that, low postural tone, called hypotonus, also causes motor movements to tend to be slow, and passive, and have less endurance (Lauteslager et al. 2020). Down syndrome children tend to carry out activities in a sitting, lying or moving position (Silva et al. 2021).

Down syndrome children have flat feet which cause balance problems (Jain et al. 2022). Due to this, the risk of children falling tends to be high and children cannot last long or get tired easily when making movements (David et al. 2024).

These various physical conditions cause movement planning and body resistance when moving to become less, children tend to get a lot of help in carrying out activities. Apart from the physical, the cognitive condition experienced by children with Down syndrome, namely in the form of intellectual disability, causes the child's understanding of instructions or commands to carry out an activity to be lacking. These physical and cognitive conditions cause a decline in children's quality of life (Ijezie et al. 2023). Quality of life is a general term that states the health condition of children with Down syndrome whose measurements are in the form of wellbeing, survival. social relationships, psychological state, a person's ability to carry out daily activities and activities independently (Purnamadyawati et al. 2022).

Physical conditions that tend to be hypotonic cause the child's motor function to be delayed, that is, the child's development is far behind his age so that the child's quality of life in terms of independent daily activities is lacking, for example, a 2-year-old child cannot walk yet so the child needs help for daily activities such as taking top position objects and difficulty playing with peers.

Poor cognitive conditions are also a factor that causes the quality of life of children with Down syndrome to decrease, children's poor understanding causes children to tend to ask for help in doing things (Imania et al. 2021).

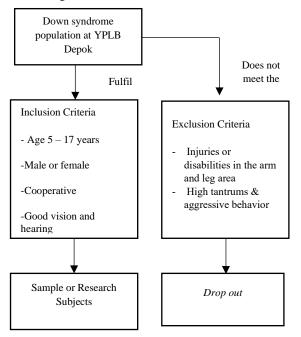
A child's quality of life is an important aspect to measure because it is an indicator of the child's health condition, namely in the form of physical and psychological well-being, survival, social relationships and independence in daily activities. From these various theoretical bases, researchers wanted to measure the gross motor function and quality of life of children with Down syndrome at the Special Education Foundation to provide a basis for providing educational programs that are appropriate to the child's condition.

#### METHOD

The type of research used is a descriptive study which aims to determine the description of motor function and quality of life of children with Down syndrome at the Special Education Foundation (YPLB) Depok. The number of samples was determined from calculations using the Slovin formula, which resulted in a sample size of 89 people from the total population in YPLB Depok. This research has passed research ethics number 122/V/2023/KEPK. The instruments used were Gross Motor Function Measurement 88 (GMFM-88) to measure children's motor function and The TNO-AZL Questionnaire for Children's Health-Related Quality of Life (TACQOL) to measure health-related quality of life. GMFM-88 consists of 88 examination items which are carried out by observing motor function from 5 dimensions, activities in lying and rolling positions (dimension A) consisting of 17 items, sitting (dimension B) consisting of 20 items, crawling and kneeling (dimension C) consists of 14 items, standing (D dimension) consists of 13 items, and walking, running and jumping (E dimension) consists of 24 items. The results are normal and late as indicated by the score of the child's motor function in each dimension. The TACQOL instrument is carried out by asking parents or caregivers of children with Down syndrome regarding the quality of life which includes aspects of physical function, motor aspects, daily habits, and social, emotional and behavioural states of the child. The TACQOL results are the cumulative scores of answers from parents or caregivers of children with Down syndrome which are interpreted as bad results if the score is 0 - < 18.6, moderate results with a score > 18.6 -37.3 and good results with a score >37.3 - 56.

#### RESEARCH RESULT

A sample of 89 people was obtained from the inclusion and exclusion criteria depicted in the flow diagram as follows:



The gender and age characteristics of the research subjects are listed in the following table:

Table 1. Frequency Distribution of Respondent Characteristics

	Gender			
	Frequency	Percentage		
Man	52	58,4%		
Women	37	41,6%		
Age				
Preschool	0	0%		
(5-6 old)				
School (6 -	3	3%		
10 old)				
Remaja (11-	86	97%		
18 old)				

Table 2. Description of Motor Function in Down Syndrome Children

	Frequency	Percentage
Normal	22	25%
Late	67	75%

Table 3. Description of the Quality of Life of Down Syndrome Children

	Frequency	Percentage
Good	2	2,2%
Currently	37	41,6%
Bad	50	56,2%

From the table above, it is known that children with Down syndrome at YPLB Depok are dominated by boys in their teens (11 – 18 years). Data has been obtained that motor function in children with Down syndrome tends to experience developmental delays from their proper age. Apart from that, data was also obtained that children with Down syndrome experience a moderate to poor quality of life.

#### DISCUSSION

Based on the research results, it was found that motor function data in children with Down syndrome were more likely to experience delays. These results are by research which states that the motor function of children with Down syndrome is impaired, namely there is a delay in development from the age they should be. This is caused by low postural tone and poor endurance (Abd-Elsamea et al. 2022). Down syndrome children have weak postural tone so their movements tend to be slow, passive, and have less endurance (Lauteslager et al. 2020). Because this is what causes the gross motor development of children with Down syndrome to be delayed compared to other children their age. Down syndrome children experience delays in both gross motor skills, fine motor skills, observation, speech and social skills (Kim et al. 2017).

The developmental delays that occur in children with Down syndrome will be reached at an older age, for example, the child will walk but at the age of 2 years or more (Ruiz-González et al. 2019). Motor function abilities influence all daily activities carried out by children. Children tend to always be helped by other people, such as taking food, eating, bathing, dressing and other daily activities (Lee et al. 2021).

In addition, disturbances in cognitive function cause children to experience limitations in understanding instructions so that their ability to carry out daily activities becomes dependent on other people. In children with Down syndrome, disturbances in cognitive function and motor function affect the quality of life (Ndeot et al 2022). The quality of life of children with Down syndrome can be seen in terms of the child's age, gender, parental support, as well as health and social problems. The quality of life of children with Down syndrome is categorized as poor due to the limitations of children carrying out daily activities normally and independently (Oche Axena Yulhan 2021).

From this, good guidance and attention are needed from the family and people around them to help stimulate their motor function and cognitive function so that children can carry out independent activities and have good emotional and social relationships, which will cause the child's quality of life to improve (Ijezie et al. 2023).

### **CONCLUSION**

Children with Down syndrome at YPLB Depok have delayed motor function, namely children with Down syndrome experience developmental delays from their normal age. Apart from that, the quality of life of children with Down syndrome at YPLB Depok is moderate to poor, which is influenced by decreased motor function and cognition. From this data, the researchers provided input to YPLB Depok to create a program related to functional gross motor activities so that children's independence could be realized, resulting in a better quality of life for children. The limitation of this research is the choice of research location. Research sites specifically for children with Down syndrome are still limited, so research needs to be carried out in other big cities.

## ACKNOWLEDGEMENT

The researcher would like to thank the Depok Special Education Foundation for providing researchers with the opportunity to research children with Down syndrome. Apart from that, the researcher would like to thank the research team of students from the Diploma Three physiotherapy study program whose scope of

research is children with Down syndrome for their hard work in collecting data.

#### REFERENCES

- Abd-Elsamea ES, Abd El-Maksoud GM, Refeat SM. 2022. Correlation between Gross Motor Proficiency and Body Composition in Children with Down Syndrome. Egypt J Hosp Med. 89(1):4235–4239. https://doi.org/10.21608/ejhm.2022.256328
- David NS, Mailani R, Faradillah KR, Ismiyasa SW. 2024. The Relationship Between Body Mass Index (BMI) and Balance in Down Syndrome Children at the X Depok Foundation. Fisiomu. 4(3):42–47.
- Ijezie OA, Healy J, Davies P, Balaguer-Ballester E, Heaslip V. 2023. Quality of life in adults with Down syndrome: A mixed methods systematic review. PLoS One [Internet]. 18(5 May):1–27. https://doi.org/10.1371/journal.pone.028001
- Imania DR, Wahyuningsih IR, Kustiyati S. 2021. Upaya Peningkatan Perkembangan Anak dengan Down Syndrome: Literatur Review. J Ilmu Kesehat. 10(2):42–56.
- Jain PD, Nayak A, Karnad SD, Doctor KN. 2022. Gross motor dysfunction and balance impairments in children and adolescents with Down syndrome: a systematic review. Clin Exp Pediatr. 65(3):142–149. https://doi.org/10.3345/cep.2021.00479
- Kim HI, Kim SW, Kim J, Jeon HR, Jung DW. 2017. Motor and cognitive developmental profiles in children with Down syndrome. Ann Rehabil Med. 41(1):97–103. https://doi.org/10.5535/arm.2017.41.1.97
- Lauteslager PEM, Volman MCJM, Lauteslager T, Van den Heuvel ME, Jongerling J, Klugkist IG. 2020. Basic Motor Skills of Children With Down Syndrome: Creating a Motor Growth Curve. Pediatr Phys Ther. 32(4):375–380. https://doi.org/10.1097/PEP.00000000000000

0743

- Lee A, Knafl K, Van Riper M. 2021. Family variables and quality of life in children with Down syndrome: A scoping review. Int J Environ Res Public Health. 18(2):1–30. https://doi.org/10.3390/ijerph18020419
- Maclennan S. 2020. Down's syndrome. InnovAiT. 13(1):47–52. https://doi.org/10.1177/1755738019886612
- Ndeot F, Sum TA, Ndinduk FD. 2022. Analisis Pertumbuhan dan Perkembangan Anak Usia Dini. J Lonto Leok. 4(2):1–12.
- Oche Axena Yulhan. 2021. Kualitas Hidup Anak dengan Down Syndrome. Pesqui Vet Bras. 26(2):173–180.
- Purnamadyawati P, Bachtiar F, Mailani R. 2022.
  Penilaian Kualitas Hidup Pasien Gagal Ginjal Kronik dengan Hemodialisis Menggunakan WHOQOL-BREF di RS Setia Mitra Jakarta. J Kesehat Glob [Internet]. 5(3):113–120.
  http://ejournal.helvetia.ac.id/index.php/jkg/article/view/5148

Ruiz-González L, Lucena-Antón D, Salazar A,

Martín-Valero R, Moral-Munoz JA. 2019. Physical therapy in Down syndrome: systematic review and meta-analysis. J Intellect Disabil Res. 63(8):1041–1067. https://doi.org/10.1111/jir.12606

- Silva YS, Silva LLG Da, Silva WC Da, Neto AGN, Pereira TDS, Araújo AKC, Tavares AJG, Weber RA, Oliveira LG De, Cunha NE, et al. 2021. Physiotherapy in Down Syndrome: A Literature Review. Int Neuropsychiatr Dis J. 15(4):20–27. https://doi.org/10.9734/indj/2021/v15i4301 60
- Varshney K, Iriowen R, Morrell K, Pillay P, Fossi A, Stephens MM. 2022. Disparities and outcomes of patients living with Down Syndrome undergoing healthcare transitions from pediatric to adult care: A scoping review. Am J Med Genet Part A. 188(8):2293–2302. https://doi.org/10.1002/ajmg.a.62854
- Windsperger K, Hoehl S. 2021. Development of Down Syndrome Research Over the Last Decades—What Healthcare and Education Professionals Need to Know. Front Psychiatry. 12(December):1–7. https://doi.org/10.3389/fpsyt.2021.749046