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Factors affecting the level of independence of activity daily living in children with down syndrome

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ABSTRACT

Background: Down syndrome (DS) is a genetic disorder that decrease child's growth, development, learning, memory, and level of independence.
Objective: This study aimed to further review what factors affect the level of independence in children with DS in daily activities.
Methods: The research used a literature review design using secondary data of published research articles about the factors that influenced the daily activities independence among children with DS. The study used Google Scholar and PubMed databases to search the articles. he inclusion criteria for the journals used were journals published in English or Indonesian, with a publication time range of 2014-2024. Non-peer-reviewed articles such as editorials, opinions, case reports, theses, or dissertations that were not officially published were not included in this review. Based on the inclusion criteria set, five journals were obtained that were relevant to the discussion in the literature review.
Results: We found 5 articles that correlated with the topic of factors that influenced the daily activities independence among children with DS. An optimal sensory development can have a positive effect on the motor development and daily living independence of DS children. The assistance from the parents, therapist, and assistive tools may improve the level of daily activities independence in children with DS.
Conclusion: This study concluded that several factors influence the independence of children with Down syndrome. These factors can be grouped into internal influences, such as sensory and motor abilities, and external influences, including parental assistance, therapist support, and technology.

Keywords: children, daily activities, down syndrome, genetic, independence

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Introduction

Children with special needs are children who experience obstacles and disturbances in their growth and development.[1] One of the people with special needs is a child with DS (DS) who has delays in almost all aspects of development.[2] In 2020, the World Health Organization (WHO) announced that about 3,000 to 5,000 children are born with DS every year, until now it is estimated that there are 8 million people with DS worldwide. [3]In Indonesia, based on Basic Health Research (Riskesdas) 2010–2018, the incidence of DS tends to increase. According to the results of Riskesdas, in 2010 the number of DS cases was recorded at 0.12%, 0.13% in 2013, and 0.21% in 2018.

DS is a genetic disorder caused by the presence of an extra or extra copy on chromosome 21.[4,5] In this case, extra chromosomes are formed due to the failure of a pair of chromosomes to separate from each other during division.[6] Chromosomes are found in every cell in the human body. Chromosomes play a role as a command in the manufacture of proteins and important molecules needed by the body.[4] The physical character of DS children has its characteristics, a fairly unique facial structure, namely having narrow eyes pointing upwards, a flat face and nose shape, an abnormal ear structure, and a small mouth shape with a slightly protruding tongue. [7,8]DS is the most common genetic disorder that can cause impairments in a child's growth, development, learning, and memory.[9] This causes the majority of DS children to have a measurably low level of independence in carrying out daily living activities (ADL).[8]

Independence is a skill that must be practiced continuously until it becomes a habit. Increasing independence is used as the main goal and is long-term in the hope of improving the quality of life in children with DS.

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Independence is understood as the state of a person who does not depend on others to conclude and believe in himself.[8,10] The characteristics of a person who can be said to be independent are having the skills to complete their responsibilities, having the skills to do tasks, and not feeling inferior.[11]

Activity Daily Living (ADL) or daily life activities meaning that the skills taught or trained concern the needs of individuals who must be done alone without the help of others. The term (ADL) or daily life activities in the world of education for children with special needs is known as Bina Diri which refers to a personal activity, containing the understanding that the skills taught or trained are related to the needs that must be done by themselves without the help of others if the conditions allow. Daily life skills including bathing, brushing teeth, dressing, cooking, eating, going to the toilet, and medical appointments can be continuously trained and improved to align with the level of independence of each DS individual. [9,12,13]

Independence is very helpful and supports children in understanding behavioral choices and risks that need to be considered, especially those related to their level of education, developmental level, decision-making activities and needs. Therefore, this shows the need to foster independence in children. Individuals with DS also have the same opportunity to learn, participate in the general public, socialize, believe in themselves, and cooperate later. Communication disorders, and mobility disorders, accompanied by disturbances in daily activities such as bathing, eating, and others can have an impact on participation in the community, such as school and work.[14]

Based on the description that has been presented, this literature review was carried out because the researcher wanted to identify factors that could affect the level of independence of children with DS in ADL.

Methods

The research used a literature review design, which used secondary data in the form of a review of research journals related to factors that could affect independence for daily living activities (ADL) in children with DS. The search for articles used in this study was conducted on two databases, namely PubMed and Google Scholar with the keywords "Down Syndrome," "Children," "Independence," and "Daily Activities." The inclusion criteria for the journals used were journals published in English or Indonesian, with a publication time range of 2014-2024. Non-peer-reviewed articles such as editorials, opinions, case reports, theses, or dissertations that were not officially published were not included in this review. Based on the inclusion criteria set, five journals were obtained that were relevant to the discussion in the literature review.

Results

Through a journal search conducted with 2 databases of high and medium standards, such as PubMed and Google Scholar, 5 Indonesian and English journals with publications published 10 years ago were found as the results of this literature review (Table 1).

White et al. (2023) conducted a cohort study, which demonstrated that independence, quality of life, and adaptive behavioral skills can improve in children with DS after using assistive technology. The study included 26 children with DS, aged 7-17 years, who used a supportive electronic device, while participants lost to follow-up or lacking the desire to participate were excluded. Measuring instruments used included the ABAS-3 to evaluate conceptual, social, and behavioral skills, the QoL-18 questionnaire to assess quality of life using a 5-point scale, and the SS-2 to measure caregiver satisfaction. Results showed significant improvements in daily living activities, independence, and quality of life after using the MapHabit system. Statistically, a significant increase was observed with a p-value of 0.0071, as participants' average GAC2 score of 48.0 at the end of the training period was 5.5 points (8.5%) higher than their initial GAC1 score of 42.5. Additionally, the QoL-18 scores for 13 out of 18 items showed statistical significance, with p-values ranging from <0.05 to <0.001, indicating a significant improvement in quality of life compared to the hypothesis score.

Yanasari et al. (2020) conducted a quantitative study examining the relationship between authoritative parenting and the independence of children with DS in performing ADL. The study involved 33 parents of children with DS who were in grades 1-6 of elementary school and attended inclusion schools. Using the PSDQ measuring instrument, which has a reliability score of 0.8, the study assessed the intensity of authoritative parenting. The results indicated a moderate relationship between authoritative parenting and the independence of DS children in performing ADL, with a statistically significant p-value of 0.003 ($p \leq 0.05$).

Neal et al. (2019) conducted a prospective, multisite, observational longitudinal practice-based evidence (PBE) study published in the *Journal of Autism and Developmental Disorders*, describing school-based physical therapy (SBPT) services and outcomes for students with DS. The study focused on 46 students in kindergarten through 6th grade who had no plans to change schools or undergo major surgery during the data collection period and had not missed more than 30% of the previous school year. The S-PTIP data form (reliability score of 0.95) documented SBPT services, and Goal Attainment Scaling (GAS) (reliability score of 0.64-0.82) was used to track progress. The results showed a statistically significant interaction between GMFCS levels and changes in student scores over a 20-week period ($F = 7.02$, $p = 0.002$). On average, students received 24.0 minutes of direct therapy and 11.6 minutes of indirect services weekly, totaling 35.6 minutes per week. After 20 weeks, 32 students (69.5%) met or exceeded their primary GAS goals, and their School Function Assessment (SFA) subtest scores increased by 2.2 to 3.7 points, indicating improved functional abilities.

Arslan et al. (2022), in a study published in the *North Clin Istanbul* journal, investigated the effects of early physical therapy (PT) on motor development in children with DS

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through a comparative study design. The study involved 58 children with DS aged 6 to 42 months, excluding children younger than 6 months, older than 42 months, those born prematurely, or those with epilepsy, intracranial hemorrhage, or hearing or vision loss. The Bayley Scales of Infant and Toddler Development III (reliability score of 0.86-0.93) was used to measure gross motor, fine motor, and composite motor scores. Results showed that children who received PT had significantly higher scores than those who did not ($p < 0.05$), with gross motor scale scores (GM-SS) of 3.88±3.46 versus 1.67±1.23, fine motor scale scores (FM-SS) of 4.29±3.24 versus 1.79±0.93, and composite scores of 64.4±19.5 versus 50.38±5.38. Additionally, children who began PT before one year of age had higher GM-SS, FM-SS, and composite motor scores ($p < 0.05$) compared to those who started PT after one year.

Aranti and Pristianto (2023), in a study published in *Physiotherapy Health Science*, investigated the effects of Neurodevelopmental Treatment, Play Therapy, and Neuro Senso on improving gross motor skills in a case report involving an 8-year-old girl with DS. The study utilized the Gross Motor Function Measure (GMFM) with a reliability score of 0.99 to assess motor skill improvements. The results showed positive changes in GMFM scores over four evaluation periods (T1, T2, T3, and T4), specifically in Dimensions D and E. Dimension D scores increased from 76.92% to 79.48%, while Dimension E scores improved from 37.5% to 38.89%. The evaluation covered five dimensions of gross motor development, assessing abilities such as lying down, rolling, sitting, standing, walking, running, and jumping.

Discussion

Compared to normal children, the majority of DS children have a measurably low level of independence[9,15]. According to Hasan Basri, there are internal and external factors that affect the formation of children's independence. Internal factors include gender, intelligence, and development. External factors are parenting, socio-cultural factors, and socio-economic environment.[16] The achievement of a child's level of independence in ADL must be through the development of the central nervous system, starting from the sensory stimulation of the well-received systems such as tactile, vestibular, proprioception, olfactory, visual, auditory, and gustatory. Sensory-motor development can be stimulated when the sensory stage of the system has passed, things that need to be trained at this stage, postural security, awareness of two sides of body, motor planning, body scheme, reflex maturity, and ability to screen input. Perceptual-motor functions consisting of eye-hand coordination, ocular motor control, postural adjustment, attention center functions, visual-spatial perception, and auditory language skills are the last stages that can be trained before ADL ability is achieved. Based on the literature review that has been carried out from the 5 articles above, good sensory development can have a positive effect on the motor development of DS children, so that it can have a good impact on the level of ADL independence. The help of parents, therapists, and technology can affect the level of independence in children with DS in carrying out daily activities.

Based on research conducted by White K, et al., 2023, stated that there is a positive impact of assistive technology (AT) on the behavior of children with DS in the family environment. The technology used is the MapHabit System (MHS). This system is in the form of a commercially available visual mapping application with the use of visual, text, and audio media as a guide to complete daily life activities. This study stated that the overall increase before and after GAC1 and GAC2 scores was numerically small, the level of statistical significance was high, although not all participants showed an increase in GAC2 scores. Scores on QOL-18 and SS-2 reflect strong positive experiences overall. This study shows that the difference before and after in the ABAS-3 assessment, although numerically small, shows meaningful and positive behavior,[9] so it can be concluded that AT can help children with DS. This is also supported by previous research by Krasniqi V, et al, 2022, which states that some ATs can help prepare individuals with disabilities, including children with DS, to live independently and acquire functional skills.[17]

Research by the Journal of Special Education J, et al, 2023, shows that one of the factors that encourage independence in children is their own parents, especially DS children who face obstacles in independence. This study states that the role of parents as role models, mentors, rewards, and coaches can have a significant impact in encouraging the independence of children with DS. This is also supported by research [8] by Yanasari E, et al., 2020, that the development of independence of children with DS is influenced by parents. Authoritative parenting is a strategy implemented by parents to help their children's level of independence. Physical Therapy (PT) contributes to helping the level of independence of DS children, as evidenced by the research of Neal G, et al., 2019, showing that with the help of school-based universities directly provide positive outcomes on the functionality of DS children.[18]

Research by Aranti, et al., 2023, shows that PT plays an important role in providing neurodevelopmental treatment, play therapy, and neuro senso, so that children's gross motor and cognitive functions will improve after an evaluation with GMFM. Dimensional changes in GMFM, especially the D (standing) and E (walking, running, and jumping) dimensions, will affect the level of independence of DS children. In the D dimension, it has increased from 76.92% to 79.48%, while the E dimension has changed from 37.5% to 38.89%. Therefore, some of these trainings will help improve gross motor and cognitive function so that it will affect children with DS.[19] This is reaffirmed by the research of Arslan F et al., 2020, showing that children with DS experience various levels of motor delay. PT assistance has a positive effect on gross and fine motor development so that it can increase participation in children with DS. [15,20]

This study on factors affecting the level of independence in ADL in children with DS has several limitations. A limitation

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of this review is the potential for bias due to the exclusive use of open-access papers, necessitated by restricted access to subscription-based journals; however, this approach ensures the included research is readily available and reproducible for all readers. Future research should consider a study design with larger and diverse samples size exploring the role of individualized support programs and environmental factors to provide a more comprehensive understanding of ADL independence in children with DS.

Conclusion

Several factors can affect the level of independence of children with DS, so they can be grouped into internal and external factors. Internal factors include sensory and motor abilities. External factors include parental assistance, therapists, and technology.

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Conflict of interest

According to the author, there isn't any possible conflict of interest related to this paper's study, writing, or distribution.

Author contributions

NKDWM conceived the study design and data collection and drafted the manuscript; NLPGKS and NKAJA collected the data and revised the manuscript.

Ethical consideration

This review study used published articles that are accessible. Thus, this study did not require any informed consent or ethical consideration.

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Table 1. Analysis of the relationship between obesity and knee osteoarthritis

Authors	Title	Methods	Results
White K, et al. (2023)	A feasibility study demonstrating that independence, quality of life, and adaptive behavioral skills can improve in children with Down syndrome after using assistive technology (PLOS ONE journal)	**Study Design:** Cohort studies **Sample:** 26 children with DS **Inclusion:** Children with DS are 7-17 years old and have a supportive electronic device **Exclusion:** Lost to follow-up and loss of desire to participate **Measuring Instruments:** **ABAS-3** (0.96 and 0.99) is used to evaluate conceptual, social, and behavioral skills. **QoL-18 Questionnaire** (0.7) used to evaluate live qualitatives, using a 5- point scale format. **SS-2** is used to measure the caregiver satisfaction scale.	The study showed improvements in children's activities of daily living, quality of life, and independence after using the MapHabit system. Statistically, a significant increase was seen with a p-value of 0.0071. The 26 participants in the study had an average GAC2 score of 48.0 at the end of the training period, which was 5.5 points (8.5%) higher than their average GAC1 score of 42.5. **QOL-18 Score:** The p-value obtained from the Wilcoxon test of one sample ranged from <0.05 to <0.001. The Quality of Life Score (QOL-18) for 13 of the 18 items showed statistical significance, indicating that the score was significantly higher than the hypothesis score, but the 5 items had scores that were not significantly different helping with all p-values > 0.05 **SS-22 Score:** The answers from 26 caregivers on each of the two questions in the SS-2 assessment were very positive. A total of 20 caregivers (76.9%) stated "strongly agree" or "agree" in responding to both questions. Only two caregivers responded negatively to two questions in the SS-2 assessment.
Yanasari E, et al. (2020)	Pola Asuh Otoritatif dengan Kemandirian Anak *Down Syndrome* dalam Melakukan *Activity Daily Living*	**Study Design:** Quantitative studies **Sample:** 33 parents of DS children **Inclusion:** parents who have children with DS who are in grades 1-6 of elementary school who attend an inclusion school. **Measuring Instruments: PSDQ** (0.8) Measure the intensity of authoritative, authoritarian, and permissive parenting **WeeFIM** (0.9) data on independence in carrying out daily living activities.	Authoritative parenting has a moderate relationship with the independence of DS children in performing ADL (p = 0.003 ≤ 0.05)

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Neal G et al. (2019)	Description of SchoolBased Physical Therapy Services and Outcomes for Students with Down SyndromeDescription of SchoolBased Physical Therapy Services and Outcomes for Students with Down Syndrome (Journal of Autism and Developmental Disorders)	**Study Design:** This study is a prospective, multisite, observational longitudinal practice-based evidence (PBE) **study:** A national study of PT COUNTS, which focuses on students with DS (n=46). **Inclusion:** Kindergarten through 6th grade students, had no plans to change schools or undergo major surgery during the school year when the researchers collected data, and had never missed more than 30% in the previous school year. **Measuring Instruments:** **The S-PTIP data form** (0.95) is used to document SBPT services. **GAS** (0.64-0.82) it is used to evaluate the functional abilities of students from kindergarten to grade 6 in an educational environment**GMFCS (0.84**) is used to identify the functional abilities of students with DS because this system provides a structured and clear way to differentiate the level of functional independence.	An F value of 7.02 with a p-value of 0.002 indicates that there is a statistically significant interaction between GMFCS levels and changes in student scores over a 20-week period. Students with DS receive an average of 24.0 minutes/week of direct therapy services and 11.6 minutes/week of services on behalf of students, for a total of 35.6 minutes/week. Overall, 32 students (69.5%) individually met or exceeded their main result, which is the GAS goals. The students' average School Function Assessment (SFA) subtest scores increased between 2.2 and 3.7 points after 20 weeks of SBPT, indicating an improvement in functional ability.
Arslan F et al. (2022)	Effects of early physical therapy on motor development in children with Down syndrome (North Clin Istanbul journal)	**Study Design:** The research design used in this article is a comparative study to compare gross and fine motor development in children with DS who receive physical therapy (PT) and those who do not receive PT. **Sample:** This study involved 58 children with DS **Inclusion:** DS children between 6 and 42 months of age. **Exclusion:** Children under 6 months and older than 42 months, premature birth, individuals with epilepsy, intracranial hemorrhage, hearing or vision loss **Measuring Instruments:** Bayley Scales of Infant and Toddler Development III (0.86-0.93) was used to evaluate gross motor, fine motor and composite motor score in children with DS	Statistically, the value of the PT group was higher than that of the non-PT group ($p<0.05$). Gross motor scale score (GM-SS: 3.88±3.46-1.67±1.23),fine motor scale score (FM-SS: 4.29±3.24-1.79±0.93),and composite score(64.4±19.5-50.38±5.38)Children who startedPT before one year ofage showed higherGM-SS, FM-SS, andcomposite motorscores ($p <0.05$)compared to those whostarted PT after oneyear of age
Aranti W, Pristianto A (2023)	Pengaruh Pemberian *Neurodevelopmental Treatment, Play Therapy,* dan *Neuro Senso* Terhadap Peningkatan Motorik Kasar Pada Anak *Down syndrome (Physiotherapy Heath Sience)*	**Study Design:** This study uses a case report study. **Sample:** 8-year-old girl An.Y. **Measuring Instrument:** Gross Motor Function Measure (GMFM) (0.99) to assess the improvement of motor skills in children with DS	This study states that changes occurred in GMFM assessments in T1, T2, T3, and T4 in Dimension D and Dimension E. Specifically, Dimension D showed an increase from 76.92% to 79.48%, with a similar increase recorded in Dimension E from 37.5% to 38.89%. The evaluation includes five dimensions related to gross motor development, ranging from the ability to lie down and roll, sit, stand, to the ability to walk, run, and jump.

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Anggraini, et al., (2014)	The Relationship Between Obesity and Factors in Individuals with the Incidence of knee osteoarthritis	**Study design:** Observational research of case control studies. **Participants:** 64 samples were divided by systematic random sampling into case groups and control groups. **Statistical test:** chi-square and statcalc test on epi info program **Measuring instrument:** x-ray results **Variable** **Independent variables:** weight, age, gender, smoking habits, and physical activity. **Dependent variable:** knee OA	There were significant results between obesity and risk factors for knee OA, such as age and gender with p-value results obtained in obesity (p=0.001, OR=7.20), age (p=0.012, OR=3.67), gender (p=0.005, OR=4.69),