

Parenting Challenges for Children with Down Syndrome and the Role of Social Support: A Literature Review

Alya Nabila Putri¹, Titi Pambudi Karuniawaty², Tristina Wardhani²

¹Faculty of Medicine and Health Sciences, Universitas Mataram

²Department of Pediatrics, Faculty of Medicine and Health Sciences, Universitas Mataram

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Abstract

Down Syndrome is a genetic disorder caused by trisomy of chromosome 21 that affects children's physical, cognitive, and health development throughout their lifespan. This condition requires complex, long-term monitoring and care, which may generate parenting stress, particularly for mothers as the primary caregivers. This literature review was conducted to examine the relationship between social support and parenting stress among parents of children with Down Syndrome based on published scientific literature. A narrative review method was applied to relevant journal articles, books, and clinical guidelines concerning Down Syndrome, parenting stress, and social support. The review found that children's clinical characteristics, the need for continuous medical care, and the psychosocial burden accompanying the care of children with DS contribute to elevated parental stress. Social support from family, friends, and professionals was shown to act as a protective factor that reduces this stress. Strengthening social support networks should become part of nursing and public health interventions for families of children with Down Syndrome to improve parents' psychological well-being and the quality of childcare.

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Corresponding Author:

Alya Nabila Putri,

Faculty of Medicine and Health Sciences, Universitas Mataram

Email: alyanabila2701@gmail.com

1. INTRODUCTION

Down syndrome is the most common genetic disorder that causes intellectual disability, resulting from an extra copy of chromosome 21 (trisomy 21). This excess chromosomal material can affect brain development, organ anatomy, and metabolic function in children from the prenatal period and is clinically characterized by impaired mental and motoric development, facial dysmorphism, and congenital malformations often accompanied by congenital heart disease, thereby requiring continuous health monitoring from the neonatal period into adulthood [1], [2], [3].

The prevalence of Down syndrome in Indonesia has shown an increasing trend over the years, and the complex medical care needs of children with Down syndrome, such as cardiac, hearing, and vision impairments, as well as developmental delays, make parents, particularly mothers, at high risk of parenting stress [4], [5], [6]. Poorly managed parenting stress can affect parents' psychological well-being as well as the quality of parent-child interaction [7].

One factor that can reduce parenting stress is social support, whether from family, friends, or professionals [8], [9]. However, understanding of how social support functions in reducing parenting stress among families of children with Down syndrome requires further review. Therefore, this literature review aims to examine the role of social support in reducing parenting stress, as well as the clinical characteristics of Down syndrome, parenting stress, social support, and the role of social support in reducing parenting stress among families with children with Down syndrome.

2. RESEARCH METHODS

This article was prepared as a literature review through a search of literature on journal articles, textbooks, and clinical guidelines discussing Down syndrome, parenting stress, and social support. The search was conducted through databases such as PubMed, Google Scholar, and ScienceDirect using the keywords Down syndrome, parenting stress, caregiver, and social support.

The literature sources used included clinical research journal articles, systematic reviews, narrative reviews, meta-analyses, textbooks, and clinical guidelines published within the last 10 years (2016–2026) in both Indonesian and English. Inclusion criteria covered full-text articles discussing the epidemiology, clinical manifestations, diagnosis, and management of Down syndrome in children, risk factors and measurement instruments for parenting stress, measurement instruments of social support, and the dynamics of the relationship between social support and parenting stress in families of children with special needs. The literature obtained was then screened by title and abstract. Relevant articles were subsequently reviewed in depth through their full text for extraction and narrative presentation.

3. RESULT AND DISCUSSION

3.1 Down Syndrome in Children

3.1.1 Definition

Down syndrome is a genetic disorder caused by an extra copy of chromosome 21, the smallest human autosome, which is responsible for the relatively high fetal survival rate in trisomy 21. This trisomy occurs due to a failure of normal chromosome separation during meiosis (nondisjunction), resulting in a gamete containing two copies of chromosome 21. This event can occur during either oogenesis or spermatogenesis. However, the majority occurs from errors in maternal meiosis I, while only about 10% of cases originate from the paternal side [1]. Trisomy 21 makes up approximately 90–95% of Down syndrome cases, while the remaining cases are caused by mosaicism (2–4%) or chromosomal translocation (2–4%) [5]. Trisomy 21 affects brain development throughout life, including brain anatomy, neurotransmission, functional connectivity, glial cell function, and energy metabolism [2].

3.1.2 Epidemiology

Globally, Down syndrome occurs in approximately 1 in 700 live births, with increased risk in mothers over the age of 35 [10]. Prevalence varies between countries according to genetic factors, environment, and prenatal screening practices. According to a report by Chen [3], the incidence of Down syndrome is approximately one case per 1,000 births. In Indonesia, Riskesdas data show an increasing prevalence trend from 0.12% in 2010 to 0.13% in 2013 and 0.21% in 2018 [4], with a current national prevalence of around 0.5% and 0.3% in West Nusa Tenggara [11].

3.1.3 Clinical Manifestations

Children with Down syndrome can be identified from the neonatal period through characteristic features such as a flat facial profile, epicanthic folds, brachycephaly, small ears, a simian crease on the palm, a protruding large tongue, a nuchal fat pad, hypotonia, and joint hyperflexibility [5]. Various organ complications follow the condition, including visual impairment (38–80%) in the form of strabismus, nystagmus, cataracts, refractive errors, and glaucoma, hearing impairment (38–78%), sleep disturbances (>50%), respiratory disorders (±36%), congenital gastrointestinal anomalies (4–10%), endocrine disorders (28–40%), urinary tract abnormalities (±3%), orthopedic complications (±30%), and dermatological problems (up to 39%) [5]. Children with Down syndrome are also prone to hearing and vision loss, congenital heart defects, obstructive sleep apnea, hematological disorders, and dementia, thus requiring highly specialized health services. Delays in motoric development, such

as crawling, walking, and speaking as well as neurobehavioral impairments in learning, language, and memory, are also characteristic features of this population [6].

3.1.4 Diagnosis

The diagnosis of Down syndrome can be established during two periods: prenatally, through screening and diagnostic testing in pregnant women, and postnatally, through staged health monitoring of the child according to age. Early prenatal detection allows parents and healthcare providers to prepare a care plan in advance. Subsequently, postnatal monitoring is conducted continuously to detect and manage the various medical complications that follow Down syndrome throughout the child's growth and development.

The American College of Obstetricians and Gynecologists (ACOG) recommends that every pregnant woman be offered the option of screening and diagnostic testing for Down syndrome. One such method is Noninvasive Prenatal Testing (NIPT) based on cell-free DNA, the most sensitive screening method, which can be performed as early as 9–10 weeks of gestation with a detection rate of 99.7%. However, high-risk results still require confirmation via chorionic villus sampling (CVS) or amniocentesis. First-trimester screening, such as nuchal translucency and maternal serum biomarkers, has a detection rate of 82–87%, second-trimester screening has a detection rate of around 80%, while integrated screening combining both can reach 95% [12].

For postnatal diagnosis, the monitoring is divided into four age stages. At 0–1 month, karyotype confirmation, echocardiography, hearing screening, thyroid function testing, hematological examination, and ophthalmologic evaluation are performed. At 1–5 years, thyroid, hearing, and eye examinations are conducted periodically, followed by screening for speech, motoric, and behavioral delays, as well as polysomnography if sleep disturbances are indicated. At 5–12 years, the focus shifts to management of chronic conditions, with annual audiometry and eye examinations, anemia and thyroid function screening, and detection of neurological symptoms and behavioral disorders such as ADHD. Throughout these stages, physicians also discuss the child's social-emotional development and the family's psychosocial support needs with parents annually [12].

3.1.5 Management

Pharmacotherapy in children with Down syndrome aims to improve brain and cognitive impairments resulting from trisomy 21 consist on four categories: symptomatic therapy based on neurotransmitter mechanisms, such as acetylcholinesterase inhibitors, GABA and NMDA receptor antagonists, serotonin reuptake inhibitors, and other agents such as lithium and antioxidants, with variable outcomes. In addition, disease-modifying therapy targeting the expression of HSA21 genes, such as DYRK1A and APP, as well as therapies related to the risk of early-onset Alzheimer's disease. Comorbidity-focused interventions address issues such as obesity, insulin resistance, and sleep disturbances, alongside non-invasive neurotherapy such as transcranial direct current stimulation (tDCS) that still requires further research [13].

3.1.6 Maintenance

The maintenance for children with Down syndrome must be delivered comprehensively and through a multidisciplinary approach. Early interventions such as treadmill training and massage therapy can accelerate the child's motoric and social development. Aerobic exercises, such as walking, swimming, and cycling, help maintain cardiovascular health and prevent obesity, while resistance and balance training help manage the muscle weakness and postural problems that are commonly occur. Given the long-term risks of dementia, obesity, and osteoporosis, regular physical activity becomes an important preventive measure for children with Down syndrome [14].

3.2 Parenting Stress

3.2.1 Definition

Parenting stress is a distressing experience arising from the demands of the parental role. An estimated 36–50% of parents experience concerns related to their child's parenting, behavior, or

development. High parenting stress is associated with increased parental depression, anxiety, and fatigue, lower quality of parenting behavior, and adverse effects on the child, such as emotional behavioral problems and reduced social competence [7].

3.2.2 Contributing Factors

The older caregiver age is associated with a better understanding of the nature and causes of Down syndrome and greater maternal maturity [15]. Socioeconomic status is closely related to the level of parenting stress, for instance, a low-income family increases the risk of stress related to meeting a child's basic needs, while low parental education contributes to a lack of knowledge about effective parenting [16], [17].

Fang et al. [7] identified three groups of factors contributing to parenting stress: parental factors, such as maternal depression, anxiety, low parenting self-efficacy, and parental age, child factors, such as externalizing and internalizing behavioral problems and difficulties with emotion regulation, and situational factors, such as parental education level, availability of adequate social support, and a harmonious partner relationship, which are associated with lower levels of parenting stress.

3.2.3 Measurement Instruments

Assessing parenting stress requires instruments with established validity and reliability so that the level of stress experienced by parents can be measured objectively and consistently across individuals. The two instruments most widely used in scientific research are the Parental Stress Scale (PSS) and the Parenting Stress Index (PSI), each with different measurement dimensions and adapted versions.

The PSS measures two dimensions: pleasure (satisfaction with parenting) and strain (the burden of parenting). The Indonesian adaptation by Kumalasari [18] keeps 15 of the original 18 items after cultural adjustment, with a reliability value >0.7 and a Cronbach's alpha of 0.828, indicating high reliability.

The PSI assesses parenting stress both generally and in relation to child-specific factors, and is available in a long form (PSI-4) consisting of 101 items across child and parent domains, and a short form (PSI-SF) with 36 items comprising the Parental Distress, Difficult Child, and Parent-Child Dysfunctional Interaction subscales. This instrument is widely used among populations of parents of children with developmental disorders, including autism and intellectual disability, with good evidence of convergent validity (CR 0.846, AVE 0.505–0.552) [19], [20].

3.3 Social Support

3.3.1 Definition and Types

Social support refers to the companionship, appreciation, and attention perceived by an individual that raises a sense of comfort within society, and is multidimensional as part of social networking [21]. Haverfield et al. [22] classified social support into five types: informational support (knowledge, advice, feedback), emotional support (concern, empathy, sympathy), esteem support (recognition of abilities and self-value), social network support (a sense of belonging to a particular group), and concrete support (goods and services).

3.3.2 Measurement Instruments

Several instruments are commonly used to measure social support, including the Multidimensional Scale of Perceived Social Support (MSPSS), the Caregiver Strain Questionnaire (CGSQ), and the Medical Outcomes Study: Social Support Scale (MOS-SSS), each with different dimensions and sources of support.

- a. The Multidimensional Scale of Perceived Social Support (MSPSS) was developed by Zimet et al. in 1988. The MSPSS consists of 12 items measuring perceived support from family, friends, and significant others using a 7-point Likert scale. Confirmatory testing by Saudi et al. [23] demonstrated good model fit (RMSEA 0.058, CFI 0.968) with an omega total reliability of 0.890.

- b. The Caregiver Strain Questionnaire (CGSQ) was developed by Brannan et al. in 1997 and later simplified into the CGSQ-SF11. This instrument measures three dimensions of caregiver strain: objective strain (concrete burdens such as financial impact), subjective internalized strain (internal negative feelings such as anxiety and guilt), and subjective externalized strain (negative feelings directed toward the child, such as anger or frustration) [24].
- c. The Medical Outcomes Study: Social Support Scale (MOS-SSS) was developed by Sherbourne & Stewart in 1991. The MOS-SSS consists of 19 items assessing four dimensions of social support: emotional-informational support, positive social interaction, concrete support, and affectionate support [25].

3.3.3 The Role and Relationship of Social Support in Reducing Parenting Stress among Parents of Children with Down Syndrome

Increased family support has been shown to significantly reduce stress, with stress contributing as a partial mediator of life satisfaction [9]. Social support influences stress both directly and indirectly through shaping the perception of stress itself [26]. Caregivers with an assistant have been reported to experience lower levels of strain than those without one [27], and a strong sense of family cohesion is relationship with higher self-efficacy, hope, and resilience, thereby reducing parenting stress [28].

According to Onyedibe et al. [8], the importance of social support in decreasing parenting stress among parents of children with Down syndrome is consistent with the stress buffering hypothesis, which states that the presence of strong social relationships, whether from family, friends, or the surrounding environment, can perceived the impact of stress. In this study, individual internal strength was also found to have a connection. Parents with limited social support were still able to manage stress more effectively if they have the strong personal adaptive capacity. Therefore, combining interventions focusing on strenght both social support and psychological guidance are needed to enable the parenting to proceed more optimally.

4. CONCLUSION

Children with Down syndrome have complex care needs that pose a challenge for parents in fulfilling their parenting role, thereby carrying a risk of parenting stress. Social support plays an important protective role in helping to ease this burden and reduce parents' parenting stress.

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6. REFERENCES

- [1] S. E. Antonarakis, B. G. Skotko, M. S. Rafii, et al., "Down syndrome," *Nature Reviews Disease Primers*, vol. 6, no. 9, 2020.
- [2] M. Pipan, "Down Syndrome and Other Abnormalities of Chromosome Number," in *Nelson Textbook of Pediatrics*, 22nd ed., R. M. Kliegman and J. W. St Geme III, Eds. Elsevier, 2025.
- [3] L. Chen, L. Wang, Y. Wang, H. Hu, Y. Zhan, Z. Zeng, and L. Liu, "Global, Regional, and National Burden and Trends of Down Syndrome From 1990 to 2019," *Frontiers in Genetics*, vol. 13, p. 908482, 2022.
- [4] Kementerian Kesehatan Republik Indonesia, *Laporan Nasional Riskesdas 2018*. Jakarta: Badan Penelitian dan Pengembangan Kesehatan, 2018.

- [5] F. Coppedè, "Risk factors for Down syndrome," *Archives of Toxicology*, vol. 90, no. 12, pp. 2917–2929, 2016.
- [6] A. AlShatti, D. Alkandari, H. AlMutairi, D. AlEbrahim, A. AlMutairi, D. AlAnsari, and L. Abduljaleel, "Caregivers' perceptions and experience of caring for persons with Down syndrome in Kuwait: a qualitative study," *International Journal of Developmental Disabilities*, vol. 67, no. 5, pp. 381–390, 2021.
- [7] Y. Fang, J. Luo, M. Boele, D. Windhorst, A. van Grieken, and H. Raat, "Parent, child, and situational factors associated with parenting stress: a systematic review," *European Child & Adolescent Psychiatry*, vol. 33, no. 6, pp. 1687–1705, 2024.
- [8] M. C. C. Onyedibe, L. I. Ugwu, C. M. Philip, and C. Onuiri, "Parents of children with Down Syndrome: Do resilience and social support matter to their experience of carer stress?," *Journal of Psychology in Africa*, vol. 28, no. 2, pp. 94–99, 2018.
- [9] E. Ekmen, O. Koçak, U. Solmaz, K. Kopuz, M. Z. Younis, and D. Orman, "How does the social support affect refugees' life satisfaction in Turkey? Stress as a mediator, social aids and coronavirus anxiety as moderators," *Sustainability*, vol. 13, no. 22, 2021.
- [10] Center for Disease Control and Prevention, "Down syndrome," 2026. [Online]. Available: <https://www.cdc.gov/birth-defects/about/down-syndrome.html>.
- [11] Kementerian Kesehatan Republik Indonesia, "Survei Kesehatan Indonesia (SKI) 2023," Badan Kebijakan Pembangunan Kesehatan, Kemenkes, 2024. [Online]. Available: <https://www.badankebijakan.kemkes.go.id/hasil-ski-2023/>.
- [12] M. J. Bull, T. Trotter, S. L. Santoro, C. Christensen, and R. W. Grout, "Health supervision for children and adolescents with Down syndrome," *Pediatrics*, vol. 149, no. 5, p. e2022057010, 2022.
- [13] N. Lorenzon, J. Musoles-Lleó, F. Turrise, M. Gomis-González, R. De La Torre, and M. Dierssen, "State-of-the-art therapy for Down syndrome," *Developmental Medicine & Child Neurology*, vol. 65, no. 7, pp. 870–884, 2023.
- [14] N. Shields, "Physiotherapy management of Down syndrome," *Journal of Physiotherapy*, vol. 67, no. 4, pp. 243–251, 2021.
- [15] N. A. El-Deen, A. A. Alwakeel, A. H. El-Gilany, and Y. Wahba, "Burden of family caregivers of Down syndrome children: a cross-sectional study," *Family Practice*, vol. 38, no. 2, pp. 159–164, 2020.
- [16] L. Wagner, "Parenting Under Pressure: How Socioeconomic Status and Stress affect Parenting," *Family Perspectives*, vol. 6, no. 2, 2024.
- [17] A. L. O. Barros, A. O. Barros, G. L. M. Barros, and M. T. B. R. Santos, "Burden of caregivers of children and adolescents with Down Syndrome," *Ciência & Saúde Coletiva*, vol. 22, no. 11, pp. 3625–3634, 2017.
- [18] D. Kumalasari, I. A. Gani, and E. Fourianalistyawati, "Adaptasi dan Properti Psikometri Parental Stress Scale versi Bahasa Indonesia," *Jurnal Psikologi Ulayat*, 2022.
- [19] M. Ríos, S. Zekri, Y. Alonso-Esteban, and E. Navarro-Pardo, "Parental Stress Assessment with the Parenting Stress Index (PSI): A Systematic Review of Its Psychometric Properties," *Children*, vol. 9, no. 11, p. 1649, 2022.
- [20] N. Daulay, N. Ramdhani, and N. R. Hadjam, "Validity and Reliability of Parenting Stress Construct among Mothers of Children with Autistic Spectrum Disorder," *Jurnal Psikologi*, vol. 47, no. 1, 2020.
- [21] J. Drageset, "Social support," in *Springer*, pp. 137–144, 2021.
- [22] M. C. Haverfield, J. Leustek, and C. Timko, "Social Support Strategies in Online Forums Among Adult Offspring of Parents with Harmful Alcohol Use," *Alcoholism treatment quarterly*, vol. 36, no. 1, pp. 86–100, 2018.

- [23] A. N. A. Saudi, R. S. Bintang, V. L. Loloallo, and N. I. Zainuddin, "Multidimensional Scale of Perceived Social Support (MSPSS): Uji Validitas Konstruk dengan Confirmatory Factor Analysis (CFA)," *Edukatif Jurnal Ilmu Pendidikan*, vol. 6, no. 4, pp. 4266–4275, 2024.
- [24] G. M. Brennan, D. E. Babinski, and D. A. Waschbusch, "Caregiver strain Questionnaire–Short Form 11 (CGSQ-SF11): A validation study," *Assessment*, vol. 29, no. 7, pp. 1351–1370, 2021.
- [25] D. S. Zanini, E. M. Peixoto, and T. C. Nakano, "The Social Support Scale (MOS-SSS): Standardizing with Item References," *Temas Em Psicologia*, vol. 26, no. 1, pp. 401–412, 2018.
- [26] E. F. Acoba, "Social support and mental health: the mediating role of perceived stress," *Frontiers in Psychology*, vol. 15, 2024.
- [27] C. N. Marsack and F. P. Hopp, "Informal support, health, and burden among parents of adult children with autism," *Gerontologist*, vol. 59, no. 6, 2019.
- [28] H. Almulla, O. Aljaloud, H. Almulla, and S. Nasser, "Caregiver burden, perceived stress, and social support among parents of chronically ill children in Saudi Arabia," *BMC Nursing*, vol. 23, no. 1, 2024.