e-ISSN : 2597-6052
MPPKI MEDIA PUBLIKASI PROMOSI KESEHATAN INDONESIA
Research Articles Open Access

Exploring Maternal Knowledge and Stimulation Practices in the Development of Children with Down Syndrome

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ARTICLE INFO

Manuscript Received: 06 May, 2025
Revised: 05 Aug, 2025
Accepted: 11 Aug, 2025
Date of Publication: 11 Sept, 2025
Volume: 8
Issue: 9
DOI: 10.56338/mppki.v8i9.7686

KEYWORDS

Maternal Knowledge;
Stimulation Practices;
Child Development;
Down Syndrome

ABSTRACT

Introduction: Down syndrome is a common genetic disorder in children, with rising cases in Central Java—from 210 in 2020 to 650 in 2024—a 63% increase in three years. Children with Down syndrome face developmental challenges across all domains including motor, sensory, cognitive, language, and social aspects. Parental involvement, especially mothers, plays a crucial role in optimizing developmental outcomes. However, observations at POTADS Semarang indicate limited maternal knowledge and inadequate stimulation practices. This study aims to explore maternal knowledge and behaviors related to developmental stimulation in children with Down syndrome at POTADS Semarang..

Methods: This analytic survey employed a cross-sectional approach conducted in August 2024 with 75 mothers meeting the inclusion criteria. Data were collected using a structured and closed questionnaire. Ethical approval was obtained from the Research Bioethics Committee of Sultan Agung Islamic University, and informed consent was obtained from all participants.

Results: The study found a significant correlation between maternal knowledge and stimulation behavior. Statistical analysis showed a 2-tailed significance value of 0.003 (<0.05). Most mothers (44%) had moderate knowledge of child development stimulation, and the majority (53.3%) demonstrated negative behaviors in providing age-appropriate developmental stimulation.

Conclusion: Among the 75 respondents, 40 (53.3%) were over 35 years old, 52 (69.3%) were unemployed, and 58 (77.3%) had completed secondary education. Spearman Rank test analysis yielded a p-value of 0.003 (<0.05), indicating a significant relationship between maternal knowledge and behaviors regarding developmental stimulation. Mothers with moderate and low levels of knowledge were more likely to exhibit negative stimulation behaviors.

Publisher: Fakultas Kesehatan Masyarakat Universitas Muhammadiyah Palu

INTRODUCTION

Down syndrome is a common genetic disorder among children. According to World Health Organization (WHO), approximately 8 million individuals worldwide are living with Down syndrome (1). Furthermore, the prevalence of Down syndrome among children under 5 years of age in Indonesia gradually increased to 0,21% in 2018, with Central Java reporting the highest number of cases—31.834 among 5-17 years old children (2). Children with Down syndrome experiences challenges in nearly all aspects of development, including motor, sensory, cognitive, language, and social (3). These developmental delays often manifest as difficulties in walking and speech, problems with chewing and swallowing, and even delayed puberty (4). Therefore, children with Down syndrome require more attention and support from their parents and families in daily life. These increased caregiving responsibilities contribute to a heavier burden on parents of children with Down syndrome compared to those with typically developing children (5).

Access to accurate information, support, and motivation from people around and healthcare professionals plays a crucial role for parents of children with Down syndrome (6,7). These factors significantly influence the quality of parenting, contribute to the child's developmental progress, and help reduce parental stress and burden (8). In the context of knowledge, attitudes, and practices, the parents especially mother, have essential role to understand how to properly care for and raise children with Down syndrome. Appropriate stimulation and care can yield substantial developmental benefits for the child (9).

The previous study conducted in Pakistan highlighted that the majority of parents of children with Down syndrome showed a good knowledge and positive attitudes towards the condition. Approximately 79% respondents acknowledge the Down syndrome, and 100% recognized the importance of physiotherapy, occupational therapy, and speech therapy in disability management (10). Similar findings were observed in Karawang, Indonesia, where most parents also showed both good knowledge and attitudes toward children with Down syndrome (11). While numerous studies have assessed parental knowledge and attitudes regarding Down syndrome and other intellectual disabilities(10–17), In contrast, the present study examines two variables, aiming to analyze the correlation between maternal knowledge and behavior concerning developmental stimulation in children with Down syndrome, with a larger sample of 75 mothers.

The Persatuan Orang Tua Anak dengan Down Syndrome (POTADS) is an association and supporting group for parents of children with Down syndrome in Indonesia. This community is organized into regional chapters, one of which is located in Semarang and currently has 110 parent members. Cases of Down Syndrome in Central Java have shown a significant increase. According to information from the Head of POTADS Central Java, recorded cases rose from 210 in 2020 to 320 in 2021, 415 in 2022, 567 in 2023, and 650 in 2024—an increase of approximately 63% over three years Based on our preliminary study about developmental milestone in children with Down syndrome involving 20 mothers in POTADS Semarang revealed that 60% lacked knowledge of language developmental milestones at 0–5 months, 30% were unaware of gross motor and cognitive milestones at 6–10 months, and 10% did not know cognitive milestones at 60–71 months. Furthermore, many mothers reported preferred to seek external therapies—such as physiotherapy, speech therapy, occupational therapy, or stimulation massage—rather than providing direct developmental stimulation at home. Based on these findings, this study aims to examine the relationship between the knowledge and their practices in providing developmental stimulation to children with Down syndrome in POTADS Semarang.

METHOD

Research Type

This study employed an analytic survey design with a cross-sectional approach to analyze the correlation between maternal knowledge and behavior regarding developmental stimulation in children with Down syndrome. The cross-sectional design allows for the simultaneous collection of all variables at a single point in time (18). The independent variable in this study was maternal knowledge of developmental stimulation, while the dependent variable was maternal behavior in providing developmental stimulation to their child with Down syndrome. To minimize potential bias and enhance validity, maternal age, occupation, and educational level were considered as confounding variables in this study.

Population and Sample/Informants

The study population included 110 mothers of children with Down syndrome registered in POTADS Semarang. A total sampling method was applied using inclusion and exclusion criteria to determine eligibility. The inclusion criteria included: 1) mothers of children with Down syndrome aged 0–6 years, 2) having at least one child with Down syndrome, 3) ability to read and write, 4) willingness to participate in the study, and 5) agreement to complete the questionnaire. The exclusion criteria included: 1) failure to complete the questionnaire, 2) mothers who were healthcare workers, or 3) having received education or training on developmental stimulation for children with Down syndrome. Following the application of these criteria, a total of 75 mothers met the requirements and were included in the study.

Research Location

The study was conducted at the Semarang branch of the (POTADS), located in Semarang, Indonesia. Data collection took place in June 2024.

Instrumentation or Tools

To collect the data, a structured questionnaire was developed, consisting of 50 items using a Guttmal scale to assess mother's knowledge and 10 items using a Likert scale to evaluate behaviour related to developmental stimulation. Prior to the study, the questionnaire was tested to verify the validity and reliability. The test involving 20 mothers from POTADS Solo, who had similar demographic characteristics to the study participants. The results indicated that the questionnaire was both valid and reliable. The Pearson Product-Moment correlation coefficient for the knowledge items was $r = 0.444$, exceeding the critical value for significance. Reliability testing showed high internal consistency, with Cronbach's alpha values of 0.955 for knowledge and 0.902 for behavior items.

Data Collection Procedures

The data collection was carried out using online platform *Google Forms* and the link was shared through a WhatsApp group for POTADS members. Respondents were required to complete all items, which included 50 questions on knowledge and 10 questions on behavior related to developmental stimulation. For the knowledge section, each item required participants to select either "true" or "false" based on their understanding of the given statement. For the behavior section, responses were measured using a four-point Likert scale: "always," "often," "rarely," and "never," based on how frequently the behavior described was practiced. Continuous follow-up was conducted to encourage participation. A total of 110 responses were submitted through the Google Form. However, 35 respondents were excluded for not meeting the inclusion criteria, resulting in a final sample of 75 eligible participants.

Data Analysis

The collected data were analyzed using SPSS version 23, both univariate and bivariate analyses were conducted. The univariate analysis was used to describe the frequency distribution of respondent characteristics, as well as the percentage of maternal knowledge and behavior related to developmental stimulation. Bivariate analysis was performed to examine the correlation between variables using the Spearman Rank Correlation Test, statistical significance was set at a p value of $< 0,05$.

Ethical Approval

This study received ethical approval from the Bioethical Committee Medical Research Sultan Agung Islamic University, with approval number 338/VIII/2024/Komite Bioetik. Prior to data collection, all participants provided informed consent. Anonymity was ensured by using respondent codes instead of names. Throughout the study, the rights, privacy, and autonomy of all participants were fully respected.

RESULTS

This study involved mothers of children with Down syndrome who were members of the POTADS community in Semarang City in 2024. Analysis of maternal characteristics in (Table 1) shows that the majority of

respondents, 40 (53.3%), were over 35 years old. Regarding employment status, 52 (69.3%) were unemployed, and 58 (77.3%) had completed secondary education.

Table 1. Characteristic of Mother

Maternal Category	Frequency (n)	Precentage (%)
Age		
20-35 years old	35	46.75
>35 years old	40	53.3
Total	75	100
Occupation		
Employed	23	30.7
Unemployed	53	69.3
Total	75	100
Education		
Primary education	10	13.3
Secondary education	58	77.3
Higher education	7	9.3
Total	75	100

Source: Primary Data, 2024

(Table 2) presents maternal knowledge regarding stimulation of development in children with Down Syndrome. The analysis results show that the majority of mothers fall into the moderate knowledge category, with 33 individuals (44%), followed by 24 (32%) in the low knowledge category, and 18 (24%) in the good knowledge category.

Table 2. Maternal Knowledge on Developmental Stimulation in Children with Down Syndrome

Maternal Knowledge	Frequency (n)	Precentage (%)
High	18	24.0
Moderate	33	44.0
Low	24	32.0
Total	75	100

Source: Primary Data, 2024

(Table 3) presents the analysis results of maternal behavior regarding developmental stimulation in children with Down Syndrome. The analysis identified that 40 mothers (53.3%) exhibited negative behavior, while 35 mothers (46.7%) demonstrated positive behavior.

Table 3. Maternal Behavior on Developmental Stimulation in Children with Down Syndrome

Behavior	Frequency	%
Positive	35	46.7
Negative	40	53.3
Total	75	100

Source: Primary Data, 2024

Table 4 presents the results of the bivariate analysis conducted on two variables: maternal knowledge and behavior regarding developmental stimulation in children with Down Syndrome. The analysis employed the Spearman Rank correlation test with a significance level of 0.05. The results show that among 33 mothers (44%) with moderate knowledge, 18 (24%) exhibited negative behavior and 15 (20%) demonstrated positive behavior. Furthermore, among 24 mothers (32%) with low knowledge, 20% showed negative behavior and 12% showed positive behavior. Statistical analysis using the Spearman Rank test yielded a p-value of 0.003 (<0.05), indicating a

significant relationship between maternal knowledge and behavior regarding developmental stimulation in children with Down Syndrome, thus higher knowledge associated with positive behavior.

The results showed that not only mothers with insufficient knowledge exhibited negative behavior, but also mothers with sufficient knowledge also exhibited negative behavior regarding developmental stimulation in children with Down syndrome.

Table 4. Bivariate Analysis of Maternal Knowledge and Behavior Regarding Developmental Stimulation in Children with Down Syndrome

Variable	Behavior				P-value
Knowledge	Positive	%	Negative	%	
High	11	14.7	7	9.3	0.003
Moderate	15	20.0	18	24.0	
Low	9	12.0	15	20.0	

Source: Primary Data, 2024

DISCUSSION

Participants Charateristic

The majority of mothers who participated in the study and had children with Down Syndrome were over 35 years old, totaling 40 individuals (53.3%). This age falls into the high-risk category. Previous studies have identified maternal age over 35 years as a risk factor for giving birth to a child with Down Syndrome (19). In terms of employment status, 52 mothers (69.3%) were unemployed, and 58 (77.3%) had completed secondary education. These findings align with previous study by Misniarti and Haryani (2022), who reported that 46.4% of mothers were aged 26-35 years and 50.7% had secondary education (19). The 20–35 year age group is generally considered an optimal reproductive period, characterized by peak reproductive organ function and physical readiness (20). Furthermore, education plays a significant role in parenting quality, including engagement in developmental stimulation activities (21). Unemployed mother or housewives may also have more opportunities to interact with their children, enabling stronger emotional bonding and more consistent fulfilment of developmental needs (22).

Knowledge is a fundamental factor in shaping an individual's actions and behaviors. A mothers' knowledge about child development plays a critical role in influencing her attitudes and caregiving practices, particularly in providing appropriate early stimulation and engaging effectively with her child. Mothers with adequate knowledge of developmental milestones are more likely to create an environment that supports their child's growth and skill development (23). The positive behavior showed in this study indicates that they are providing appropriate developmental stimulation to help their children with Down syndrome reach key milestones. This finding aligns with a previous study, which reported that 94% of participating mothers also demonstrated positive behavior practices (24).

This study highlights the significant association between maternal knowledge and behavioral practices regarding developmental stimulation in children with Down syndrome. The findings indicate that mothers with moderate levels of knowledge tend to demonstrate more positive behavioral practices, particularly in providing appropriate early stimulation to support their child's development. This align with previous research conducted at Mergangsan Primary Health Care, which also reported a positive correlation between maternal knowledge and stimulation practices for children aged 0–12 months (25). This study also uncovered several gaps in knowledge, particularly in aspects related to gross motor development. Similarly, negative behavioral practices were most frequently observed in the stimulation of fine motor skills. These gaps suggest the need for targeted educational interventions aimed at enhancing maternal understanding in these specific developmental domains.

Such interventions could include structured parenting workshops, home-based coaching sessions, and peer-support group activities facilitated by trained healthcare professionals. Implementation strategies should emphasize community-based approaches, culturally appropriate content, integration with local health services such as Posyandu and Puskesmas, and ongoing monitoring to evaluate effectiveness and ensure sustainability. Furthermore, Susanti and Adawiyah (2020) emphasized that higher maternal knowledge is associated with more effective and supportive parenting behaviors, whereas limited knowledge often results in less optimal stimulation practices (26). The results

of the current research also show that mothers with high knowledge still have negative behaviors, but there are also mothers with low knowledge but have positive behavior, which means that not everyone with good knowledge has positive behavior or vice versa.

To enhance maternal knowledge and skills in providing developmental stimulation for children with Down Syndrome, it is essential to implement parent support programs, particularly for mothers who are the primary caregivers. Children with Down Syndrome are individuals with special needs who require specific healthcare services that differ from those of typically developing children (28). There is currently no medication that can cure Down Syndrome; its management involves various therapies aimed at assisting and training individuals with DS to achieve a productive and independent life. Early intervention through therapy is crucial to achieve optimal outcomes (29).

Knowledge is one of the factors that can influence the formation of a person's attitudes and perceptions (30). The Theory of Planned Behavior (TPB) explains that behavior is driven by intention, which in turn is influenced by attitudes, perceived norms, and perceived behavioral control. The better a mother's knowledge about developmental stimulation in children with Down Syndrome, the more likely she is to exhibit positive behavior.

Although this study found a significant relationship between maternal knowledge and behavior regarding developmental stimulation in children with Down Syndrome, certain limitations must be acknowledged. First, data collection were conducted online using Google Forms due to the geographical distribution of POTADS Semarang members, who do not all reside in Semarang City but are spread across various regions such as Ungaran, Salatiga, Grobogan, Demak, Pati, Blora, Tegal, and Pekalongan. While online data collection is practical, it may introduce response bias and limit the ability to directly observe maternal behaviors.

In addition, the limited availability of studies specifically addressing maternal knowledge and behavior related to developmental stimulation in children with Down Syndrome presents a challenge in building a focused body of literature. As a result, this analysis relies on general child development literature, which may not fully capture the distinct developmental profiles of children with Down Syndrome.

Cases of Down Syndrome in Central Java have shown a significant increase. According to data from the Head of the Central Java Chapter of the POTADS, the number of recorded cases rose from 210 in 2020 to 320 in 2021, 415 in 2022, 567 in 2023, and 650 in 2024—representing a 63% increase over the span of three years. Therefore, future research should involve larger and more diverse populations, utilizing a combination of qualitative and quantitative approaches to obtain richer data, and developing region-specific frameworks to assess and enhance maternal practices. By addressing these limitations, future studies can provide more comprehensive evidence to support the development of policies and programs aimed at optimizing early developmental outcomes for children with Down Syndrome in Indonesia.

Moreover, the limited availability of research specifically addressing maternal knowledge and behaviors related to developmental stimulation in children with Down syndrome posed a challenge in constructing a focused literature base. As a result, the analysis relied on general child development literature, which may not fully reflect the distinct developmental profiles of children with Down syndrome.

Future research is encouraged to involve larger and more diverse populations, utilize a combination of qualitative and quantitative approaches to capture richer data, and develop region-specific frameworks for assessing and improving maternal practices. By addressing these limitations, future research can provide more comprehensive evidence to support policy and program development aimed at optimizing early developmental outcomes for children with Down syndrome in Indonesia.

CONCLUSION

This study confirms a significant relationship between maternal knowledge and developmental stimulation behavior in children with Down Syndrome within the POTADS Semarang community. Among the 75 respondents, 40 mothers (53.3%) were aged over 35, 52 (69.3%) were unemployed, and 58 (77.3%) had completed secondary education. Statistical analysis using the Spearman Rank test yielded a p-value of 0.003 (<0.05), indicating a significant association between maternal knowledge and behavior regarding developmental stimulation in children with Down Syndrome. Mothers with moderate and low levels of knowledge were more likely to exhibit negative behavior, highlighting the crucial role knowledge plays in supporting the development of children with Down

Syndrome. This study encountered logistical and contextual barriers in accessing and disseminating information within the parent community, such as POTADS Semarang.

Future research should include a larger and more representative sample and adopt a mixed-methods approach to gain deeper insights into the role of mothers in supporting children with Down Syndrome. Strengthening maternal knowledge through community-based interventions and healthcare services may substantially contribute to improving developmental outcomes for children with Down Syndrome in Indonesia.

AUTHOR'S CONTRIBUTION STATEMENT

Endang Susilowati led the overall study design, including the formulation of the research topic, objectives, methodology, data analysis, and initial manuscript drafting. Arum Meiranny contributed to the development of the methodology section, data presentation, and discussion, and was actively involved in manuscript revision. Ghina Rihadatul 'Aisy was responsible for statistical analysis, data processing, preparation of research instruments, and visual presentation of data, as well as interpretation of quantitative findings. Tri Indah Winarni provided expert input related to Down syndrome and contributed to the interpretation and discussion of findings within this context. Agustini Utari contributed her expertise in child development, ensuring the relevance and accuracy of interpretations related to developmental stimulation. All authors reviewed and approved the final version of the manuscript.

CONFLICTS OF INTEREST

We declare that there is no conflict of interest regarding the publication of this article. We have no relevant financial or non-financial interests, affiliations, or relationships that could be perceived as influencing the research, authorship, or publication of this manuscript.

DECLARATION OF GENERATIVE AI AND AI-ASSISTED TECHNOLOGIES IN THE WRITING PROCESS

During the preparation of this manuscript, we used generative AI tools (e.g., ChatGPT by OpenAI) to assist in refining the language and grammar of the text. The AI was not used to generate original scientific content, analyze data, or interpret results. We, the authors, take full responsibility for the content, accuracy, and integrity of the final manuscript.

SOURCE OF FUNDING STATEMENTS

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. All research activities were self-funded by the author team as part of their academic collaboration.

ACKNOWLEDGMENTS

We gratefully acknowledge the support of POTADS Semarang for facilitating access to participants and providing valuable assistance during data collection. We also thank all the participating mothers for their valuable time and willingness to contribute to this study. Special thanks to our academic mentors and colleagues for their constructive feedback and encouragement during the preparation of this manuscript.

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