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PARENTAL ROLES IN THE ORAL HEALTH MAINTENANCE OF CHILDREN WITH DOWN SYNDROME : A SCOPING REVIEW

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Abstract

Background : Globally, people with disabilities account for more than 1 billion individuals or 15% of the population. In Indonesia, the 2018 Susenas data reports that 14.2% (30.38 million) of the population lives with disabilities. Children with Down syndrome exhibit distinct orofacial characteristics, including a higher prevalence of periodontal disease, malocclusion, delayed tooth eruption, mouth breathing habits, and congenital dental anomalies such as hypodontia and microdontia. Purpose : This literature review aims to analyze the role of parents in maintaining oral health and supporting oral hygiene practices in children with Down syndrome. Methods : A literature search was conducted using databases (PubMed and Scopus) following PRISMA-ScR guidelines, with inclusion criteria limited to articles published within the last 10 years. Results : The review indicates that children with Down syndrome have a high prevalence of periodontal disease, malocclusion, and poor oral hygiene status (OHI-S), mainly due to functional limitations. Although the DMF-T index tends to be lower compared to other disabilities, oral health problems remain significant. Parents play a crucial role in assisting daily oral hygiene practices, ensuring access to dental care, and supporting preventive behaviors. However, limited parental knowledge and awareness, along with restricted access to dental services, contribute to suboptimal oral health outcomes. Conclusion : Parental involvement is essential in maintaining oral health in children with Down syndrome, particularly in overcoming functional limitations. However, inadequate knowledge and limited access to preventive and promotive oral health services hinder optimal care. Strengthening parental education and improving access to dental health services are necessary to enhance oral health outcomes in this population.

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Introduction

According to the World Health Organization (WHO), over one billion people approximately 15% of the global population live with various forms of disabilities, and this figure continues to grow. The United Nations (UN) also reports that around 10% of the population in developing countries experience either temporary or permanent disabilities. Data from Indonesia's 2018 National Socioeconomic Survey (Susenas) revealed that 14.2% of the nation's population, equivalent to about 30.38 million individuals, have disabilities. To safeguard equal rights and opportunities for persons with disabilities, Indonesia enacted Law Number 19 of 2011, ratifying the Convention on the Rights of Persons with Disabilities. Furthermore, Law Number 36 of 2009 on Health mandates the government to ensure the availability of health services and to support people with disabilities in living independently and productively, both socially and economically. Health programs for individuals with disabilities are therefore directed toward maintaining a dignified, healthy, and productive life (Pini & Rigo, 2016). This commitment is reinforced by Law Number 8 of 2016 on Persons with Disabilities, which guarantees that individuals with disabilities are entitled to have their needs fulfilled (Study & Aljameel, 2021).

Health refers to a state of overall physical, mental, spiritual, and social well-being, rather than simply the absence of illness or physical weakness, and enables individuals to live socially and economically productive lives. In Indonesia's National Medium-Term Development Plan (RPJMN) for 2020–2024, health development is pursued through the Healthy Community Movement, aiming to achieve universal health coverage by strengthening primary health care and promoting preventive and promotive approaches, supported by innovation and technology, including

health services for people with disabilities (Goud et al., 2021), supported by innovation and the use of technology, WHO (2011) emphasizes that persons with disabilities tend to have poorer health outcomes, lower education levels, reduced income, and higher poverty rates than those without disabilities, largely due to limited access to adequate services, financial constraints, and various barriers in daily life. According to (Gupta et al., 2025), This is related to their limitations, such as motor, physical, and intellectual limitations, which make it difficult for them to maintain oral health and communicate their oral health needs. Therefore, they depend on their parents for self-care and oral health. This is in line with the results of the 2015 Supas (National Population and Child Protection Survey), which found that 1.02% of people with disabilities experienced difficulties in self-care. Parents of people with intellectual disabilities influence the education and development of their children. According to (Surija et al., 2024), parents as the foundation for children's behavior and are the main targets in public health promotion.

Down syndrome is a chromosomal abnormality present at birth, resulting from a nondisjunction error during embryonic cell division. Typically, two copies of chromosome 21 are formed, yielding a total of 46 chromosomes. In contrast, individuals with Down syndrome possess an extra copy of chromosome 21, producing a total of 47 chromosomes (Gupta et al., 2025).

The World Health Organization (WHO) reports that the condition occurs in approximately 1 out of every 1,000 to 1,100 live births worldwide, with an estimated 8 million individuals affected globally. Each year, between 3,000 and 5,000 newborns are diagnosed with Down syndrome. Cases of Down syndrome in Indonesia have increased by 8% over the past five years. According to the Center for Data and Information, the number of Down syndrome cases in Indonesia reached 0.21% in 2018, compared to 0.13% in 2013 in children aged 24-59 months. The extra chromosome results in changes in physical characteristics, such as specific physical signs and a lack of cognitive or intellectual abilities. Mental retardation and developmental delays in these children result in delayed motor and speech development, making it difficult to care for themselves, including maintaining dental and oral health (Porovic et al., 2016).

Oral and dental health can affect overall body health, including nutritional deficiencies and other symptoms of disease. People with disabilities show a higher prevalence and severity of oral health problems compared to people without disabilities. High rates of caries, tooth loss, periodontal disease, retained deciduous teeth, and supernumerary teeth, along with malocclusion, are oral health problems experienced by people with disabilities (Willis et al., 2020). For people with intellectual disabilities such as Down syndrome, maintaining dental and oral health presents a unique challenge and challenge in terms of dental services. This leads to poor dental and oral health problems for people with Down syndrome due to a lack of adequate care.

According to research conducted by (AlJameel et al., 2020) The oral cavity conditions of Down syndrome patients include abnormal labial crown shape, partial anodontia, delayed eruption, periodontal tissue damage, low caries prevalence, malocclusions such as crowded, posterior crossbite, and anterior openbite. The oral cavity conditions of Down syndrome patients show a malocclusion percentage of 46.67%, macroglossia 35.56%, and dental anomalies 17.77%. Meanwhile, dental health maintenance is in the good category of 31.1% and the poor category of 68.9%. The incidence of caries using the DMF-T index shows an average of 1.84, which is included in the low category according to WHO. These data indicate that children with Down syndrome are susceptible to abnormalities and condition of the teeth and mouth. The role of parents is in the moderate category (76%) and tooth brushing skills are in the moderate category (52%). These data indicate that parents play a very important role in training and improving children's skills such as brushing their teeth. This study aims to explore and synthesize the existing evidence on the role of parents in maintaining oral health and supporting oral hygiene practices in individuals with Down syndrome.

Methods

Search Strategy

The scoping review research used the reporting standards outlined in the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement. The literature search was obtained from 2 databases : Scopus, PubMed. The number of included articles was 15 articles with a minimum publication year of 2015 or the last 10 years in English. The article search used keywords (("down syndrome OR children with down syndrome OR special needs children OR intellectual disability" AND ("oral health OR oral hygiene OR dental care") AND ("parent OR caregiver OR mother OR father)).

Research Question

The guiding question for this scoping review is : *What roles do parents or caregivers play in maintaining the oral and dental health of children with Down syndrome?* The Population, Concept, and Context (PCC) framework is applied to assess the suitability and relevance of this question for the present scoping review.

PCC Framework

Table 1. PCC Framework

Population (P)	People with Down Syndrome
Concept (C)	Maintaining dental and oral health through the role of parents/caregivers (knowledge, attitudes, practices, involvement and support)
Context (C)	Family environment (tooth brushing routine, supervision, education), and access to dental health services.

Inclusion Criteria

Studies involving people with Down Syndrome. Studies involving parents or primary caregivers of people with Down Syndrome. Studies that discuss the role of parents/caregivers in maintaining dental and oral health (knowledge, attitudes, practices, involvement, support). Primary studies (quantitative, qualitative, cross-sectional, cohort, case-control, intervention).

Exclusion Criteria

Studies that do not specifically address people with Down Syndrome. Articles that focus only on general medical aspects (e.g. cardiovascular, neurological) without touching on dental/oral health. Studies that only assess the dental health of people with Down Syndrome without linking it to the role of parents/caregivers. Articles in the form of editorials, opinions, or short reports without research data.

Data Collection

Data collection process involved a systematic search of the PubMed and Scopus databases, focusing on English-language publications from 2015 to 2025. After exporting the search results, duplicate entries were removed, and studies were screened by title and abstract. Articles meeting the eligibility requirements underwent a full-text evaluation guided by the established inclusion and exclusion criteria. The findings from the selected studies were synthesized narratively.

Result

The search for articles was conducted using two databases : PubMed (n = 32) and Scopus (n = 112), resulting in a total of 144 articles. Of these, 11 articles were identified as duplicates and removed prior to the selection process, leaving 133 articles for the screening stage. During the title and abstract selection stage, 67 articles were excluded because they were not original research articles, leaving 66 articles for the full-text search. Of these, 18 articles were inaccessible due to limited full-text availability, resulting in only 48 articles being fully assessed. Thirty-three articles were excluded because they did not examine the role of parents or caregivers in maintaining dental and oral health in children with Down syndrome. Thus, 15 articles met all inclusion criteria and were included in this literature review. The detailed process for selecting included articles is presented in the PRISMA-ScR flowchart. (Figure 1)

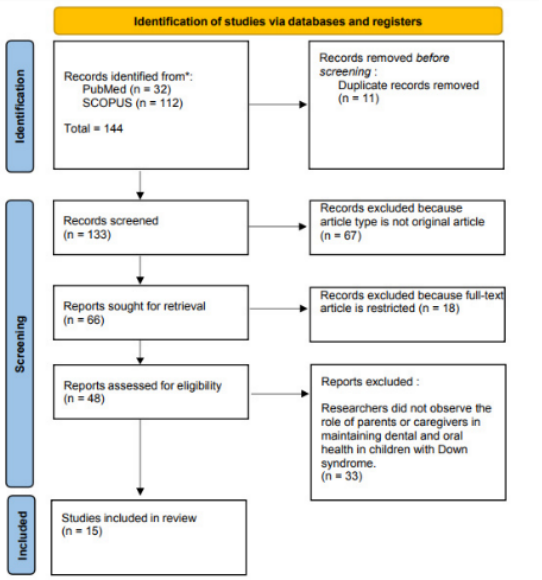


Figure 1. PRISMA-ScR Flow Diagram

Table 2. Data Extraction Table

No	Article Title	Author (Year)	Results	Outcomes
1.	The relationship between parents' oral hygiene knowledge and practices in children with Down Syndrome	(Sosiawan et al., 2022)	Parental knowledge is significantly related to dental hygiene practices in children with DS. Education improves care skills.	Oral health education for parents can improve the oral hygiene of children with DS.
2.	Dental health care for children with Down Syndro	(Stensson et al., 2022)	Parents reported special needs of children with DS during	The support of clinics and professionals is essential to

	me - parental perspectives		dental care; difficulties with child behavior and access to services.	help parents.
3.	Mothers' perceptions of oral health in children with Down Syndrome	(AlJameel et al., 2020)	Maternal perceptions influence priorities and access to children's dental care.	Education and psychosocial support for parents can increase concern.
4.	Impact of oral health on caregivers of children with Down Syndrome	(Surija et al., 2024)	Caregivers experience stress and psychological burden due to oral care for children with DS.	A mentoring program for caregivers is needed to reduce stress and improve the quality of care.
5.	Hygienic behaviors and use of dental care services in children with disabilities including Down Syndrome	(Schnabl et al., 2025)	Children with DS have a low frequency of visits to the dentist; hygiene practices depend on parental involvement.	Active parental involvement improves oral hygiene behavior of children with DS.
6.	Oral health status among children with Trisomy 21 compared to controls	(AlSarheed, 2015)	Children with DS have a higher prevalence of plaque and gingivitis than controls.	The role of household care is very important to reduce the risk of oral disease.
7.	Stress and self-efficacy of caregivers in maintaining oral health of children with Down Syndrome	(Elrefadi et al., 2022)	Parents' stress levels and self-efficacy influence the quality of dental care for children with DS.	Interventions should improve parents' coping and self-efficacy.
8.	Oral health education and dental care access for families with children with Down Syndrome	(Pini & Rigo, 2016)	Many families have not received formal education about DS's oral hygiene.	Dental health education needs to be integrated into community programs.
9.	Quality of Life and Oral Health Outcomes Among Parental Caregivers of Children with Down Syndrome	(Elrefadi et al., 2022)	The condition of the caregiver's mouth is related to the family's QOL.	Attention is needed to the oral health of both children and parents.

10.	Strategies for Improving Oral Hygiene in Pediatric and Adolescent Populations with Down Syndrome	(Silva et al., 2020)	Recommends adaptive techniques, special aids, and education for families.	Adaptive strategies increase the effectiveness of oral hygiene maintenance.
11.	Family Experiences in Providing Oral Health Care for Children with Down Syndrome	(Richter et al., 2025)	Main obstacles: child behavior, clinic facilities are not DS friendly.	Disability-friendly clinics and training of health workers are needed.
12.	Parental Insights into Oral Health Issues and Access to Dental Services in Down Syndrome	(Az Zahra et al., 2021)	The review revealed numerous access barriers and a lack of policy support.	Policy-based interventions are needed to improve access.
13.	Addressing Obstacles to Dental Care Access in Individuals Living with Down Syndrome	(Hung et al., 2025)	Barriers: cost, distance, attitude of medical personnel.	Professional education and access policies will improve oral health in children with Down syndrome.
14.	Parents' experiences in accessing dental care for children with Down Syndrome	(Porovic et al., 2016)	101 parents reported challenges when visiting the clinic; some had positive experiences when the clinic was friendly.	Good communication is needed between parents and medical personnel.
15.	Regional studies on oral health of children with Down Syndrome and caregiver roles	(Gupta et al., 2025)	Local studies in Indonesia & developing countries: low parental education, limited community support.	Community-based educational and support interventions are needed.

Table 3. The role of parents in maintaining dental and oral health outcomes in people with Down syndrome

No.	The Role of Parents/Caregivers	Information
1.	Dental and oral health maintenance services (AlJameel et al., 2020) (AlSarheed, 2015)	Dental and oral health maintenance services explain that people with Down syndrome have the right to receive regular dental and oral health services such as tartar cleaning to achieve optimal health levels.
2.	Training and assistance in maintaining dental and oral health (Sosiawan et al., 2022) (Gupta et	Training and support for independent living explains that parents are

	al., 2025) (Stensson et al., 2021)	involved in helping and supervising Down syndrome sufferers in maintaining dental and oral hygiene, such as brushing their teeth and giving antiseptic mouthwash.
3.	Socialize and interact without fear regarding dental and oral health (Stensson et al., 2022) (Yehia et al., 2024) (Silva et al., 2020)	Socializing and interacting without fear explains that people with Down syndrome exhibit angry interactions when the other person doesn't understand the direction of the communication because they have difficulty speaking and feel embarrassed. Therefore, when meeting new people, they don't want to interact and tend to be introverted, requiring intensive parental care and supervision as their behavior can change at any time.

Discussion

The role of parents in providing dental and oral health care services related to the dental and oral health issues of people with Down syndrome increases with age, and the need for care also increases. People with Down syndrome show poor DMF-T and OHIS indices, and increased rates of gingivitis and periodontitis. This is related to the intellectual disability experienced and the lack of parental awareness regarding regular dental and oral health checks and care for their children at health services (Elrefadi et al., 2022). In addition, there is still a lack of health facilities in providing optimal dental and oral health services for people with Down syndrome due to the lack of health professionals who deal with people with Down syndrome.

Research result (Stein Duker et al., 2022) In Riyadh, the prevalence of caries and gingivitis is high among the poor, and periodontitis is increasing due to the decreased immune system of people with Down syndrome. This is in line with (Richter et al., 2025) The majority of patients with Down syndrome who come to health services are from low socioeconomic backgrounds and have difficulty accessing health services due to transportation constraints and the distance from their homes to health service centers. Research results (Sosiawan et al., 2022) In Bosnia and Herzegovina, the DMFT and OHI-S indices of Down syndrome patients aged 13-18 years were the highest. However, the results of the OHI-S and DMF-T examinations on all respondents aged 0-18 years divided into three groups showed a discrepancy, with the OHI-S index being in the very good category and the DMFT index in the very poor category. This was because parents knew they would be undergoing a dental examination and tried to provide attention by helping their children brush their teeth (Droubi et al., 2021).

Periodontitis is closely associated with poor dental and oral hygiene. However, maintaining oral health in individuals with Down syndrome requires more than routine tooth brushing and medication. The use of antiseptic mouthwash alone is not sufficient to prevent or manage periodontitis. Comprehensive and consistent care is necessary, including proper tooth brushing techniques, caregiver supervision, and regular professional dental care such as scaling for tartar removal. Individuals with Down syndrome are particularly vulnerable to periodontitis due to immune system deficiencies, which further emphasizes the importance of preventive and supportive care (Stensson et al., 2022). Periodontitis problems increase due to functional issues experienced by people with Down syndrome, such as mouth breathing, impaired tooth eruption, macroglossia, and malocclusion. Research results (Hung et al., 2025) People with Down syndrome in Sweden receive care at both general and specialist dental clinics. However, parents of people with Down syndrome are more satisfied with the care provided by specialist dental clinics because pediatric dentists are more patient and involve their children in every aspect of the treatment process (Silva et al., 2020). In addition, pediatric dentists have more extensive experience and knowledge of the general and dental health of people with Down syndrome. This is in line with research (AlSarheed, 2015) Dental and oral health care for people with Down syndrome requires a good relationship between healthcare professionals, patients, and families, as well as effective communication. Healthcare professionals inform parents about the type of care provided, ensuring parents feel secure.

The role of second parents in training and supporting independent living for Down syndrome sufferers through early prevention such as diligently

brushing teeth in the correct way and at the right time and conducting regular dental and oral health checks at health services so that problems in the oral cavity can be detected early before they get worse.

Research result (Silva et al., 2020) Children with DS at SLB YPAC showed a good OHI-S index of 75% in 9 children, 5 of whom were 11 years old. In addition, 2 children aged 14 and 17 years had a moderate OHI-S index and 1 child aged 15 years had a poor OHI-S index. This is because most parents have helped and taught their children to brush their teeth until their children can do it themselves without assistance, although not yet correctly. This is in line with research (Stensson et al., 2021) that most parents help their children brush their teeth twice a day.

Periodontitis is caused by excessive and uncontrolled presence of pathogenic bacteria in plaque. To reduce plaque levels, antiseptic mouthwash can be used as a preventative measure and to control supragingival plaque formation. As explained by (Schnabl et al., 2025) Recent research has shown that supragingival plaque can influence the growth of subgingival plaque, which harbors pathogenic bacteria, which in turn impacts the health of individuals with Down syndrome. The condition of the oral cavity is exacerbated by the disability experienced. Therefore, to reduce the risk of increasing dental and oral health problems with age, parents must diligently and disciplinedly help and supervise individuals with Down syndrome in brushing their teeth, providing antiseptic mouthwash, and conducting regular dental and oral health checks. As explained by (Yehia et al., 2024) Dental and oral health promotion activities can be carried out using lecture techniques, namely demonstrating to parents how to brush teeth and the importance of maintaining oral hygiene for Down syndrome sufferers as well as educating them about dental and oral health problems that Down syndrome sufferers often experience.

The third role of parents is to accompany people with Down syndrome in socializing and interacting without fear of communication disorders that can lead to unclear speech and difficulty speaking. Furthermore, malocclusion is caused by poor bone growth, orofacial muscle weakness, and an abnormal tongue position (Az Zahra et al., 2021). Malocclusion changes frequently experienced by people with Down syndrome include malocclusion features such as mandibular advancement, anterior open bite, and posterior crossbite due to changes in the dental arch that cause crowding. To facilitate communication with people with Down syndrome during the treatment process, alternative communication methods are needed. This is explained by (Droubi et al., 2021) *Augmentative and Alternative Communication* (AAC) encompasses nonverbal communication strategies that utilize facial expressions, gestures, images, symbols, sounds, and written language. The *tell-show-do* method is used to facilitate understanding of dental and oral health procedures by demonstrating, explaining, and practicing each treatment stage. Therefore, communicating treatment steps to individuals with Down syndrome demands greater time investment and patience from practitioners. Explained by (Richter et al., 2025) People with Down syndrome experience functional limitations that cause difficulty speaking due to having a large, protruding tongue. This can be reduced with age and addressed with a functional therapeutic approach, such as blowing balloons, blowing soap bubbles, and chewing gum, with continued practice, this will appear to decrease (Fageeh et al., 2022).

People with Down syndrome often cry, don't laugh, and become angry when experiencing toothache. This is because they have difficulty verbalizing their symptoms, so parents must be sensitive to sudden emotional changes in their children. This is in line with research (Surija et al., 2024), when a person with Down syndrome experiences pain, they exhibit different moods. They may sometimes cry, indicating they're not feeling well. When they have a toothache, they stop laughing. The parents immediately took their child to a health care facility for a checkup. However, as they were leaving, an argument broke out between the mother and father, who refused to accompany them to the health care facility.

Conclusions and Suggestions

Parental involvement plays a crucial role in maintaining oral health in children with Down syndrome, as parents are responsible for supervising daily oral hygiene practices, facilitating effective communication to understand children's needs, and ensuring access to preventive and professional dental care however, functional limitations, communication barriers, and limited parental knowledge, along with restricted access to oral health services, remain significant challenges that hinder optimal oral health outcomes, highlighting the need for strengthened promotive and preventive strategies targeting both children and their caregivers.

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