

Problems in Maintaining Oral Health in Children with Down Syndrome: A Pilot Study with In-Depth Interview Analysis

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Abstract

A program called the Usaha Kesehatan Gigi Sekolah (UKGS) is used in Indonesia to promote the oral and dental health of schoolchildren. There is no exception for schools that accept students with special needs, including those with Down syndrome (DS).

The aim of study was to identify the issues that DS students in SLB have in maintaining their dental and oral health and to offer solutions. The pilot study involved 9 participants consisting of local UKGS stake holders, parents of DS students and homeroom teachers with three people, respectively. who were randomly selected in Karanganyar Regency, Central Java, Indonesia. Parents and homeroom teachers were interviewed using questions including food consumption, maintaining dental hygiene and improving dental health. UKGS stakeholders were interviewed using questions regarding the implementation of the UKGS program in SLB in their working area.

Based on in-depth interviews, the main problems in maintaining oral health in DS students are uncontrolled consumption of sweet foods and drinks, lack of teeth brushing skills and not seeking help when there is an oral disorder. Education related to these special issues is needed to raise awareness among parents and teachers of students with Down syndrome in SLB.

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Introduction

School children with Down syndrome (DS) have a higher risk of dental caries. Research has shown that maintaining dental health to prevent caries in students with DS is more important than in students without DS.¹ Dental caries is a complex illness, with dietary choices playing a key role in how it starts². A survey conducted among parents of children with DS in Belgium concluded that 66% of their children had had dental treatment in the previous 6 months; however, only 20% of these children were not given specific oral hygiene instructions and brushed their teeth only once a day. Another study revealed that the children with DS had poor oral health due to difficulties in performing dental procedures³.

The main dental problem in children with

DS is malocclusion, which increases the risk of caries and periodontal disease⁴. Orofacial characteristics such as muscle hypotonia¹ can cause hypersalivation and masticatory problems, which occur with the lower levels of oral hygiene. Other influencing factors are the lack of dental care, poor eating habits, drug use and a lack of parental awareness, which all contribute to lower levels of oral hygiene in children with DS⁵.

Students with DS have poorer functional skills than those without DS and have a dependence on caregivers. These poorer functional skills lead to obstacles to performing activities of daily living (ADL)⁶. ADL represents the daily routine activities that healthy children and adults can do without assistance. The inability to perform ADL can lead to unsafe conditions and decreased quality of life. One aspect of ADL is personal hygiene, which is an individual's ability to bathe, toilet and clean themselves, including in relation to oral hygiene, hair and nails⁷. Students with DS are known to be unable to perform dental and oral hygiene; they therefore require special attention and assistance, both from teachers at school and parents at home⁸. In Indonesia, every school is

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responsible for promoting oral health through a programme called Usaha Kesehatan Gigi Sekolah (UKGS). Special schools for children with DS are not exempt. The purpose of this study was to analyse the problems in maintaining the oral health of students with DS in special schools through in-depth interviews with parents, teachers and those involved in UKGS to identify solutions to these problems.

Materials and methods

Participant

Prior to conducting research on a larger scale, a pilot study was conducted through in-depth interviews with a limited number of participants. A pilot study, which is typically a smaller-scale study that aids in planning and modifying the major study, is the initial step of the complete research methodology⁹. This pilot study was conducted at an SLB in Karanganyar Regency, Central Java, Indonesia, in June 2022. There were 9 participants in this study consisting of stake holders from the local UKGS program (three people), parents of DS students (three people) and guardians class (three people) which were randomly selected. All participants gave their consent prior to the interview. Data saturation was achieved by involving these 9 people. Data saturation is one of the principles of qualitative research methodology where data collection is no longer needed considering that information redundancy has already occurred if further data collection is continued. Data saturation also indicates that adequate data collection has been achieved too late¹⁰.

In-depth Interview Structure

Wawancara mendalam kepada orang tua siswa DS dan wali kelas disusun The in-depth interview for the parents of students with DS and homeroom teachers was structured around three themes: food consumption, the maintenance of dental hygiene and actions to improve dental health. The interview had a total of 19 questions (coded as P-Q1 to P-Q19) for the parents (Table 1) and 12 (coded as T-Q1 to T-Q12) for the homeroom teachers (Table 2). Each participant was interviewed separately with no specific duration; the interviews lasted until all the questions had been answered. Each interview was recorded using an audio recorder. Each question under each theme was calibrated and validated through panel discussion under the

principal investigator of the Faculty of Medicine, Universitas Sebelas Maret.

Data Analysis

All interviews were recorded and transcribed verbatim and reviewed by the principal investigator. Subsequently, data reduction, data presentation, data interpretation and conclusions were established (Table 3).

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Code	Question
S-Q1	Has the UKGS program been implemented in special school? <i>Is the implementation routine?</i> <i>What activities are carried out?</i>
S-Q2	What are the obstacles that cause the oral health school program not yet implemented?
S-Q3	What programs have been made to support the maintenance of oral health for DS students?
S-Q4	Has been any training for teachers and parents of DS students on how to maintain oral health?

Table 3. Interview questions for stakeholder.

Results

Participant Information

There were six participants, one man and five women, aged between 30 and 58 years. The details of the participant characteristics are displayed in Table 4.

Group	Code subject	Age (years)	Sex	Education
Parent	P1	51	Male	Bachelor
	P2	31	Female	Junior High School
	P3	52	Female	Senior High School
Teacher	T1	58	Female	Magister
	T2	58	Female	Bachelor
	T3	30	Female	Bachelor
Stake holder	S1	41	Female	Dentist
	S2	51	Female	Dentist
	S3	47	Female	Medical Doctor
M= Male ; F=Female				

Table 4. Subject Characteristics.

Interviews with parents of students with Down syndrome.

Food consumption

Regarding the frequency of sweet food and drink consumption, parents reported that their children liked sweet drinks; if they were denied them, they rebelled. This situation is reflected in the following answer:

"He can drink iced tea four times a day; if I don't comply, I will be beaten" (P-Q1).

In addition, the parents had never received guidance on which foods and drinks affected or damaged dental health:

"I've never had any counselling on foods that are damaging to teeth"(P-Q2)

"counselling about foods that have an effect on teeth doesn't exist"(P-Q5)

The frequency of eating fruits and vegetables was not a problem; the children were given vegetables in every meal. Fruit intake was 3–4 times a week, as long as there were no sour fruits:

"He is most happy when he consumes fruit and vegetables. For any kind of fruit, he doesn't like it if it is as sour as oranges, he doesn't want to eat it" (P-Q3)

"During the meal, my husband and I always eat vegetables" (P-Q4)

"I provide fruit at home 3–4 times a week" (P-Q4)

Maintaining dental hygiene

Maintaining dental hygiene reflected not only the frequency but also the timing of tooth brushing. The parents said that toothbrushing occurred twice a day, both times after bathing:

"She brushes her teeth twice a day, while bathing" (P-Q6, P-Q7 and P-Q8)

Parents also reported that their children were able to brush their teeth, but the techniques used were not correct. It seems that the children only followed direction and did not have a good technique. In addition, when brushing their teeth, they accidentally swallowed toothpaste:

"He can do it, but he only imitates the direction of the toothbrush. I don't know if his teeth are clean or not" (P-Q9)

"She can do it, but it's not perfect. The problem is she sometimes swallows the toothpaste" (P-Q9)

Regarding providing examples of toothbrushing, parents reported that the father set an example while showering:

"Yes, yes....because he took a shower with his father, his father brushed his teeth and then he copied"(P-Q10)

Parents also stated that they had never received education on how to perform toothbrushing properly. In addition, they said that they really needed activities to improve the brushing skills of their children:

"I've never had training on how to do toothbrushing properly, especially for my children" (P-Q11)

"There needs to be an activity that teaches how to do toothbrushing properly with proper techniques for my child" (P-Q12)

Parents reported that their children rinsed their mouths when they had finished consuming sweets and sweet drinks, but they needed to be reminded:

"If he finishes consuming sweets or sweet drinks, he just rinses. But sometimes you have to remind him; if you don't, he often forgets" (P-Q13)

Dental health improvement measure

The third aspect was the use of fluoride toothpaste. Parents reported giving their children fluoride toothpaste despite having never received guidance from the school:

"Yes, we are used to using fluoride toothpaste at home. We have never received counselling on how to choose suitable toothpaste from my son's school" (P-Q14 and P-Q15)

Parents reported that they had never checked their child's oral and dental health and had never received counselling on the importance of the routine control of oral and dental health:

"I have never had my child examined by the dentist or at the health centre" (P-Q16 and P-Q17)

"Never received counselling on the importance of dental and oral health control" (P-Q18)

If their child did not complain of abnormalities in the mouth, they were not examined by the dentist or public health centre.

Tooth decay therefore continued until tooth loss occurred:

"...Once the teeth were left until they turned black. I rubbed them many times, but the black did not disappear. It disappeared about 3 months ago due to the tooth loss". (P-Q19)

Interviews with homeroom teachers

Food consumption

Regarding controlling the consumption of sweet foods, there was no special effort made in schools; schools just reminded the parents:

"..... if it is from the school itself, it cannot be prohibited parents must also tell them not to eat too much chocolate or too many sweets" (T-Q1)

However, teachers encouraged students with DS to like eating fruit and vegetables through classroom education, live demonstrations and showing pictures of types of fruits and vegetables:

"Education is through introducing and showing

pictures of vegetables and fruits. And we tell the student that they should be eaten regularly” (T-Q2)

Maintaining dental hygiene

Teachers monitored the frequency and timing of toothbrushing at a predetermined time, which occurred once a week. Teachers asked students whether they had brushed their teeth after breakfast and before going to bed:

“We don’t yet monitor regularly every day.... However, regarding one particular subject, we usually instruct students to brush their teeth at least twice a day, after breakfast and before going to bed at night. Then we ask one of the students to confirm that they’ve done it” (T-Q3 and T-Q4)

A demonstration of the proper brushing technique had never been performed by teachers:

“We have never performed a demonstration before....” (T-Q5)

Teachers reported that there had been no specific effort to monitor the toothbrushing skills of students with DS. In addition, teachers had never been trained on how to brush teeth correctly, even though it is necessary:

“There is no special programme on oral health that is regularly held by UKGS..... Usually, we look for information on social media or the internet....” (T-Q6)

“Well, we really need an integrated programme to improve toothbrushing skills; this is important because we can't present the information just once or twice, we have to do it many times; but sometimes later they forget....” (T-Q7)

However, teachers reported that they had briefed students on rinsing or toothbrushing after consuming sugary foods and drinks:

“We have also advised children to always rinse their mouths or brush their teeth after eating chocolate, biscuits, cakes... or syrup.....any sweet drinks or food....” (T-Q8)

Dental health improvement measures

Teachers reported that they had never specifically urged parents to use fluoride toothpaste but had always urged them to take care of their children's health. Teachers did not encourage parents to check their children's dental health on a regular basis:

“We urge parents to maintain oral and dental health but do not specifically say to use fluoride toothpaste” (T-Q9)

“We have never urged parents to have their

children's dental health checked regularly” (T-Q10)

The teachers also reported that there were no regular checks of students' oral health, and there had never been an appeal to parents to have their child's oral health checked by a dentist immediately if abnormalities are detected in the mouth:

“There has been no appeal from teachers to parents of students with DS to check children's dental health” (T-Q11 and T-Q12)

Discussion

The results of the study indicate that the problems in maintaining oral health among students with DS lie in the uncontrolled consumption of sugary foods and/or drinks, a lack of toothbrushing skills and not seeking help when abnormalities in the mouth are detected. Problems with the consumption of sweet foods and/or drinks occur because parents cannot control their children's desires, and at school, there is also no particular control of the consumption of sweet foods and/or drinks. The uncontrolled consumption of sweet foods and/or drinks increases the risk of caries in children with DS; therefore, this is a problem that needs to be addressed. This is consistent with the results of research demonstrating that the consumption of sweet foods 3 to 5 times per week puts children at risk of developing dental caries¹¹.

A lack of brushing skills is also a problem in maintaining the dental and oral health of students with DS. This is understandable because these students have poor functional skills, thus allowing for obstacles to arise in ADL⁵. This problem must be overcome because toothbrushing skills are an important factor in maintaining oral health. The lack of toothbrushing skills causes suboptimal plaque removal, thus increasing the risk of dental caries¹².

Another problem is not seeking help from a dentist when a child has a mouth abnormality. Parents said that their children never complained of toothache, and the tooth decay was therefore not checked by a dentist or health centre. As a result, tooth decay continued until tooth loss occurred. This shows the lack of parental attention to the condition of their child's dental and oral health. An examination of a child's oral cavity should be conducted periodically so that any abnormalities can be immediately identified.

Visits to the dentist are aimed at periodically monitoring children's dental and oral health while also reducing the risk of tooth loss caused by caries. Thus, even though the child does not complain of pain, it is necessary to check with a dentist or health centre so that existing abnormalities can be managed promptly and appropriately. This is in accordance with the theory presented by American Academy of Pediatrics (AAP)¹³ that routine dental examinations are important to see the overall development of children's teeth as well as early protection against dental disorders such as cavities, dental caries and gum inflammation. Continuous dental care helps children and adults maintain optimal oral health throughout life.

There are no routine activities that serve to broaden the knowledge of parents and teachers or monitor dental and oral health, which may trigger the occurrence of the aforementioned problems. The poor understanding of parents and teachers of how to maintain the dental and oral health of students with DS has resulted in a lack of attention by parents at home and teachers at school to this issue. This is consistent with research findings that the level of understanding of parents affects the dental and oral health of children with DS. Parents need to be given the necessary training, especially on how to brush teeth correctly. The lack of motor skills in children with DS and the role of parents in training and helping children brush their teeth effectively require special attention¹⁴.

Parents and teachers play a key role in the health behaviour of children, including children with DS. The health behaviour of parents or teachers can influence children's behaviour through predisposing factors, available factors and reinforcing factors. One thing that can be done at the predisposition stage is to increase the understanding of parents and teachers, followed by changing the habits of the role model to suit behaviours involved in maintaining and improving proper oral and dental health behaviours. These activities can guide and improve the dental and oral health behaviour of children with DS¹⁵.

Individuals with DS have poor oral health; therefore, a special programme is needed for them. This is supported by a study by Kencana *et al.*¹⁶ who described the effect after dental and oral health counselling interventions on the brushing skills of children with special needs.

Thus, a regular special programme related to the maintenance of dental and oral health of students with DS in special schools is required involving teachers and parents so that problems can be resolved. The programme can be included in the UKGS programme organised by the regional Department of Health or public health centre. The UKGS programme has been running for a long time, but the target has not been achieved for students with special needs in special schools, including those with DS. With the findings of this study, it is hoped that there will be a special programme designed that can be conducted regularly and continuously with optimal results.

This study was the first stage of the Research and Development (R & D) design which consists of five stages, including Analysis, Design, Development, Implementation and Evaluation. The findings of this study are used as a basis for moving to the second stage, which is the design stage. Based on the results of the problem analysis in the first phase of this research, at the design stage a dental and oral health promotion model will be designed that involves parents and teachers of students with DS. The design of the model will be developed in the third stage, namely development. Testing of the model will be carried out in the fourth stage, namely implementation. Then the test results will be analyzed and evaluated in the fifth stage, namely the evaluation stage. The results of the evaluation are used as a

Basis for repairing and perfecting the model, so that the final result will be obtained in the form of a dental and oral health promotion model that will be used to address problems in the maintenance of dental and oral health for students with DS.

Conclusions

The main problems in maintaining oral health in students with DS are not controlling the consumption of sweet foods and drinks, a lack of toothbrushing and not seeking help when there are mouth abnormalities. Education related to these issues is required to raise awareness and should be provided regularly and continuously to parents and schools.

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Declaration of Interest

The authors declare no conflict of interest.

Domain	Subdomain	Code	Questions	
Food consumption	The frequency of consumption of sweet foods and drinks	P-Q1	Do your children often consume sugary foods and drinks?	
		P-Q2	Have you ever received health education about foods/drinks that can damage your oral health?	
	The frequency of eating fruits and vegetables	P-Q3	Does your child like to eat fruit and vegetables?	
		P-Q4	Do you try to provide fruit and vegetables at home?	
		P-Q5	Have you ever received health education about foods/drinks that support oral dental health?	
Maintaining dental hygiene	The frequency and time of tooth brushing	P-Q6	How often does your child brush their teeth?	
		P-Q7	On a daily basis, when does your child brush his/her teeth?	
		P-Q8	Do you always remind your child when he/she forgets to brush his/her teeth?	
	How to tooth brushing	P-Q9	Can your child brush his/her teeth alone?	
		P-Q10	Have you ever provided an example of toothbrushing to your child?	
		P-Q11	Have you ever received training on how to brush teeth properly?	
		P-Q12	Do you feel the need for an integrated programme to improve the toothbrushing skills of children with DS?	
	Improving dental health	How actions to maintain dental hygiene after consuming sweet foods.	P-Q13	How does your child perform toothbrushing after consuming sweet foods?
			The used of fluoride tooth paste	P-Q14
		The frequency of regular visits to the dentist in a year		P-Q15
P-Q16	Are you diligent in getting your child's dental health checked by a dentist/the public health centre?			
P-Q17	Do you have difficulties in checking your child's dental health?			
Improving dental health	The act of seeking a dentist when there are abnormalities in the mouth.	P-Q18	Have you ever received health education on the importance of routine dental health checks for children with DS?	
		P-Q19	What actions do you take when your child has toothache?	

Table 1. Interview questions for parents of students with Down syndrome.

Domain	Subdomain	Code	Questions
Food consumption	The frequency of consumption of sweet foods and or drinks	T-Q1	What efforts do you make to control the consumption of sweet foods among students with DS?
	The frequency of eating fruits and vegetables	T-Q2	What efforts do you make to encourage students with DS to like eating fruits and vegetables?
	The frequency and time of tooth brushing	T-Q3	What efforts do you make to monitor the time and frequency of toothbrushing on a daily basis among students with DS?
		T-Q4	What efforts do you make to monitor the toothbrushing skills of your students?
		T-Q5	Have you ever demonstrated toothbrushing to your students?
Maintaining dental hygiene	How to performed a tooth brushing	T-Q6	Have you ever received training on how to brush teeth properly?
		T-Q7	Do you feel the need for an integrated programme to improve toothbrushing skills for students?
	How actions to maintain dental hygiene after consuming sweet foods	T-Q8	Have you ever explained to your students how to clean their teeth after consuming sweet foods?
		The used of fluoride tooth paste	T-Q9
Improving dental health	T-Q10		Have you ever asked parents to regularly check their child's dental health?
	The frequency of regular visits to the dentist in a year	T-Q11	Have you ever received health education on the importance of routine dental health checks for children?
	The act of seeking a dentist when there are abnormalities in the mouth	T-Q12	Have you ever asked parents to immediately take their child to the dentist if there are abnormalities in the mouth?

Table 2. The interview questions for homerun teacher.

References

- Ghaith B, Al Halabi M, Khamis A, Kowash M. Oral health status among children with Down syndrome in Dubai, United Arab Emirates. *J Int Soc Prev Community Dent* 2019;9(3):232-239.
- Muzaffar A, Bhat R, Penugonda B, Cardenas MPR, Godder B, Chaudhry A, Vikina, D. Analysis of Dental Caries Experience and Total Sugar Consumption as per the National Health and Nutrition Examination Survey (NHANES). *J Int Dent Med Res* 2022;15(4):1647-1652.
- Stensson M, Norderyd J, Van Riper M, Marks L, Björk M. Parents' perceptions of oral health, general health and dental health care for children with Down syndrome in Sweden. *Acta Odontol Scand*. 2020;79(4):248-255.
- Alexis Díaz-Quevedo A, Maomy Lucero Castillo-Quipe H, Joselyn Atoche-Socola K, Ernesto Arriola-Guillé L. Review Evaluation of the craniofacial and oral characteristics of individuals with Down syndrome: A review of the literature. *J Stomatol Oral Maxillofac Surg*. 2021;122(6):583-587..
- Deps TD, Angelo GL, Martins CC, Paiva SM, Pordeus IA, Borges-Oliveira AC. Association between dental caries and down syndrome: A systematic review and meta-analysis. *PLoS One*. 2015;10(6):1-11.
- da Cruz Netto OL, Rodrigues SCM, de Castro MV, da Silva DP, da Silva RR, de Souza RRB, et al. Memorization of daily routines by children with Down syndrome assisted by a playful virtual environment. *Sci Rep*. 2020;10(1):3144-3161.
- Edemekong PF, Bomgaars DL, Sukmaran S, Schoo C. *Activities of Daily Living*. Treasure Island (FL): StatPearls Publishing; 2022.
- Irwan AA, Triswanti N. Hubungan keterbatasan anak sindrom down dalam menjaga kebersihan gigi mulut dengan terjadinya karies gigi di slb dharma bhakti dharma pertiwi bandar lampung. *J Ilmu Kedokt dan Kesehat*. 2017;4(2):119-128.
- In J. Introduction of a pilot study. *Korean J Anesthesiol*. 2017;70(6):601-605.
- Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant [Internet]*. 2018;52(4):1893-1907.
- Austregésilo SC, de Goes PSA, de Sena Júnior MR, Pazos CTC. Clustering of oral and general health risk behaviors among adolescents. *Prev Med Reports*. 2019;15:1-6.
- Pay MN, Widiati S, Sriyono NW. Identifikasi faktor yang mempengaruhi perilaku anak dalam pemeliharaan kebersihan gigi dan mulut: Studi pada Pusat Pengembangan Anak Agape Sikumana Kota Kupang, Nusa Tenggara Timur, Indonesia. *Maj Kedokt Gigi Indones*. 2017;2(1):27-34.
- American Academy of Pediatrics. Periodicity of examination, preventive dental services, anticipatory guidance/counseling, and oral treatment for infants, children, and adolescents. *The Reference Manual of Pediatric Dentistry*. Illinois: American Academy of Pediatrics; 2022:253-265.
- Sosiawan A, Wahjuningrum DA, Setyowati D, Suhartono M, Audrey NW, Mawantari TP, et al. The relationship between parents' oral hygiene knowledge and children with Down Syndrome's oral hygiene via OHI-S. *F1000Research*. 2022;11:374-389.
- Saskianti T, Dewi AM, Putri NMI, Octafianto A. Parents' Behavior Related to Caries Status of Children with Down Syndrome in Surabaya. *Acta Med Philipp*. 2021;55(8):811-815.
- Kencana IGS, Artawa IMB, Gejir IN. Pengaruh penyuluhan kesehatan gigi terhadap keterampilan menyikat gigi pada anak disabled children di SLB Negeri Tabanan 2021. *J Kesehat Gigi (Dental Heal Journal)*. 2022;9(1):7-15.