



The Development of Psycho-educational Module of Dental Management for Primary Caregivers and Teachers of Autism Children: A Qualitative Study in Special Region of Yogyakarta, Indonesia

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Abstract

BACKGROUND: The prevalence of autism increases globally and in Indonesia. Children with autism experience intellectual, behavioral, and anxiety disorders, including fear of dental care. These children often experience difficulty brushing teeth and are reluctant to visit dental care facilities. The poor oral and dental cleanliness in children with autism may increase the risk of dental and oral diseases such as periodontal disease and caries. One *preventive* effort is providing psycho-education to the child and the people surrounding them (parents or caretaker and teacher). Psycho-education modules should be adequate and based on the client's needs.

AIM: The aim of the study was to explore the contents of the psycho-educational module as a guide for primary caregivers and teachers to prevent dental and oral health problems of the child with autism.

METHODS: We conducted a qualitative study using focus group discussions (FGD) and in-depth interviews from 12 November to 26 December 2020. This study involved 11 primary caregivers and 14 teachers of the autism-special school in Yogyakarta, Indonesia. The FGD and in-depth interviews were recorded and verbatim transcribed and were analyzed by thematic content analysis.

RESULTS: We found three topics required to maintain the dental and oral health of a child with autism, namely: Management of behavior in autistic children, oral-dental treatment, and nutrition management in dental-oral health in autistic children. Available materials used practical and straightforward language.

CONCLUSION: The study findings provide an important information as a new approach contained in the module on maintaining oral health to improve the health status of autistic children.

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Introduction

Autism is a developmental disorder that appears in individuals during the 3 years of life, characterized by difficulties in communicating and interacting and *stereotypical* and *repetitive* activities [1]. The number of autistic children increases and becomes a global health crisis regardless of national, ethnic, or social status every year. One hundred forty four thousand one hundred two have been recorded by The Special School Statistics Data Center in Indonesia as 2019. This number has increased when compared to 2018 which was about 133.826 autistic student had been recorded in Indonesia. The projection of the number of people with autism in Yogyakarta can be seen from the increase in the number of approximately 4–6% each year, and the rate of increase over for 10 years reaches 25% [2].

Children with autism had greater dental need and were more prone to developing dental problem as compared to children in general. This is due to the

limitations that autistic children have [3]. In general, dental and oral health status in autistic children is the same as children and does not show specific dental and oral health problems. The condition that distinguishes it from typical children is their behavior, where autistic children cannot interact and communicate, becoming the biggest obstacle in dental care [3], [4]. Below is a picture of plaque and gingival conditions of autistic children (Figures 1 and 2).

The study results by Naido *et al.* (2018) on 149 autistic children in the South Africa found that the most autistic children have high caries, poor oral hygiene, and all have gingivitis [5]. The results of research by Rachmawati *et al.* (2019) on 35 autistic children at the Autism Special School Branjangan Jember Regency of Indonesia found that the level of oral hygiene was in the moderate category (57.1%) and the prevalence of caries and periodontal disease was 70% [6].

This condition is due to children with autism often consuming sweet and sticky foods. In addition, autistic children tend to eat between meals and



Figure 1: Plaque conditions (autistic children, female, 12 years old)

increase their daily sugar intake (more than two tablespoons) [7], [8], [9]. Autistic children had irregular brushing habits, less able to receive instructions for maintaining oral and dental health from dental health workers, parents or caretakers, and teachers. This is due to the limitations existing in them, such as being unable to clean their oral cavity, thereby increasing the risk factor for damage to the teeth and surrounding soft tissues [5], [10], [11], [12].



Figure 2: Gingival conditions (autistic children, male, 14 years old)

Dental and oral health of autistic children is the responsibility of all relevant parties, including parents or caregivers and also teachers have an important role in maintaining oral and dental health in autistic children [13]. Parents and caregivers are the primary decision-makers in health-care matters for children with special health-care needs; thus, they play a key role in achieving the best oral health outcomes for their children [8].

The involvement of teachers in maintaining oral and dental health in autistic children is very much necessary, considering that teachers are the second parents of children who are in school. Autistic children who attend school need attention from teachers, so teachers need information about maintaining oral health in autistic children to maintain dental health. Parents

or caretakers and teachers should have education and participation in programs about the importance of oral health care, which also affects the general health of their children.

At present, there is no module for primary caregivers and teachers on the maintenance of dental and oral health in autistic children on maintaining dental and oral health in autistic children in Indonesia. It is necessary to develop the module according to the needs to improve the dental and oral health of autistic children. The study aims to explore the contents of the psycho-educational module as a guide for parents or caretakers and teachers to prevent dental and oral health problems of the child with autism.

Methods

Research design

This qualitative research applied the qualitative experimental design to explore the needs of primary caregivers and teachers to identify the materials required in the module to prevent dental and oral health problems in children with autism. The first author, a doctoral candidate in dentistry at Gadjah Mada University, conducted this research. The Research Ethics Commission of the Faculty Dentistry, Gadjah Mada University, Indonesia, approved this study with 00533/KKEP/FKG-UGM/EC/2020 on October 19, 2020. Before focus group discussions and in-depth interviews, written informed consent was obtained from each participant.

Participants and study setting

The research was carried out at the autism-special school of Taruna Alquran in Yogyakarta, Indonesia. The study involved 11 primary caregivers and 14 teachers. The sampling technique in this research is purposive sampling. The inclusion criteria of participants were primary caregivers who took care of autistic children with mild and moderate classifications daily and teachers who taught in autistic classes with mild and moderate classifications. Researchers focus on data saturation and the meaning of the information provided by primary caregivers and teachers related to the purposes of the study.

The participant's characteristic is described in Table 1. Most respondents were female, mostly aged 23–36 years, and had obtained a bachelor's degree.

Data collection

Due to pandemic conditions, data collection was through online meetings. The initial data collection method was Focus Group Discussion (FGD) using a

Table 1: The Characteristic of Participants

Characteristics	Primary caregivers		Teachers		Total	
	n	%	n	%	n	%
Sex						
Female	7	63.64	9	64.28	16	64
Male	4	36.36	5	35.72	9	36
Total	11	100	14	100	25	100
Ages (Years)						
23–36	8	72.72	11	78.57	19	76
37–50	3	27.28	3	21.43	6	24
Total	11	100	14	100	25	100
Educations						
Diploma	4	36.36	0	0	4	16
Bachelor	6	54.54	12	85.72	18	72
Postgraduate	1	9.1	2	14.28	3	12
Total	11	100	14	100	25	100

guide. Data collection started from November 12 to December 26, 2020 by conducting FGD with primary caregivers and teachers. FGD and in-depth interviews were conducted in Indonesian and voice recordings. Each FGD involved 5–6 participants and the research team. The average time of each data collection was 45–60 min, according to the reliable guidelines tested previously [14]. Furthermore, to improve the module, the researchers conducted an expert panel with scientific group participants, namely, dental nursing academics, psychologists, pediatric dentists, and dental therapists.

All authors developed and interview guidelines based on the literature. Three experts of dentists, psychologists, and nutritionists review the interview guidelines. Before being used in the target group, the FGD/in-depth interview guidelines piloting to three primary caregivers and teachers who have one thing in common characteristics with the target group. We raised several questions and identified the proper understanding of the question and investigation for each question.

The following are some sample questions about the material:

1. In your opinion, do you need a module to support dental health for autistic children? Do you have any ideas for what information or materials will be included in the module and what media will you use?
2. Is it necessary for the module to load on how to convey to autistic children about maintaining oral health?

Explanation of the study and informed consent was done before the interview. Participation in this study was voluntary, and participants could refuse to answer questions that they did not want to answer.

Data analysis

The FGD and in-depth interviews were recorded, transcribed, and analyzed using the open code 4 software. One coder generated code categories and all research team members actively participated in categorizing and defining the domains. Initial results were usable to retrieve further data directly. Then, the data collection and examination were under the same steps, as in the initial stage, to produce data saturation

(i.e., no significant variation). Themes were derived from data provided by focus groups and individual interviews.

Trustworthiness

Credibility, dependability, confirmability, and transferability were components of the trustworthiness of this study. Credibility, the principal investigator researcher and the team, reverified the informants to ensure the correctness of the data in the interview guidelines. Dependability was carried out through the research team conducting data inquiries. The researchers verified the research steps starting from the transcribed data, the results of data reduction, and the research process notes. The research team conducted the data analysis. Confirmability has been done by recording data systematically including field notes. Transferability was carried out by ensuring the participant criteria and data saturation.

Ethics

The ethical principles were adopted based on Helsinki's World Medical Declaration. The first principle was respect for the person by fully explaining the research and informed consent to participants. Participants had full rights to accept or refuse to be research respondents. The researcher guaranteed the confidentiality of participant data. The research data would only be known by the research team and stored on a computer that could only be accessed by the research team using a password. This study is safe, does not harm, or poses a physical or psychological threat to participants. All participants are treated fairly; all are treated equally, whether primary caregiver or teachers. This study was received ethical approval number: 00533/KKEP/FKG-UGM/EC/2020 on October 19, 2020.

Results

Main theme

We identified three themes needed in the module on maintaining oral health in children with autism: (1) Management of dental and oral health behavior in autistic children, (2) oral and dental care in autistic children, and (3) nutritional management of dental and oral health in autistic children (Figure 3).

Management of dental and oral health maintenance behavior in autistic children

Triangulation from primary caregivers and teachers showed that the most challenging is managing autism behavior and communicating with the autistic

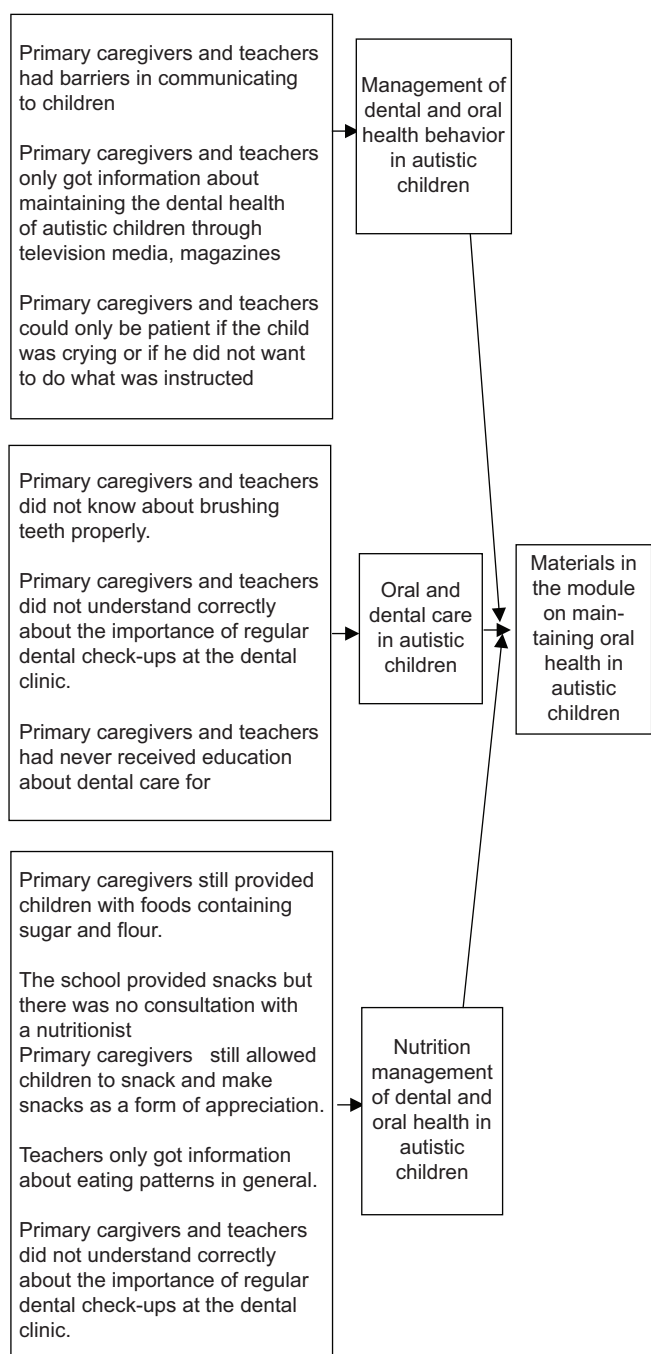


Figure 3: The three themes in the module on maintaining dental health in autistic children

child. They need knowledge and skill in implementing behavior management when carrying out dental care for autistic children. It is required to improve communication and cooperation during dental care. The communication technique chosen is adapted to the child's condition and needs.

Yes, we are very overwhelmed in taking care of children's teeth such as brushing their teeth, children do not want to listen and sometimes I just let them go because I have to take care of other things (FGD; primary caregivers, 35 years old).

It is rather difficult to teach them; you have to be patient and calm. Even though I was tempted to buy

snacks, they still do not want to brush their teeth (FGD; primary caregivers, 32 years old).

I, as a teacher, also feel overwhelmed; moreover, I teach them to brush their teeth only from general information. So it is good if there is a particular module on dental health behavior management. and I think it is beneficial and helps us in teaching how to brush teeth to children (FGD; teacher, 28 years old).

Dental and oral care for autistic children

We also found that teachers and caregivers need information about dental care at home and school. According to them, the limitations of autistic children in caring for their teeth may cause dental health problems so that it can interfere with their activities at home and school.

It is difficult when they have a toothache; I cannot do anything. I do not want to come to the dentist... keep crying and struggling like that. If my child has a toothache, I am stressed (FGD; primary caregivers, 35 years old).

Primary caregivers find it challenging to get information about dental and oral care for autistic children, so it becomes an obstacle or barrier in teaching their children.

I have tried to guide children to brush their teeth as far as I know, but they still brush their teeth as they please... so I really need to be told how to teach them to brush their teeth properly (FGD; primary caregivers, 34 years).

At school, there are tooth brushing activities that are part of self-development lessons. So I only know about the material from that only. there is little information and we have never known about how to maintain dental health in autistic children (FGD; teacher, 42 years).

Nutritional management of dental and oral health in autistic children.

Another theme that arose was the need for nutritional management in autistic children. They believe that regulating an appropriate diet can make autistic children more controlled behavior and dental health.

I have tried to reduce the flour in my child's diet but I cannot eliminate flour because my son really likes to eat flour snacks. I did not give them, but they could buy them at a shop near the house (FGD; primary caregivers, 34 years old).

Especially my son. he likes sweet things, I know it is not good for his teeth, he will cry later he will cry until he gets the desired food if given vegetables he will refuse, I cannot bear to see my child cry (FGD; primary caregivers, 29 year).

However, some primary caregivers give food to autistic children as same as the family menus.

My children eat what we eat like fried chicken, so there is no special food for them. Indeed, I saw that my child had eaten starchy food, so it recurred immediately. (FGD; primary caregivers, 35 years old).

School has provided snacks to children, but the caregivers still give them different snacks. It is challenging to teach children if there is no consistency between teachers and primary caregivers.

The school provides additional food such as cakes that do not contain flour; that is all because, so far, in providing supplementary food to our children, I have not consulted anyone. So, teachers get information about nutrition for autistic children from existing guides such as self-development guides (FGD; teacher, 44 years old).

Sometimes I see that what we teach to children is not in line with what parents apply; I often see parents still providing their children with snacks, chocolate, and cakes made of flour. Therefore, I want teachers and parents to understand eating patterns for autistic children. Be consistent between home and school (FGD; teacher, 35 years old).

Discussion

Information regarding maintaining oral health for autistic children is limited, for caregivers and teachers who provide dental and oral health education. They need a training program to improve their knowledge and skill. Through this training, it is expected that they understand the information clearly and apply it to autistic children to increase the dental health of autistic children [8]. Primary caregivers and teachers identify their preferences and needs for improving knowledge on behavioral management, dental care, and nutritional management of autistic children's dental health.

Most research found that autistic children showed opposing behaviors when receiving dental treatment [15]. Autistic children perceive dental treatment as a threat, so they can be aggressive and look for ways to protect themselves [16]. This behavior is the biggest challenge in caring for autistic children's teeth. This makes dental procedures slow and complex [17].

Similar to the previous study, our primary caregivers do not get children to cooperate in dental care. Participants responses indicated that it was challenging to have their child's teeth checked by a dentist. There have been various efforts, such as promising to give snacks or toys, but their children still refused to check their teeth. To manage the negative behavior of autistic children during dental treatment, specific, techniques, and strategies can be used based

on the psych-educational intervention model aiming at changing behavior and cooperation. The interventions used include health promotion with goals to change behavior, combined with preventive interventions [18].

Dental care for autistic children involves an interdisciplinary approach to improve social communication skills and support primary caregivers and teachers [19]. Providing dental and oral care to autistic children both at school and home requires patience and thoroughness, it is expectable parents or caretakers and teachers can understand the mental condition of children. A good understanding of the behavior of autistic children can help provide dental health care in an empathetic and appropriate way [20].

After receiving the psycho-educational program, parents and teachers are expected to implement dental health care at home and school. It is expected to develop children's habits about basic dental care. Primary caregivers and teachers who receive training programs showed an increasing knowledge, attitudes, and behavior. They were able to apply them to their children so that it is expectable that the children's dental health status will improve [21].

Our study found that primary caregivers and teachers do not know dental care for autistic children. They do not know how to brush their teeth properly and there still many of them who do not bring their children to do regular dental check-ups at dental health facilities. They need training on dental and oral care to increase knowledge, attitudes, and behavior and apply it to their children. Hence, it is expectable that the dental health status of autistic children will improve.

This is consistent with the results of Murshid's (2014) study of 450 parents of autistic children in Riyadh Saudi, which it has been founded that there are only a view number of parents who received direct oral hygiene instructions from dentists, and even fewer of parents received information from other sources, such as brochures and other media [15].

Parents also reported difficulties in brushing the teeth of the autistic children due the sensory sensitivities of their children, and the unpredictable-sometimes aggressive-behavior that may require physical restraints [22], [23]. Parents of children with autistic are as such subject to physical, financial, and psychological burdens. Time pressures, greater necessity for parenting, increased investment in healthcare, and scarcity of medical aid coverage collectively may result in more fatigue, stress, and anxiety among autistic parents [24]. On the other hand, children with autistic are dependent mainly on their parents for their daily needs, dietary choices, and general and oral hygiene [25].

The role of primary caregivers and teachers is very important, so they should be given education about maintaining dental hygiene and good dietary practices for children with autism. Knowledge of the risk factors

that will occur if they ignore dental and oral hygiene will increase their responsibility for the children's dental and oral health [8], [26].

Our study also found that primary caregivers and teachers did not know clearly about healthy eating patterns for autistic children yet. They still give their children food containing flour, sugar, and sweets a snack or form of appreciation. It indicates that parents or caretakers do not provide special food to their children, the food eaten is the same as other family menus. According to the teachers, primary caregivers still provide their children with sweet and sticky snacks at school.

The food for autistic children is generally the same as food for other normal children, which must meet balanced nutrition and still have to pay attention to aspects of food selection. The diet generally applied to children with autism is a gluten-free and casein-free diet. Controlling eating patterns in autistic children are not only important from a behavioral aspect but are also very important for dental health [27], [28]. According to the primary caregivers and teachers, it is necessary to provide information or guidance on choosing the right food for autistic children so that they are consistent in their implementation and do not confuse children.

That in a program aiming at increasing children's independence, it is necessary to involve aspects of collaboration or communication between parents or caretakers, and teachers. Communication will allow consistency between stimulation at home and school. In addition, teachers' support can help, motivate, or assist children in achieving appropriate behavior [29].

Research strengths and limitations

This study has some strengths in the form of interview guidelines that have been compiled by the team based on the literature and have been reviewed by scientific experts, namely, dentists, psychologists, and nutritionists so that their validity can be recognized. In addition, the interview guide was piloted to groups that have the same characteristics as the target group.

However, this research also has limitations. Due to the pandemic conditions, researchers could not directly do the FGD and in-depth interviews, so it was conducted through online platform, by expecting the process will be going well without any network disturbances.

Conclusions

Primary caregivers and teachers do not understand correctly about maintaining the dental

health of autistic children yet. Primary caregivers or teachers need a psycho-education program using a dental health maintenance module with material based on needs, namely, behavioral management, oral care, and nutritional management of dental and oral health for autistic children. It is expectable that, through the psycho-education program, primary caregivers and teachers can improve knowledge, attitudes, and implement dental health of autistic children at home and school to reach degree of dental and oral health of autistic children.

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