Autism Spectrum Disorder and Oral Healthcare: A Qualitative Study of Parents' Perspectives in Padang City, Indonesia

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ABSTRACT

Background: *Children with autism spectrum disorder, particularly those with mental and behavioral impairments, are affected regarding their oral health and impact their quality of life. Furthermore, perceptions of parents are also important in assessing the planning appropriate oral healthcare. The purpose of this study was to explore parent's perspectives regarding barriers oral healthcare, tooth brushing behavior and the recommendation strategies to improve oral health status among individual with ASD in Padang city, Indonesia.*

Method: *A purposive sample of six parents in public autism care centre in Padang city participated in focus groups addressing barriers maintain oral healthcare. Focus groups were transcribed and coded using qualitative content analysis. Primary themes included barriers oral healthcare, toothbrushing behavior and recommendations to improve oral healthcare. Content analysis was performed using NVivo software.*

Result: *Parents noted barriers conducted oral hygiene such as drooling, tongue thrust and hard to focus relatively. Mothers noted general improvements in awareness of control diet and have used several media to help their children understand how to brush their teeth properly. Knowledge gaps included until when parents should help children brush their teeth and special oral healthcare. They expect that in the future, the government more attention to oral health of individuals with special needs. The role of the general dentist is crucial, and they expect the dentist to be more patient when caring with patients with special needs.*

Conclusion: *Our findings indicate a need for comprehensive educational intervention and improved communication from policy maker, dentist, public health and prevention leaders in oral health care and dental hygienists to increase oral healthcare knowledge and practice of parents with ASD to better quality of life..*

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INTRODUCTION

ASD have quite high prevalence, with ASD found 1:50 in school age children 1. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria of people with ASD have communication deficits, may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items. Several ASD individuals showing mild symptoms and others have severe symptoms. The symptoms of ASD show from early childhood2 such as social communicative deficits, difficulties with social interaction and transitioning between activities3,4.

Individuals with ASD who have mental and behavioral impairments similarly impact their oral health. In general, individual with ASD significantly poorer oral hygiene and gingival condition than healthy5. However, the most prevalent oral health problems are caries6, 7 and periodontal disease8. Suhaib's study shows greater caries among ASD people than their siblings9. In contrast, another study show ASD children had fewer caries experiences than general health children10. Periodontal disease reported a high prevalence11, one study indicates the prevalence of caries among ASD children was 69.4% 12.

The oral health condition is made worse with a bad dietary habit, less frequency of tooth brushing and need assistance for tooth brushing. The high rate of sweets intake causes greater caries as well as ASD people. Most ASD children less frequent brushing of teeth in the mornings8 and used toothpaste13. In individuals with ASD could fail to do adequate teeth brushing independently be present main risk factor increase caries9.

Individuals with ASD experience significantly more health problems than the general population. An exploration the causes of oral healthcare problems and how to improve oral health status among children with ASD based on parent's perspectives is important to determine the proper oral health promotion. This qualitative study explores barriers oral healthcare, tooth brushing behavior and the recommendation strategies to improve oral health status among individual with ASD in Padang city, Indonesia.

RESEARCH METHOD

This study utilized qualitative approach with focus group discussion to explore parent's perspectives regarding oral healthcare, tooth brushing behavior and the recommendation strategies to improve oral health status among individual with ASD in Padang city, Indonesia. Semi-structured focus groups were conducted to engage participants in in-depth discussion of their perceptions, knowledge, and habits.

The study used the interpretivist paradigm in which the development of a meaningful understanding of reality is the result of a dialogue between researchers and their subjects. The interviews were conducted by the first author and a research assistant, who both have a background in public health, are fluent in the local language, and have lived in the area. The interviews were conducted in the local language or a combination of the local language and Indonesian. The study area was comprehensively explored to enhance validity. Triangulation of data collection methods was conducted through in-depth interviews to achieve a more complete understanding. To enrich the data, consider combining focus groups with individual interviews.

The study received ethical approval from the Andalas University of Padang, (No. 014/KEP/FK/2019). Written informed consent was obtained from the parents who were willing to join this study. The ASD parents recruited a purposive sample of 6 mothers of ASD children in the Autism Care Centre of Padang city to participate in semi-structured focus group. The focus group discussions took approximately 60 minutes.

The data analysis has been conducted precisely, consistently, and exhaustively. This involved recording, systematizing, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible. A common approach to conducting thematic analysis involves a six-step process: familiarization, coding, generating themes, reviewing themes, defining, and naming themes, and writing up.

The responses of participants to focus group questions were categorized in accordance with the focus group interview guide. Using codes, emergent themes within the data were found. Each topic generated thematic categories, and all participant replies were considered thematic elements. The frequency of comments citing a given thematic element was used to determine the themes. NVivo, a computerized qualitative informatics application, was used to conduct content analysis.

RESULTS

The study consisted of a set of semi-structured interviews with 6 ASD mothers were conducted to explore the Parents' perspectives regarding barriers oral healthcare, tooth brushing behavior and the recommendation strategies to improve oral health status among individual with ASD in Padang city, Indonesia. Parents with ASD chidren talked special needs children difficult to brush their teeth properly due to some reasons involved parafunctional habit (tongue thrust), hard to focus relatively and dependent toothbrushing behavior. Most parents accompanied their children to brush their teeth and demonstrated how to brush

properly and did at least twice a day, in the morning and evening or before sleep.

Table 1. Overview of Parents' Perspectives

Categories	Subthemes	Examples of parents speaking
Difficulty Tooth brushing	Parafunctional habit	" Brushing too hard due to loss of sensibility around the lips and face, and trouble swallowing are typical symptoms of drooling. Also, tongue thrust habit".
	Trouble focusing	"My child appears erratic in their ability to follow directions".
	Dependent toothbrushing	"Twice a day, in the morning and evening did toothbrushing with parent"
Barriers to Oral Healthcare	Limited knowledge	"I have limitation knowledge regarding toothbrushing properly for children with autism"
	Behavioral constraints	"To open the mouth of an Autism child is not easy."
		"My child has a tendency towards repetitive actions and hyperactive behaviour."
Recommendation to improve oral health status	Special education program	"It should be more community educative program especially in children with special needs because parents still lack knowledge about oral health.
	Special Training for Dentist	"Not all dentists are patient with Autism children. In the future, it is expected that there will be a lot of dentists who will be able to care for patients with special needs. "

ASD parents have a high awareness of controlled diet or food consumption due to their children being sensitive while consuming gluten. Therefore, their parents carefully with their children food consumed. In the other hand, several ASD parents have limited knowledge regarding how to maintain oral hygiene

specifically for children with autism and need to improve. ASD parents tried to use several media to help their children understand how to brush their teeth properly with video and pictures, but unsuccessful. Parents accompanied children with autism to visit the dentist in emergency conditions only when their children were in pain. The reasons were their children have behavior constraints such as difficult open mouth, repetitive behavior and some children have hyperactive tendencies.

Parents are dissatisfied with present oral health policies for children with special needs. They propose a combined oral health teaching and practice approach for individuals with special needs. The program would benefit from engaging media education. They also propose educating those parents with special needs on how to enhance oral hygiene properly. They expect that in the future, the policy maker, dentist, public health and prevention leaders in oral health care and dental hygienists more attention to oral health of individuals with special needs. In addition, they expect the dentist to be more patient when caring with patients with special needs.

DISCUSSION

ASD parent talked special needs children difficult to brush their teeth properly due to some reasons involved drooling, tongue thrust and hard to focus relatively. Similarly, El Khatib et al (2014) study showed children with ASD more uncooperative behavior than healthy children14. Oral sensitivity was substantially related to home toothbrushing participation15. Previous study showed seventy-nine percent of parents did not feel adequately informed about the various oral hygiene prevention techniques for their ASD children and desired education on the daily management of oral hygiene16. The parents understand the contributions of enhanced dexterity to their child's oral health for increased opportunities for their child to learn about becoming more independent17. The awareness produce creativity such as modifications handle length and size of toothbrush18.

The case-control study's result that ASD children's sugar intake is comparable to that of general children is encouraging. Although caries history and caries status were comparable in children with and without ASD, 67.6% of children with ASD had caries19. This should be cause for concern, especially considering how difficult it is to treat children with ASD with dental care. Most special need children never visited a dentist. The majority of special needs children reported visit dental professional rarely20. These problems caused by negative behavior of special needs patient, lack of the dentist's knowledge and skill regarding special need dentistry, difficulty access to the dental clinic, inflexible admission procedures and financial problem21-23. The dentist should improve special skills involved in behavior management and treating children with special needs care. Professional collaboration necessary proactive to educate and train parents/caregiver maintains their child oral hygiene properly.

Overall, oral health status among individuals with ASD in Padang city has worse problems. Several factors were found to have played a prominent role in oral health status children with ASD. Dental health preventive approaches such as use fluoride in toothpaste above 1000 ppm helps to remineralize the tooth24. Fluoride water and fluoride salt can be a useful oral health policy for government to support. In addition, toothpaste, vanish and pit and fissure sealant are also very important in preventive dentistry.

This study offers valuable insights into parental perspectives on oral healthcare for children with ASD. However, the generalizability of these findings may be limited due to certain methodological

factors. Firstly, the small sample size of 6, although typical of qualitative studies, makes it difficult to explore how education, background, or socioeconomic status might affect these findings. Additionally, as is common with qualitative studies, the small sample size means the findings may not be representative of all autistic parents. There may also be a recruitment bias, as participants in the discussion groups were volunteers. It could be argued that individuals who are better at coping are more likely to volunteer to speak about their experience. Therefore, we may not gain an accurate perspective of the full scope.

Parents expect for the future, government and related professional have attention to general health and dental health individuals with special needs. The parents also need oral health education for ASD children. General dentist role is very important, they expect the dentist more patient when handling special needs people. Health policies regarding special needs dentistry very needed and hope existence special need dentist in Indonesia.

CONCLUSION

The application of qualitative research techniques allowed us to understand the oral healthcare experiences of parent with ASD children and explore the barriers maintain oral healthcare, toothbrushing behavior and recommendations to improve oral healthcare. It is essential that dental professionals understand parents' experiences to enable them to have a positive influence on their behavior and provide oral healthcare plans for children with ASD. In addition, policy maker, dentist, public health and prevention leaders in oral health care and dental hygienists important to support awareness, knowledge and practice oral healthcare especially among parents with ASD children.

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