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Round 1

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Submission accepted.

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The authors studied the barriers to oral healthcare experienced by caregivers living with intellectual disability. This paper explored the barriers of oral healthcare by caregivers in institutionalized intellectual disability using qualitative study.

To publication in Journal of Dentomaxillofacial Science , manuscript need some scientific modification as below.

Thank you! We found your valuable feedback on our manuscript and we have followed your suggestions.

1. In the Introduction, the author stated the importance of oral health care among intellectual disability. However the author why the ID people had poor oral condition.

Thank you! We found your valuable feedback on our manuscript and we have added the information and reference of the reason of poor oral hygiene among ID people

2. In the Data Analysis. The author did not mention the qualitative study of data analysis software that they used for analysis

Thank you for your valuable feedback. We have added the NVIVO 12.0 program that we used for analysis

3. In the Results. The authors only mention one and two quotations from the interviewee. Please add more quotations in each themes.

Thank you for catching this. We have followed your suggestion and changes have been made accordingly.

4. In the Discussion. The authors did not explain the oral problems among ID people.

Thank for your valuable feedback. We have followed your suggestion and changes have been made accordingly.

5. Please state that “The authors report no conflict of interest”.

We found your valuable feedback on our manuscript and we have added in the Conflict of Interest before references.

6. Please add some references related to oral problems among ID people

Thank your valuable feedback

Exploring Barriers to Oral Healthcare Experienced by Caregivers Living with Intellectual Disability: A Qualitative Study

Abstract

Objective: People with intellectual disability often have poor oral health, which can negatively impact their quality of life. It has been unclear which barriers that contributes to this, especially among institutionalized intellectual disability in Padang city. This qualitative study explores the underlying barriers to oral healthcare from the perspective of the caregivers as well as people who living with them.

Material and Methods: Qualitative exploration was undertaken using in-depth interviews with caregivers in the public intellectual disability institution, Padang city. Data were collected from three caregivers. Thematic analysis identified key themes to explore in depth of the barrier oral healthcare among individuals with ID used N-vivo software.

Results: Both individual and caregiver barriers to oral healthcare are offered to people with intellectual disability. These barriers include severity disorder, lack of focus and uncontrolled dietary intake. Caregivers lack knowledge and information regarding their rights to oral healthcare for individuals with special needs, the imbalance ratio caregiver and financial problem were also barriers.

Conclusion: Individuals with ID face several barriers in maintain oral hygiene such as severity of disorder, the lack of attention, imbalance ratio of caregivers and children, dietary intake, oral health education of caregivers, and financial problems.

Keywords: intellectual disability, oral healthcare, caregiver, qualitative study

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Introduction

Most common developmental disability is an intellectual disability (ID), affecting 1-3% of the population¹. Intellectual disability is a mental disorder that impacts adaptive functioning in the conceptual domain, social domain, and practical domain². Intellectual disability begins during the developmental period, chronic and often co-occurs with other mental conditions such as attention-deficit/hyperactivity disorder, depression, and autism spectrum disorder³.

Functional disabilities of ID children have an impact on their daily living hygiene individuals especially in oral hygiene. In addition, mental deficiency causes the deficiencies in chewing or swallowing, a longer time of the mastication process could be too poor for the bolus to be mixed with saliva. As a consequence, the food was refused and the collection of more debris accumulation compared normal children. Previous study show individual with ID have poorer in oral hygiene and periodontal conditions than the general population^{4, 5}. Most prevalence of oral problems in mentally retarded subjects with 49.6% dental caries, 39.1% poor oral hygiene status and 31.6% periodontal disease⁶. The risk of oral health problems is higher in people with intellectual disabilities. Previous study revealed that institutionalized ID individuals in Padang City had significantly lower OHIs, dental malocclusion, higher caries, more

periodontal disease, and a greater demand for dental care⁷.

Frequent uncooperativeness of ID children presents a further challenge for normal dental treatment procedures⁸ and parent's ID is mostly low income and did not afford access to dental care. Level of income as a financial barrier to access dental care and lack of parental awareness is a major contributory factor for low dental coverage⁹.

One of an easy and efficient solution for reducing oral health problem through daily tooth brushing effectively. Tooth brushing more than once a day or once a day had significantly lower caries indices. The caregivers of ID people whose genuine interest in dental health would help the subjects to proximal tooth cleaning. Tooth brushing ability is one aspect of adaptive behavior needed extraordinary awareness intended for parents or caregivers^{10, 11}.

Few studies explanation about oral health problems among ID children in Indonesia. Important for exploration barriers to oral healthcare experienced by caregivers living with ID children in the sole institution of Padang, West Sumatra as a foundation for raising this population's oral healthcare.

Material and Methods

The present study presents findings from a qualitative approach of the barriers for institutionalized individuals with ID to maintain oral healthcare, as well as care caregiver's perspectives. The research ethics of the Faculty of Medicine, Andalas University approval for the research under ethical consideration with the approved number of 014/KEP/FK/2019. Prior to taking part in the study, each research subject supplied written informed consent.

A targeted recruitment through purposive sampling, three caregivers of ID have eligibility criteria participate in in dept interviews. The inclusion criteria are ID caregivers have worse oral hygiene and tooth brushing behavior inappropriately. The exclusion criteria are caregivers who refuse to join this study. Semi-structured interviews with ID caregivers to explore in depth of the barrier oral healthcare, to identify recommendations and strategies for improving oral health status among individual with ID.

Data Analysis

All interview was carried out in Bahasa and recorded on audio. Thematic analysis was the method chosen by the researchers to find, examine, and report themes. The researchers reviewed the recurring themes that emerged from the individual interviews frequently throughout the data collection procedure. Following the completion of the data collection, the two researchers (VN and AB), working independently, listened to and read each transcript to become familiar with the information. We also checked for recurrent themes and created preliminary codebooks manually and using the NVIVO 12.0 program. The topics were discussed by the researchers, who then combined comparable ideas while removes or recoding others after building agreement. This made it possible to fit a final codebook to the data. NVIVO 12 was used to generate the categories and sub codes.

Results

Theme 1: Identity characteristics personal and related factors causes several individuals with ID do not conduct to brushing teeth properly.

Institutionalized ID caregivers described their children difficult to brush teeth properly due to slow response to receiving the instructions. Several children did toothbrushing only once a day. The caregivers did not toothbrushing control every day. They said a lack of attention did their

teeth as a result of the imbalance ratio of caregivers and children (1:13). A caregiver participant answered:

“Difficult to focus one by one because there are not enough caregivers to take care all children”

This perspective was extended by another caregivers:

“Hard to instruction the right way to brush their teeth with step by step”

When caregivers talked about why they use a manual toothbrush, manual toothbrush reasons were very common and tended to be associated with cheap and easy to find. Some ID children have motoric limitation. The caregivers described never use and didn't know about an adaptive toothbrush for individual with specific limitation. As expressed by a caregiver:

“Only use a manual toothbrush. Some children toothbrushing dependently due to motoric limitation”

Theme 2: Caregivers experiences regarding maintain oral hygiene for ID people

The caregivers did diet control or food consumed among Institutionalized ID children. Unfortunately, many visitors give bread, chocolate products and other snacks to ID children directly. This situation cannot be prohibited. Unfortunately, the caregivers have basic information related to how to brush teeth properly. They knew the frequency of toothbrushing is twice a day brushing and toothbrushing with brushing all surfaces of the teeth. The caregivers also educated their children with simulation step by step and did brush teeth together. There are not media or inadequate facility to improve knowledge and skill, particularly in oral health. ID caregivers reminded individual with Institutionalized ID to do toothbrushing two times while taking a bath in the morning and evening. The caregivers said that never carried individuals with ID to a dentist because financial problem. One caregiver conveyed:

“We have poor knowledge related how to improve toothbrushing skills specifically for children with mental retardation, so we need it”

Another caregiver extended on this:

“Education about how to maintain the dental health of children with special needs, especially in with mental disabilities is very needed”

Theme 3: Caregiver's perspectives to improve oral hygiene for ID people

In general, caregivers unsatisfied with current health policies regarding oral health for special needs. They suggest to oral health education and practice program for individuals with special needs simultaneously. The program will be better with interesting media education. They also recommend teaching media focuses on how to improve oral hygiene and do brush teeth properly for the individual with special needs, especially in mental retardation people.

They expect for future, government, and related professional care more to general health and dental health individuals with special needs. General dentist role is very important, they expect the dentist more patient when handling special needs people. The parents also need oral health education for special needs children. Health policies regarding special needs dentistry very needed and hope existence special need dentist in Indonesia. As reported from a caregiver:

“Unsatisfied, because there is no priority promotion, education and practice program dental health in children with special needs”

One caregiver conveyed:

“Not yet satisfied, because there aren’t program and dental health services especially for mentally disabled children”

Discussion

Based on the interview, ID caregivers described their children difficult to brush teeth properly due to slow response to receiving the instructions, lower awareness caregivers (imbalance ratio between caregivers and children) and didn't visit a dentist regularly cause the financial problem and subjective reason that no dental complaint from their children. These results were similar with recent studies that showed worse oral health status in individuals with special needs and control group may due to limited access to dental care, lower awareness of oral health care and lack of special needs dentistry training^{12, 13}.

In addition, mental deficiency causes the deficiencies in chewing or swallowing, a longer time of the mastication process could be too poor for the bolus to be mixed with saliva. Thereby, the bolus could not reach the optimal plasticity for a "safe swallow. Consequently, the food was refused and the collection of higher debris accumulation in the oral cavity. Calculus was present for 71% of adults, 10% covering more than a third of the surface of the worst tooth in adult ID. Mental retardation also showed the enamel defects, as we know that enamel has a protective role, thereby loss of enamel exposes is generally unable to recover. In addition, ID people have significantly increased odds for poor chewing, belching while eating, constipation, habitually protruding tongue, bad breath, tooth grinding, food spilling while eating, and sleeping with their mouth open aggravated severity of the poor oral hygiene. Accumulation of plaque, debris and calculus impact to the periodontal lesion¹³⁻¹⁶. In contrary, other studies found the lower prevalence of caries due to higher *S. mutans* -specific IgA concentrations, although did not adequately explain the causal relationship and individuals with DS are more likely to get dental care annually in some country¹⁷.

Dietary habits in sweets intake as the risk factors related to caries teeth of children with IDs. The high presence of caries on children has a significant association with consumed sugary liquids during main meals. Mild/moderate disabilities children more consume sweets than severe or profound disabilities children^{15, 18}. Bakry and Alaki study (2012) informed a significant association between soft diet intake and caries rate ($p = 0.001$) in children with ID subjects¹⁹.

The severity of individuals with ID an essential risk factor in influencing caries rates. Children with severe disability had significantly more caries rates due to low physical abilities in toothbrushing, prolonged retention of food in the oral cavity and uncooperative dental procedures. Some mild severity of IDs children does toothbrushing independently without modification toothbrush handle side. Several individuals those moderate severity of IDs need toothbrush modified to perform daily toothbrushing activity. Individuals with cerebral palsy have specific motor skills problems, hence inadequate toothbrushing properly²⁰. Toothbrushing activity in severe cases of IDs necessary assistance by their caregivers. Brushing skill methods should according to the severity type and child characteristics of disability. The lack of chewing ability in some individuals with ID causes prolonged retention of food in the oral cavity and impact high number of caries status.²¹

Another study similar to our finding that high dental treatment need, especially untreated decay (more than 70%)²². The problem to dental treatment is uncooperativeness of ID presents a further challenge for normal dental treatment procedures and a financial barrier to access dental care. The oral health status of people with intellectual disabilities has an association with poverty. Filling teeth were not found because of financial reason. Parent's ID is mostly low income and did not affordable access to dental care. Level of income as a financial barrier to access dental care and lack of parental awareness is a major contributory factor for low dental coverage^{9, 23}. Untreated caries became a premature loss of the deciduous tooth. Pratap et al in 2016 found ID

people have more missing, misaligned teeth and often affected with malocclusion. The previous investigation was successful in establishing the effect of the premature loss of deciduous tooth on the malocclusion of the permanent tooth⁴.

Finally, an oral health problem in institutionalized living ID causes by multifactorial such as the personal characteristics (level of disability), oral biological factors, caregivers dental awareness, diet control, behavior disorders, oral health education for parents/caregivers, financial problems and general dentist awareness. The cost of services and inflexible admission procedures also problems from the dental professional's perception^{24, 25}.

Caregivers suggest to oral health education and practice program for individuals with special needs simultaneously. The program will be better with interesting media education. They also recommend teaching media focuses on how to improve oral hygiene and do brush teeth properly for the individual with special needs²⁶.

Conclusion

ID caregivers defined several barriers to maintain oral healthcare due to multifactorial issues such as the severity of disorder, the lack of attention, imbalance ratio of caregivers and children, dietary intake, oral health education of caregivers, and financial problems.

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