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RECEIVED 01 May 2024

ACCEPTED 24 October 2024

PUBLISHED 13 November 2024

## CITATION

Alshatrat SM, Al-Omari WM, Tabnjh AK,  
Al-Bakri IA and Selvaraj S (2024) A case-  
control study on oral health knowledge and  
dental behavior among individuals with  
developmental delays in Jordan: caregiver  
perspective.  
Front. Dent. Med 5:1426568.  
doi: 10.3389/fdmed.2024.1426568

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# A case-control study on oral health knowledge and dental behavior among individuals with developmental delays in Jordan: caregiver perspective

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**Aim:** the aim of this study is to assess oral health knowledge and dental behavior among individuals with developmental delays intellectual and developmental disabilities (IDD) in comparison with individuals without (IDD) in Jordan.

**Methods:** A case-control study was conducted among 317 caregivers of individuals with IDD ( $n = 168$ ) and control ( $n = 149$ ) groups, which involved the completion of the questionnaire. A closed-ended, validated self-designed questionnaire was distributed. The questionnaire included questions addressing participants' oral health knowledge and behavior. Convenience sampling was used to select the caregivers from centers associated with IDD by collecting data from nearby locations. Using SPSS<sup>®</sup> software Version 22 with a 0.05 level of significance data were analyzed. A Chi-square test and contingency-table analysis were performed on the data.

**Results:** Caregivers for individuals with IDD in Jordan were less knowledgeable about different oral health aspects than control group ( $P$  value  $< 0.05$ ). Fewer individuals in the IDD caregiver group brushed their teeth once or twice daily (83.2%), compared to the control group (93.3%). Only 22.6% of the IDD participants could brush their teeth without assistance. On the other hand, the IDD group consumed significantly less sugary foods and soda than the control group ( $P$  value  $< 0.05$ ).

**Conclusion:** The lack of knowledge among IDD caregivers in Jordan is critical which can result in poor oral health outcomes for this vulnerable population. Increasing the knowledge level for the IDD caregivers on the specific needs for IDD individuals is highly important to enhance their understanding of oral health and improve their quality of life. Caregivers with IDD should receive training programs given by oral health professionals about the need for regular dental check-up and effective oral hygiene care reduce the risk of having dental problems and oral disease.

## KEYWORDS

oral care, dental behavior, oral health knowledge, intellectual and developmental disabilities, special need

## 1 Introduction

Oral health has a large impact on general health and oral health-related quality of life. Most oral diseases are preventable or reduced by good oral hygiene techniques, healthy diet, and effective treatment options (1–3). Good oral health may reduce the risk of oral complications for healthy and special need individuals, such as intellectual and developmental disabilities.

Intellectual and developmental disabilities refer to a delay that affects more than one developmental area, such as social/personal, gross/fine motor, speech/language, cognitive, or daily living tasks (4). There are three categories of developmental delay: mild (functional age is less than 33% of chronological age), moderate (34%–66% of chronological age), and severe (functional age is less than 66% of chronological age) (5).

Health disparities between persons with intellectual and developmental disabilities (IDD) and those without IDD, according to recent research (6–8). People with IDD have worse oral health than those without, according to studies, which raises serious concerns about their oral health (9, 10). Additionally, a comprehensive analysis by Anders and Davis (9) has explicitly demonstrated that, in contrast to those without IDD, those with IDD had a greater frequency of periodontal disease and neglected dental caries. Recent studies have shown that poor dental health can have serious consequences for overall health, including strong correlations with aspiration pneumonia and major chronic illnesses such as diabetes, stroke respiratory disease and cardiovascular disease (11–17).

A person's psychological and social wellbeing are significantly impacted by their oral health. For instance, poor dental health can result in toothaches, the anxiety that goes along with them, trouble carrying out daily tasks, poorer social relations, and decreased nutrient intake (18–24). Cognitive impairments are the most common impairment among young people (25). Autism, intellectual disability, anoxic brain damage, stroke, and post-traumatic injury that causes learning problems are a few examples of cognitive disorders (24). One in six children in the US (from 2009 to 2017) between the ages of 3 and 17 were found to have developmental problems, a rise from prior years (24, 26–28).

Disorders that have a detrimental effect on a person's physical, intellectual, and emotional development are known as intellectual and developmental disabilities (IDD). All racial, ethnic, and socioeconomic groups are susceptible to these disorders occurring *in utero*. They can also develop after birth because of trauma, illness, or other environmental factors (29).

Individuals with IDD usually have complicated oral health needs owing to congenital and developmental defects that may be further affected by behavior patterns and communication challenges (9). Patients with IDD require more time, patience, understanding of dental health, training in home care, and general caregivers' abilities than patients without ID (30).

In addition to the absence of fundamental information about oral health and poor training, frequently describe a lack of time and recalcitrant patients as challenges to delivering oral hygiene treatment to people with IDD (31). The purpose of this study

was to measure the oral health knowledge and dental behavior among individuals with developmental delays in Jordan. Regular preventative dental treatment is crucial to preserving excellent oral health since people with disabilities are more susceptible to oral illnesses owing to underlying congenital defects and an inability to get the necessary care to preserve oral health which can be achieved by assessing the level of knowledge and behavior and instilling when its lacking. Therefore, the purpose of this study is to evaluate dental knowledge and behavior among people with developmental disabilities.

## 2 Materials and methods

This study was conducted in accordance with the World Medical Association Declaration of Helsinki (32). To answer the study objectives, a self-designed questionnaire was used in this study. The questionnaire was formulated in the official Jordanian language; the Arabic language. Back translation was conducted to ensure accuracy and consistency of the questionnaire. The Expert panel of two professional colleagues established the content validity of the questionnaire, and the Average Congruency Percentage (ACP) was 92% indicating acceptable application for the questionnaire in this study. The reliability of this study (test-retest) was achieved by administering the questionnaire twice to the same participants ( $n = 10$ ). Cronbach's alpha was used to test the internal reliability of this questionnaire. The coefficient of Cronbach's alpha was 0.75 indicating the items have acceptable internal consistency. A pilot study was made by giving the questionnaire to ten volunteers of caregivers of individuals with IDD to answer the questionnaire on behalf of individuals with IDD and provide feedback on the questionnaire clarity, content, and format, during meeting at the IDD'S centers. The participants of the pilot study were not included in the study. The caregiver comments were taken into consideration for the final study. The Sample Size Calculator software was used in this study and the sample size calculations provided with a confidence level of 95%, a margin of error of 5%.

Three sections were included in the questionnaire: First section consisted of items covered demographic information (5 items), Second section included items covered information about participant's oral-health knowledge (12 items), and the third section included items covered participant's dental behavior (7 items). The degree of disability severity for the participants was provided by the principal of the center which obtained from the participant's record.

A list of the different areas in Jordan was obtained from the Ministry of Social Development contains list of centers associated with IDD. The centers who agreed to participate in the study were included. Convenience sampling was used for this study by collecting data from nearby locations. The researcher visited the centers who are willing to participate and asked to circulate the questionnaire to their members to answer the questions on respondent's behalf. A paper format of the questionnaire was available in these centers with a cover letter that explaining the purpose of the study. A full confidentiality of the obtained data

was ensured and the participation of the study was voluntary. Regarding the control group, it was composed of individuals without developmental delay from the same geographic location of the centers who agreed to participate in the study by collecting data from nearby locations such as, schools, mall, and parks. After one to three weeks, the questionnaire was collected. A reminder note was sent for those who had not responded to encourage them to reply. the deadline was set for receiving the questionnaires after six weeks from the initial sending. The number of the questionnaires were sent to all individuals with developmental delay was 200, out of which 168 questionnaires were filled and sent back. However, 149 filled questionnaires from the control group were sent back out of 200 that were sent.

All the data were reported in group form. The software package, SPSS Version 23, was used to analyze the data with a 0.05 level of significance. A chi-square test and contingency table analysis were performed on the data.

### 3 Results

The final sample sizes for IDD and control groups were ( $n = 168$ ) and ( $n = 149$ ), respectively. Data showed that 11.3% of individuals with IDD had a mild disability, 33.9% had a moderate disability, and 54.8% had a severe disability. The average age of the total sample was 37 years. Table 1 provides detailed information regarding the socio-demographic characteristics of participants with IDD and control group.

Concerning the responses of the participants to oral-health knowledge, caregivers for individuals with IDD scored significantly lower than the control group on the majority of

items ( $P$  value < 0.05). However, there was no discernible difference in the responses to the questions about plaque, the cause of caries, sugars, and their relationships to general health ( $P$  value > 0.05). Table 2 displays information regarding oral

TABLE 2 Oral health knowledge among individuals with developmental delay compared to the control group.

Questions	Developmental delay <i>n</i> (%)	Control <i>n</i> (%)	<i>P</i> -value
<b>1. Dental plaque is formed by colonizing bacteria</b>			
Yes	99 (58.9%)	90 (60.4%)	0.188
No	12 (7.1%)	4 (2.7%)	
Don't Know	57 (33.9%)	55 (36.9%)	
<b>2. Dental caries mainly caused by the bacteria</b>			
Yes	119 (70.8%)	117 (79.1%)	0.157
No	23 (13.7%)	18 (12.2%)	
Don't Know	26 (15.5%)	13 (8.8%)	
<b>3. Having sugars can lead to dental caries</b>			
Yes	148 (88.6%)	140 (94.0%)	0.109
No	12 (7.2%)	8 (5.4%)	
Don't Know	7 (4.2%)	1 (0.7%)	
<b>4. Having soft drinks affect dental health</b>			
Yes	142 (85.0%)	141 (94.6%)	<b>0.017*</b>
No	12 (7.2%)	5 (3.4%)	
Don't Know	13 (7.8%)	3 (2.0%)	
<b>5. Is there any relationship between oral health and overall health?</b>			
Yes	127 (76.5%)	125 (83.9%)	0.096
No	17 (10.2%)	15 (10.1%)	
Don't Know	22 (13.3%)	9 (6.0%)	
<b>6. It is normal for your gum to bleed during brushing</b>			
Yes	80 (47.9%)	31 (20.8%)	<b>0.001*</b>
No	76 (45.5%)	112 (75.2%)	
Don't Know	11 (6.6%)	6 (4.0%)	
<b>7. It is normal for your gum to be red</b>			
Yes	78 (46.4%)	49 (32.9%)	<b>0.026*</b>
No	75 (44.6%)	89 (59.7%)	
Don't Know	15 (8.9%)	11 (7.4%)	
<b>8. It is normal for your gum to be swelling</b>			
Yes	38 (22.6%)	5 (3.4%)	<b>0.001*</b>
No	119 (70.8%)	139 (93.3%)	
Don't Know	11 (6.5%)	5 (3.4%)	
<b>9. Brushing teeth regularly protects your teeth</b>			
Yes	145 (86.3%)	142 (95.3%)	<b>0.012*</b>
No	13 (7.7%)	6 (4.0%)	
Don't Know	10 (6.0%)	1 (0.7%)	
<b>10. You need to visit a dentist only when you have a toothache</b>			
Yes	86 (51.2%)	32 (21.5%)	<b>0.001*</b>
No	71 (42.23%)	116 (77.9%)	
Don't Know	11 (6.5%)	1 (0.7%)	
<b>11. You need a hard toothbrush to clean your teeth</b>			
Yes	62 (36.9%)	7 (4.7%)	<b>0.001*</b>
No	95 (56.5%)	136 (91.3%)	
Don't Know	11 (6.5%)	6 (4.0%)	
<b>12. Dental floss is necessary to keep your teeth clean</b>			
Yes	87 (52.1%)	113 (75.8%)	<b>0.001*</b>
No	57 (34.1%)	20 (13.4%)	
Don't Know	23 (13.8%)	16 (10.7%)	

\*Significant result,  $P < .05$ .

TABLE 1 Socio-demographic characteristics of participants with developmental delay and control group.

Characteristics	Developmental delay <i>n</i> (%)	Control <i>n</i> (%)
<b>Gender</b>		
Male	103 (61.3%)	100 (67.1%)
Female	65 (38.7%)	49 (32.9%)
<b>Age</b>		
<18	32 (19%)	97 (65%)
18–40	95 (56.5%)	37 (25%)
>40	41 (24.5%)	15 (10%)
<b>Education</b>		
Elementary	152 (91%)	132 (88.6%)
Middle school	9 (5.4%)	17 (11.4%)
High school	4 (2.4%)	0 (0%)
Collage and more	2 (1.2%)	0 (0%)
<b>Family Income (JD)</b>		
<250	143 (85.1%)	2 (1.3%)
250–500	4 (2.4%)	70 (47.0%)
500–1,000	1 (9.5%)	64 (43.0%)
>1,000	20 (11.9%)	13 (8.7%)
<b>Insurance</b>		
Yes	138 (82.6%)	100 (67.1%)
No	29 (17.4%)	49 (32.9%)

health knowledge among individuals with IDD compared to the control group.

The results of the participant’s dental behavior indicated that fewer individuals in the IDD group brushed their teeth once or twice daily (83.2%), compared to the control group (93.3%) (*P* value < 0.05). Only 22.6% of the participants with IDD were capable of brushing their teeth without assistance, in contrast to the control group’s 100%. In addition, the control group uses more fluoridated toothpaste than those with IDD (*P* value < 0.001). In contrast, the IDD group consumed significantly less sugary foods (*P* value < 0.05) and soda (*P* value < 0.001) than the control group. However, there was no significant difference between groups regarding the use of dental floss or the frequency of using mouthwash (*P* value > 0.05). Table 3 displays the participants’ responses to questions regarding dental behavior.

### 4 Discussion

Global Developmental delays (GDD) were reported with a prevalence between 1%–3% in children under the age of five, thus considered one of the most common conditions encountered in the pediatric clinics, with most common underlying causes linked to structural or genetic brain

abnormalities (33). Recent study in Jordan, reported that the genetic causes were predominant with only 28% of the patients diagnosed with global developmental delay/intellectual disability were associated with metabolic disorders (34). However, investigations yielded broad estimates for IDD, partly attributed to variations in patient populations and diagnostic methods (35). Nevertheless, recent advancement in technology enabled more accurate diagnosis. Although, some studies reported that the causes of one-third of the cases of developmental or cognitive delay can be identified by history and examination only (4), it is of paramount importance that proper diagnosis of the GDD be established at early stage to define appropriate intervention strategies. This may prevent further invasive tests and ensures better overall outcome for both the patients and the carers (36). To our knowledge, no previous data have been tracked about the prevalence of GDD amongst Jordanian population, neither about oral health knowledge and practice among affected patients, which makes the current study a pioneering investigation about this subgroup of the population. Furthermore, Jordan does not have national database regarding developmental delays or disabilities, which makes this study particularly important.

The findings of the current study unequivocally demonstrated significant differences between the subjects with IDD and the healthy individuals regarding oral health knowledge. The delayed growth group showed lower level of knowledge in the majority of the investigated domains. Despite the fact that IDD group demonstrated comparable knowledge about the correlation between bacteria, and caries, and that both groups were aware of the significance of oral health to general health, developmental delay group had obvious deficits in knowledge concerning the association between consumption of soft drinks and oral health. Additionally, the delayed growth group could not relate the bleeding, swelling and color of gingiva to the existence of a disease. Besides, responses regarding tooth brushing frequency, consistency of tooth brush and the importance of dental flossing for good oral health were more appropriately answered by the healthy control group.

Moreover, majority of the delayed growth group also believed that visiting dentist is necessary only at the incidence of a toothache. This may lead to progression of existing oral diseases to advanced state and consequently may reduce the effectiveness of any preventive measures taken to retard the initiation of the diseases.

Apparently, the inadequate oral health knowledge amongst individuals with delayed growth disorders were partly reflected in their dental behavior, as frequency of tooth brushing was more commonly practiced by healthy individuals. However, although minority of growth delay group individuals brushed their teeth unassisted, the majority (83.3%) brushed their teeth once or twice daily. This may be attributed to lack of individuals with delayed growth the necessary manual dexterity or lack of appropriate training to brush their teeth independently (37), though showed high degree of commitment and support provided by their caregivers. This is contrary to previous study where 90% of intellectually delayed patients brushed their teeth by themselves (37). Moreover, it was noteworthy to find out that

TABLE 3 Dental behavior among individuals with developmental delay compared to the control group.

Variable	Developmental delay	Control	<i>P</i> -Value
How often do you brush?			<b>0.018*</b>
Once or more	139 (83.2%)	139 (93.3%)	
Occasionally	28 (16.8%)	10 (6.6%)	
Ability to brush			<b>0.001*</b>
Completely without help	38 (22.6%)	149 (100%)	
Completely with help	130 (77.3%)	0 (0%)	
How often do you floss your teeth?			0.530
Once or more a day	23 (13.7%)	25 (16.8%)	
Occasionally	144 (85.7%)	124 (83.2%)	
How often do use mouth-rinse?			0.456
Once or more a day	39 (23.2%)	40 (26.8%)	
Occasionally	129 (76.8%)	109 (73.2%)	
Do you use fluoridated toothpaste?			<b>0.001*</b>
Yes	83 (49.4%)	113 (75.8%)	
No	33 (19.6%)	6 (4.0%)	
Don’t know	52 (31.0%)	30 (20.1%)	
Frequency of eating sweets			<b>0.011*</b>
Once or more a day	139 (82.7%)	141 (94.6%)	
Occasionally	17 (17.3%)	8 (5.4%)	
Frequency of drinking soda/day			<b>0.001*</b>
1–2 cans	106 (63.1%)	147 (98.7%)	
3–4 cans	60 (35.7%)	2 (1.3%)	
None	2 (1.2%)	0 (0%)	

\*Significant result, *P* < .05.

the growth delay individuals consumed sweets less frequently compared to their healthy peers. Their dietary habits could have been most likely modulated by their caregivers in an attempt to reduce the incidence of dental caries and the resultant need for treatment that imposes extra health care burden. Correlation between sugar and dental decay is well documented and disseminated oral health information (38). Surprisingly, despite the growth delay individual's knowledge about correlation between consumption of soda and dental health was not fully established, their consumption was less frequent compared to healthy individuals. This behavior may have also been controlled by caregivers and indicates satisfactory level of awareness regarding drawbacks of fizzy drinks. However, knowledge and practice do not always interrelate (38) and knowledge alone does not appear to adequately motivate desired oral health behavior. Similar contradiction between knowledge and practice was observed regarding tooth flossing. Although, oral health knowledge of growth delay individuals was inadequate, but practicing of tooth flossing was comparable to their healthy counterparts (39).

Previous literature clearly reported that children, adolescents and adults with IDD experienced poorer oral health, including more tooth loss, more severe periodontal diseases, and higher caries incidence with a lower rate of restorative care, as compared to the general population (9, 18, 24). This poorer oral health provides strong indicator on the extent of oral health inequality of IDD group compared to general population (24). Provided that oral diseases are largely preventable; this could also reflect the extent of the current health care (40). Therefore, oral health inequality gap can be significantly reduced by improving the care and providing more support and education (40).

The current study suggests that delayed growth individuals and their caregivers had inappropriate oral health knowledge and this may partially explain their poor oral health behaviors compared to healthy individuals. Lack of appropriate knowledge can lead to increased risk for oral diseases (41, 42). Inadequate oral health knowledge was considered the main risk factor for dental caries development among Saudi children aged-10–14 years (41). Besides, oral health behaviors were also correlated with oral health knowledge, therefore, it was concluded that promoting oral health knowledge is crucial for improving oral health behaviors (42). Furthermore, poor quality of life was directly associated with oral diseases in IDD group (18, 19), and oral health knowledge was found to indirectly affect the oral health related quality of life (43).

The literature lacks adequate information about the oral health knowledge and oral behaviors of the IDD individuals. The current study agrees with previous study in which adolescents with mild or border line intellectual disabilities found to visit the dentist less regularly and brush less frequently (44). The IDD group also reported using unfluoridated tooth paste less than healthy controls (38). Likewise, they showed higher rate of untreated decay and more microcavitated lesions than their peers from the general population (44). These lesions, in the absence of health-promoting behaviors such as less frequent brushing, use of

unfluoridated tooth paste and inability to brush teeth appropriately unassisted, are more likely to progress to advanced lesions, especially in the absence of good oral-health knowledge as demonstrated in the current study. It is believed that oral-health knowledge supplemented by oral health behaviors may prevent the progression of oral diseases and prevent the onset of these oral diseases, thus improving the quality of life (41, 42).

Gingival and periodontal diseases were the most commonly reported in IDD people (45). Needless to say, there are abundance of literature to associate periodontal inflammation with serious systemic illnesses which represent a considerable oral as well as systemic health burden (46). This subgroup of population represents a high-risk category due to frequently reported poor plaque control that predisposes to oral diseases (47). Therefore, instilling oral health knowledge and enforcing appropriate oral hygiene practices are of utmost importance. The awareness and training concerning the consequences of oral diseases have to be enhanced for caregivers, professionals and oral health services providers for adults suffering from intellectual and growth delay (48). Adopting holistic patient-centered approach in undergraduate and postgraduate curriculum was also recommended (49).

Although the current study employed reliable questionnaire, it could have been further enriched if data were obtained from direct interviews with the caregivers. Also, recruited participants were institutionalized and not residing at home under their caregiver's direct care, thus comparison between the institutionalized and home residing individuals with IDD was not possible. Furthermore, the views presented are mostly those of the caregivers not of the individuals with delayed growth. Further research is warranted to explore the views of the affected individuals themselves and the correlation between level of knowledge and the status of oral health. Another limitation can be the unmatched gender distribution of the participants recruited in the study. Hence comparison based on gender could be of minimum strength. Previous studies demonstrated gender based differences (50, 51). Notwithstanding these limitations, to our knowledge this is the first research that reports on the oral health knowledge and oral health behavior among people with IDD in Jordan.

## Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding authors.

## Ethics statement

The studies involving humans were approved by Jordan University of Science and Technology. The studies were conducted in accordance with the local legislation and

institutional requirements. The participants provided their written informed consent to participate in this study.

## Author contributions

SA: Conceptualization, Data curation, Funding acquisition, Investigation, Project administration, Resources, Supervision, Writing – original draft, Writing – review & editing. WA-O: Writing – original draft, Writing – review & editing. AT: Formal Analysis, Software, Supervision, Writing – original draft, Writing – review & editing. IA-B: Writing – original draft, Writing – review & editing. SS: Writing – original draft, Writing – review & editing.

## Funding

The author(s) declare financial support was received for the research, authorship, and/or publication of this article. This research was funded by Jordan University of Science and Technology Research Grant No: 20170032.

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## Acknowledgments

We acknowledge the Deanship of Research at JUST for funding the research (Grant number 20170032).

## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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