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Oral hygiene habits, perceived barriers, and burden reported by caregivers of children and adolescents with disabilities

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ABSTRACT

Objetive: To determine oral hygiene habits, barriers, and burden reported by caregivers of children and adolescents with disabilities (CAD) in Talca, Chile. **Materials and methods:** A cross-sectional study was applied to caregivers of this vulnerable population. Children and adolescents were characterized using sociodemographic variables, diagnosis, and a degree of functional dependence, and their caregivers were characterized based on sociodemographic variables. Oral hygiene habits of CAD were determined along with the barriers faced by caregivers when maintaining oral hygiene on CAD and the burden reported by caregivers. **Results:** Out of 62 caregivers, 93.5% reported that CAD performed oral hygiene practices, either with or without assistance or supervision from the caregiver. Additionally, 91.4% used a manual toothbrush; 94.8% used toothpaste; 84.4% did not use dental floss; 84.5% did not use mouthwash; 50.0% brushed twice a day; and 75.7% of caregivers assisted CAD with their oral hygiene practices. Regarding barriers, 60.0% found it difficult to access all the areas of the CAD›s mouth, and 49.1% identified anxiety in the child as a challenge during oral hygiene. Finally, 53.2% of caregivers experienced severe overload. **Conclusions:** Most caregivers reported that CAD engaged in oral hygiene practices and received assistance. They even reported that they faced barriers to performing children›s oral hygiene and that they were severely overloaded.

Keywords: oral hygiene; dental care for people with disabilities; caregiver burden; caregivers.

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INTRODUCTION

Disability and functional dependence in a child or adolescent with disability (CAD) can affect daily activities including oral hygiene. According to the United Nations Children's Fund (UNICEF) (1), globally, one in ten children and adolescents aged 0 to 17 years has some form of disability. In Chile, according to the Third National Disability Study (ENDISC III), 14.7% of children and adolescents aged 2 to 17 years have a disability; 37.2% have a permanent and/or long-term condition—most commonly psychosocial, mental, or intellectual difficulties—, and 25.7% require assistance (2).

The caregiver is the person who provides continuous support at home and in daily activities to a person with disability, either voluntarily or in a paid role, and may or may not be a family member (3). This role entails both objective and subjective effects on the caregiver's life, collectively referred to as caregiver burden. A higher level of burden may lead to deterioration in both mental and physical health (4-6). In this context, performing oral hygiene for a CAD can represent a significant challenge for the caregiver. In this regard, studies have described caregivers' perceptions of this experience, identifying both facilitators and barriers (7).

Moreover, oral hygiene and oral health among people with disabilities are poorer than the general population (8-11). Therefore, the degree of the CAD dependence, the barriers faced by caregivers when performing oral hygiene, and the caregiver's burden may all influence the dental cleaning experience. Understanding these factors could help generate evidence that enables dentists treating CAD to better recognize and empathize with the realities of caregivers and their living contexts. This awareness should be incorporated when designing oral health promotion strategies for CAD to support the maintenance of their oral health and quality of life, while also facilitating and improving the effectiveness of caregivers' work and reducing their burden.

Accordingly, the aim of this study was to determine oral hygiene habits, perceived barriers, and burden reported by caregivers of CAD in Talca, Chile.

MATERIALS AND METHODS

A descriptive cross-sectional study was conducted. The study population consisted of caregivers of CADs enrolled in institutions for persons with disabilities in Talca, Chile, between August 2021 and July 2022. All institutions in Talca serving CADs aged 2 to 17 years were invited to participate; there were 14 institutions according to data provided by the Office for Disability of the Municipality of Talca and the National Disability Service (SENADIS) of the Maule region, Chile. Of these, only five agreed to participate. Subsequently, all caregivers from these institutions were invited to take part (n = 164). Inclusion criteria were as follows: agreeing to participate; being adult caregivers (≥18 years old) of CADs aged 2 to 17 years; being primary and informal caregivers; and belonging to institutions for persons with disabilities that had agreed to participate in the study. The exclusion criterion was having difficulties understanding or answering the questions in the data collection instruments. The final sample comprised 62 caregivers.

Three questionnaires specifically designed for this study and two validated scales were used as data collection instruments. A pilot test was conducted to assess question comprehension and the time required for completion among caregivers of CADs. The first questionnaire was designed to characterize caregivers using sociodemographic variables (sex, categorized age, relationship to the CAD, educational level, health insurance, occupation, allowance for caregiver role, place of residence, number of household members, and oral hygiene training). For CAD characterization, sociodemographic variables (categorized age and sex) and diagnosis were also recorded. The second questionnaire assessed CAD's oral hygiene habits (use of toothbrush, type of toothbrush, use of toothpaste, dental floss, mouthwash, gauze, or other oral hygiene elements, as well as frequency and timing of brushing, type of assistance during oral hygiene, and supervision). The third questionnaire assessed caregivers' perceived barriers to performing oral hygiene for CAD (19 Likert-scale questions, one open-ended question, and one ordinal question).

Regarding validated scales, the first was the Barthel Index, used to assess CAD functional dependence. It evaluates ten activities of daily living, classifying the degree of dependence as total (<20 points), severe (20-35 points), moderate (40-55 points), mild (≥60 points), or independent (100 points). This scale demonstrates good interobserver reliability, with Kappa coefficients ranging from 0.47 to 1.00; and intraobserver reliability ranging from 0.84 to 0.97. In terms of validity, it is a good predictor of mortality insofar as it measures disability, and both are strongly correlated; moreover, it is related to the response to rehabilitation treatments, where patients with a lower degree of disability show a better response to rehabilitation (12).

The second validated scale used to evaluate caregiver burden was the Zarit Burden Interview, which contains 22 Likert-type questions. Its results are summed, classifying the caregiver into the following categories: no burden (≤46 points), mild burden (47-55 points), and severe burden (≥56 points). The scale shows high interobserver reliability, with an intraclass correlation coefficient of 0.71 in its original study, and between 0.71 and 0.85 in international validations; furthermore, it shows high face, content, and construct validity across different linguistic adaptations; and, regarding criterion validity, it shows a high correlation with similar instruments (13).

The data were obtained through the application of the instruments to the caregivers. To achieve this, an appropriate schedule was coordinated for each caregiver, and they were contacted by telephone due to the COVID-19 pandemic. Data were analyzed using descriptive statistics, with summary measures: mean ± standard deviation (SD) for quantitative variables, and absolute and relative frequencies for qualitative variables. In relation to the open-ended question about barriers, answers were grouped and presented using absolute and relative frequencies. Furthermore, the SPSS program version 28 was used.

The study was approved by the Scientific Ethics Committee of the Faculty of Dentistry at Universidad de Concepción (No. 08/21), Chile. Likewise, informed consent was obtained from the patients.

RESULTS

According to the caregivers' sociodemographic characteristics, 58.1% (n = 36) were aged 30–44 years; 91.9% (n = 57) were women; 90.3% (n = 56) were the mothers of the CADs themselves; 37.1% (n = 23) had completed university-level higher education; and 56.5% (n = 35) had received oral hygiene training from a dentist (Table 1).

Table 1. Sociodemographic characteristics of caregivers of children and adolescents with disabilities.

Variable	n	%
Sex		
Female	57	91.9
Male	5	8.1
Categorized age		
22-29 years	2	3.2
30-44 years	36	58.1
45-59 years	23	37.1
60-61 years	1	1.6
Relationship		
Mother	56	90.3
Father	5	8.1
Grandmother	1	1.6
Educational level		
Incomplete primary education	1	1.6
Complete primary education	6	9.7
Complete secondary education	15	24.2
Complete technical higher education	13	21.0
Complete university education	23	37.1
Complete postgraduate education	4	6.5
Health insurance		
Fonasa (National Health Fund)	40	64.5
Isapre (Private Health Insurance Institutions)	13	21.0
Armed Forces	3	4.8
None	6	9.7
Occupation		
Homemaker	25	40.3
Works outside the home	26	41.9
Works from home	11	17.7
Caregiver allowance		
No	62	100.0
Yes	0	0.0
Place of residence		
At home	62	100.0
Number of household members		
Two	8	12.9
Three	14	22.6
Four	25	40.3
Five	7	11.3
Six	7	11.3
Seven	1	1.6
Oral hygiene training		
Self-acquired knowledge	24	38.7
Dentist	35	56.5
Other	3	4.8

Regarding the sociodemographic characteristics, diagnosis, and CADs functional dependence level, 37.1% (n = 23) were aged 6-12 years, 32.3% (n = 20) were 13-17 years old, and 30.6% (n = 19) were 2-5 years old. Likewise, 74.2% (n = 46) were male; 61.2% (n = 38) had autism spectrum disorder according to caregiver reports; and 53.2% (n = 33) presented mild functional dependency (Table 2).

Table 2. Sociodemographic characteristics, diagnosis, children and adolescents with disabilities functional dependence level.

Variable	n	%
Sex		
Female	16	25.8
Male	46	74.2
Categorized age		
2-5 years	19	30.6
6-12 years	23	37.1
13-17 years	20	32.3
Diagnosis[1]		
Autism spectrum disorder	38	61.2
Down syndrome	15	24.1
Other conditions	9	14.7
Level of functional dependency[2]		
Independent	7	11.3
Mild	33	53.2
Moderate	18	29.0
Severe	0	0.0
Total	4	6.5

[1] Diagnosis reported by caregivers.
[2] According to the Barthel Index.

On the other hand, 93.5% (n = 58) of caregivers reported that CADs practiced oral hygiene, either with or without caregiver assistance or supervision. Among them, 91.4% (n = 53) used a manual toothbrush, 50.0% (n = 29) brushed twice a day, and 43.1% (n = 25) received total assistance with oral hygiene from their caregivers (Table 3).

Table 3. Oral hygiene habits of children and adolescents with disabilities.

Variables	n	%
Oral hygiene practices[1]		
Yes	58	93.5
No	4	6.5
Toothbrush use[2]		
Yes	58	100.0
No	0	0.0
Type of toothbrush[2]		
Electric	4	6.9
Manual	53	91.4
Triple-head	1	1.7
Toothpaste use[2]		
Yes	55	94.8
No	3	5.2
Dental floss use[2]		
Yes	9	15.5
No	49	84.4
Mouthwash use[2]		
Yes	9	15.5
No	49	84.5
Gauze use[2]		
Yes	1	1.7
No	57	98.3
Other[2]		
Yes	1	1.7
No	57	98.3
Brushing frequency[2]		
Less than once a day	2	3.4
Once a day	8	13.8
Twice a day	29	50.0
Three times a day	18	31.0
More than three times a day	1	1.7
Brushing after breakfast[2]		
Yes	42	72.4
No	16	27.6
Brushing after lunch[2]		
Yes	25	43.1
No	33	56.9
Brushing at night[2]		
Yes	56	96.6
No	2	3.4
Other brushing time[2]		
Yes	12	20.7
No	46	79.3
Specific other brushing times[3]		
After the afternoon snack	4	33.3
Before going out	3	25.0
At school	2	16.7
Between meals	2	16.7
Before breakfast and the afternoon snack	1	8.3
Type of assistance in oral hygiene[2]		
Partial	19	32.6
Total	25	43.1
None	14	24.1
Supervision during oral hygiene[2]		
Yes	8	13.8
No	50	86.2

[1] Percentage based on the total sample of caregivers (n = 62).
[2] Percentage based on CADs who practiced oral hygiene (n = 58).
[3] Percentages calculated based on the 12 CADs who brushed at another time.

Table 4. Caregiver barriers to performing oral hygiene for children and adolescents with disabilities.

Barriers	n	Category										Mean ± SD
		Never		Almost never		Sometimes		Almost always		Always		
		n	%	n	%	n	%	n	%	n	%	
1. Do you consider that you have difficulties or barriers to performing oral hygiene for the CAD?	62	13	21.0	4	6.5	16	25.8	10	16.1	19	30.6	3.3 ± 1.5
2. Is it difficult for you to find time to perform oral hygiene for the CAD?	61	36	59.0	0	0.0	16	26.2	5	8.2	4	6.6	2.0 ± 1.3
3. Is it difficult for you to have a comfortable space to perform oral hygiene for the CAD?	62	55	88.7	0	0.0	2	3.2	2	3.2	3	4.8	1.4 ± 1.0
4. Is it difficult for you to have the financial resources to acquire the necessary items for the CAD's oral hygiene?	62	51	82.3	0	0.0	9	14.5	0	0.0	2	3.2	1.4 ± 1.0
5. Do you experience any negative emotions when performing oral hygiene for the CAD, such as discomfort, tension, overwhelm, or fear?	62	33	53.2	1	1.6	16	25.8	2	3.2	10	16.1	2.3 ± 1.5
6. If you are alone, is it difficult for you to perform oral hygiene for the CAD?	57	43	75.4	0	0.0	4	7.0	2	3.5	8	14.5	1.8 ± 1.5
7. If you need help, do you have the assistance of another person during the CAD's oral hygiene?	56	21	37.5	1	1.8	5	8.9	1	1.8	28	50.0	3.3 ± 1.9
8. Is it difficult for you to obtain the CAD's cooperation during oral hygiene?	56	14	25.0	2	3.6	19	33.9	5	8.9	16	28.6	3.1 ± 1.5
9. Is it difficult for you to perform oral hygiene for the CAD when he/she becomes anxious or nervous?	57	12	21.1	1	1.8	11	19.3	5	8.8	28	49.1	3.6 ± 1.6
10. Is it difficult for you to get the CAD to follow your instructions during oral hygiene?	57	22	38.6	0	0.0	17	29.8	4	7.0	14	24.6	2.8 ± 2.6
11. Is it difficult for you to keep the CAD's head steady while performing oral hygiene?	56	34	60.7	1	1.8	10	17.9	3	5.4	8	14.3	2.1 ± 1.5
12. Is it difficult for you to open the CAD's mouth when performing oral hygiene?	55	31	56.4	0	0.0	14	25.5	5	9.1	5	9.1	2.1 ± 1.4
13. Does the CAD feel uncomfortable when you place any oral hygiene element in their mouth?	61	31	50.8	1	1.6	13	21.3	6	9.8	10	16.4	2.4 ± 1.6
14. Does the CAD feel uncomfortable with the flavors, smells, or textures of oral hygiene elements (toothpaste, mouthwash, toothbrush, others)?	61	36	59.0	2	3.3	10	16.4	2	3.3	11	18.0	2.2 ± 1.6
15. Does the CAD bite any of the elements used during oral hygiene (toothbrush, finger brush, gauze, floss applicator, others)?	62	22	35.5	3	4.8	9	14.5	6	9.7	22	35.5	3 ± 1.7
16. Does the CAD bite you during oral hygiene?	57	51	89.5	1	1.8	2	3.5	2	3.5	1	1.8	1.3 ± 0.8
17. Does the CAD hit you during oral hygiene?	57	46	80.7	3	5.3	6	10.5	1	1.8	1	1.8	1.4 ± 0.9
18. Is it difficult for you to access all areas of the CAD's mouth when performing oral hygiene?	55	8	14.5	0	0.0	9	16.4	5	9.1	33	60.0	4 ± 1.5
19. Do you consider it important to perform oral hygiene for the CAD?	62	0	0.0	0	0.0	0	0.0	0	0.0	62	100.0	5.0 ± 0.0

CAD: child or adolescent with disability.

Regarding caregivers' barriers to performing oral hygiene for CADs, analysis of the mean score for each item showed that all caregivers (n = 62) considered it important to perform oral hygiene for CADs (item 19); 85.5% (n = 47) reported some degree of difficulty in accessing all areas of the mouth (item 18); 78.9% (n = 45) experienced some degree of difficulty when performing oral hygiene if the CAD was anxious or nervous (item 9); when assistance was needed, 37.5% (n = 21) reported never having the help of another person during the CAD's oral hygiene (item 7); 79.0% (n = 49) perceived that they had difficulties or barriers to performing the CAD's oral hygiene (item 1); and 64.5% (n = 40) of CADs bit one of the elements used during oral hygiene (toothbrush, finger brush, gauze, floss applicator, among others) (item 15) (Table 4).

Moreover, regarding the open-ended question, "What other barriers did you encounter when performing oral hygiene for the CADs?", 88.7% (n = 55) of caregivers provided a response. Among them, 34.5% (n = 19) reported difficulty brushing the molars; 20.0% (n = 11) had difficulty brushing the anterior teeth; and 16.4% (n = 9) experienced difficulty cleaning the tongue because the CAD would not stick it out (Table 5).

Similarly, in response to the questions "How have these barriers changed over time?" and "To what would you attribute this change?", 54.8% (n = 34) of caregivers reported that the barriers had decreased over time (Table 6).

Table 5. Other barriers to performing oral hygiene for children and adolescents with disabilities reported by caregivers.

Other barriers*	n	%
Difficulty brushing molars	19	34.5
Difficulty brushing anterior teeth	11	20.0
Difficulty cleaning the tongue because the CAD would not stick it out	9	16.4
Gag reflex triggered by the toothbrush	5	9.1
Swallowing the toothpaste	5	9.1
Difficulty using or refusing dental floss	5	9.1
Others	33	59.4

* Responses correspond to 55 caregivers, who could report more than one barrier.

Table 6. Evolution over time in barriers to performing oral hygiene for children and adolescents with disabilities and caregivers' reported reasons.

Evolution of barriers over time	n	%	Main reasons reported by caregivers
Have decreased	34	54.8	The CAD has matured, better understands instructions, and cooperates more. A routine has been established and a habit has been acquired. Strategies have been used to facilitate brushing, improving the CAD's motivation. Sensory alterations have decreased.
Have remained the same	11	17.7	Difficulties persist over time.
Have increased	17	27.4	The CAD is more aware of what they dislike and expresses it. CAD is stronger and is sometimes aggressive when caregivers attempt to perform oral hygiene. The CAD wants to brush alone and does not want help.

CAD: child or adolescent with disability.

Regarding caregiver burden, ZBI mean (SD) = 57.0 (14.2), indicating severe burden. Thus, 53.2% (n = 33) of caregivers presented severe burden; 24.2% (n = 15) showed no burden; and 22.6% (n = 14) had mild burden (Table 7).

When analyzing the mean score of each item on the Zarit Caregiver Burden Scale, most respondents felt that their family member with a disability depended on them, felt fear for their future, and believed they should be doing more for them (Table 8).

Table 7. Caregiver burden status of children and adolescents with disabilities according to the Zarit Caregiver Burden Scale (13).

Burden status	n	%
No burden (≤46 points)	15	24.2
Mild burden (47-55 points)	14	22.6
Severe burden (≥56 points)	33	53.2

Table 8. Distribution and mean scores of the Zarit Caregiver Burden Scale by question.

Barriers	Category										Mean ± SD
	Never		Rarely		Sometimes		Quite frequently		Nearly always		
	n	%	n	%	n	%	n	%	n	%	
1. Do you feel that your relative asks for more help than they really need?	20	32,3	6	9,7	19	30,6	5	8,1	12	19,4	2,7 ± 1,4
2. Do you feel that, because of the time you spend caring for your relative, you do not have enough time for yourself?	14	22,6	2	3,2	13	21,0	3	4,8	30	48,4	3,5 ± 1,6
3. Do you feel overwhelmed trying to balance caring for your relative with other responsibilities (work, family)?	6	9,7	9	14,5	18	29,0	5	8,1	24	38,7	3,5 ± 1,3
4. Do you feel embarrassed by your relative's behavior?	21	33,9	5	8,1	23	37,1	8	12,9	5	8,1	2,5 ± 1,3
5. Do you feel angry when you are around your relative?	51	82,3	2	3,2	7	11,3	1	1,6	1	1,6	1,4 ± 0,8
6. Do you think that caring for your relative negatively affects your relationship with other family members?	34	54,8	4	6,5	15	24,2	4	6,5	5	8,1	2,1 ± 1,3
7. Are you afraid for your relative's future?	10	16,1	2	3,2	12	19,4	4	6,5	34	54,8	3,8 ± 1,5
8. Do you feel that your relative depends on you?	4	6,5	1	1,6	13	21,0	7	11,3	37	59,7	4,2 ± 1,2
9. Do you think your health has worsened because of having to care for your relative?	28	45,2	5	8,1	15	24,2	5	8,1	9	14,5	2,4 ± 1,4
10. Do you feel tense when you are near your relative?	43	69,4	4	6,5	12	19,4	0	0,0	3	4,8	1,6 ± 1,1
11. Do you feel that you do not have as much privacy as you would like because you have to care for your relative?	25	40,3	4	6,5	16	25,8	6	9,7	11	17,7	2,6 ± 1,5
12. Do you feel that your social life has been negatively affected by having to care for your relative?	31	50,0	8	12,9	9	14,5	3	4,8	11	17,7	2,3 ± 1,5
13. Do you feel uncomfortable about distancing yourself from your friends because you have to care for your relative?	45	72,6	9	14,5	4	6,5	0	0,0	4	6,5	1,5 ± 1,0
14. Do you feel that your relative considers you the only person who can care for them?	26	41,9	3	4,8	9	14,5	5	8,1	19	39,6	2,8 ± 1,7
15. Do you feel you do not have enough income to cover the expenses of caring for your relative, in addition to your other expenses?	18	29,0	3	4,8	15	24,2	5	8,1	21	33,9	3,3 ± 1,8
16. Do you feel that you will not be able to care for your relative much longer?	39	62,9	6	9,7	12	19,4	1	1,6	4	6,5	1,8 ± 1,2
17. Do you feel that you have lost control of your life since your relative's illness began?	38	61,3	7	11,3	10	16,1	3	4,8	4	6,5	1,8 ± 1,2
18. Do you wish you could leave the care of your relative to someone else?	46	74,2	0	0,0	12	19,4	3	4,8	1	1,6	1,6 ± 1,0
19. Do you feel uncertain about what to do with your relative?	42	67,7	2	3,2	14	22,6	2	3,2	2	3,2	1,7 ± 1,1
20. Do you think you should do more for your relative?	11	17,7	1	1,6	13	21,0	4	6,5	33	53,2	3,8 ± 1,5
21. Do you think you could care for your relative better?	22	35,5	3	4,8	11	17,7	5	8,1	21	33,9	3,0 ± 1,7
22. Overall, how much “burden” do you feel because of having to care for your relative?	2	3,2	13	21,0	20	32,3	12	19,4	15	24,2	3,4 ± 1,1

DISCUSSION

This study described CADs' oral hygiene habits and caregivers' perceived barriers and burden. A high proportion of children practiced oral hygiene, caregivers reported numerous barriers when performing oral hygiene for the CADs, and many caregivers experienced severe burden.

Most caregivers were women (91.9%), similar to the 89% observed by Stensson et al. (14), the 90% reported by Floríndez et al. (15), and the 80% mentioned by Sosiawan et al. (16), consistent with the profile of the informal primary caregiver—typically the main, unpaid person responsible for caregiving and without formal caregiver training (4). Most were mothers (90.3%), which aligns with the 76.2% reported in the ENDISC III survey in Chile (2), the 87.2% reported by Silva et al. (9), the 73.6% obtained by Arias and Muñoz-Quezada (17), and the 89% found by Stensson et al. (14). In this regard, mothers often perceive caring for their children as a natural duty that no one else can fulfill as they do, and culturally transmitted beliefs about motherhood influence their performance as caregivers (18).

A large proportion of caregivers had completed university education (37.1%), similar to the 40.28% reported by Qiao et al. (19). However, this differs from Asencios-Ortiz and Pereyra-Zaldívar (20), who reported only 4.6%, and from Swartz and Collins (5), who found that caregivers with higher burden levels had lower educational level.

Most caregivers worked outside the home (41.9%), a lower percentage than that observed by Asencios-Ortiz and Pereyra-Zaldívar (20) (63.6%), and, on the other hand, higher than that reported in the study by Barros et al. (6), where between 11.9% and 20.3% of caregivers worked; however, those studies did not specify whether they worked inside or outside the home. This finding suggests that the participating caregivers in this study had to balance their work outside the home with their caregiving duties, possibly requiring support from another person to assist while they were away at work.

It was found that most caregivers received oral hygiene training from a dentist (56.5%), differing from Stensson et al. (14), who reported that most respondents were instructed by a dental hygienist, and only 13% received information from other parents. It is worth mentioning that in this study, 38.7% of caregivers reported having self-acquired knowledge about oral hygiene, highlighting the need for targeted caregiver education on this topic. It is worth mentioning that, in our study, 38.7% of the caregivers relied on their own knowledge regarding oral hygiene, which highlights the need to educate them on this topic.

Regarding oral hygiene habits, most CADs were partially or fully assisted by their caregivers (75.7%), similar to the 73.4% reported by Silva et al. (9), higher than the 45% reported by Chu and Lo (21), and lower than the 97.2% found by Du et al. (22). These findings indicate that a large proportion of caregivers assumed this task as part of their daily caregiving duties. Similarly, the preference for the manual toothbrush stood out (91.4%), a figure similar to the 97.9% reported by Silva et al. (9) and the 100.0% recorded by Carvalho et al. (23), but different from what was described by Deshpande et al. (24), who reported that over 60% of respondents believed electric toothbrushes facilitated hygiene.

It was observed that most CADs brushed twice daily (50.0%), similar to what was reported by Du et al. (22) (62.9%), which aligns with the recommendation to brush twice daily to reduce biofilm formation (25-27). However, this frequency does not ensure brushing effectiveness, as this study only included caregiver-reported information. It is worth noting that the time when brushing was least performed was after lunch. In this context, some of the CADs attended classes and had lunch at their educational institution, where the caregiver could not control the brushing time. It would be important to know if, in these cases, the minors brushed autonomously, or if they were assisted or supervised by an adult belonging to their school. On the other hand, a tendency not to use dental floss was observed, with only 15.5% using it, despite its recommended use to reduce biofilm formation (25-27). Our result aligns with the 15.9% reported by AlHumaid et al. (28); it is lower than the 37.5% observed by Silva et al. (9), and higher than that observed by Subasi et al. (29), where none of the CADs used floss. At the same time, few caregivers reported difficulty using floss or that the minor did not want to be flossed, suggesting they might not use it due to a lack of awareness regarding its indication and benefits.

Regarding caregivers' barriers to performing oral hygiene for CADs, it is noteworthy that all participants considered this practice important for these children. This finding is similar to that stated by Constance et al. (30), who reported that caregivers recognized the value of toothbrushing for maintaining good oral health. However, the difficulty in accessing all areas of the mouth, as well as brushing the molars, anterior teeth, and tongue, suggests that oral hygiene may not have been optimal. It was also observed that the behavior of CADs acted as a barrier (78.9%), which is consistent with George et al. (31), who reported that 60.4% of CADs resisted during toothbrushing; with Malta et al. (32), who found that 68.6% of caregivers had difficulties with this activity; and with the study by Silva et al. (9), where 73.4% of caregivers reported difficulty and 89.9% of CADs did not cooperate during brushing. Furthermore, these findings align with Constance et al. (30), who indicated that some caregivers found it difficult to perform dental hygiene on CADs due to resistant or tantrum-like behaviors, leading them to avoid such confrontations.

Most caregivers reported that these barriers decreased over time. Although maturation of the CAD was a factor that benefited the majority of caregivers in this group, it also made the task difficult for others, as is the case for CADs who became more aware of what they disliked and expressed it. It also seems that caregivers' consistency in establishing routines, creating habits, and using strategies to motivate the CAD during hygiene would be a possible recommendation. This aligns with Constance et al. (30), who reported that some parents used positive reinforcement, such as praise or rewards, to make brushing an enjoyable activity. Another possible barrier that could be considered is the lack of oral hygiene training, which was reported by a group of caregivers when mentioning they only had self-acquired knowledge.

Regarding the burden, most caregivers experienced severe burden (53.2%), which is associated with deterioration of mental and physical health, detriment to economic status due to absenteeism or reduced working hours, and lack of educational opportunities (5). These findings are similar to the 56% reported by Kayadjanian et al. (33) and higher than those reported by Arias and Muñoz-Quezada (17), who found that 48.6% of caregivers did not experience burden.

Concerning the responses to the questions of the Zarit Burden Interview (ZBI), the results were consistent with Montero et al. (18), who noted that caregivers "always believe that the person they care for depends entirely on them." These authors also mentioned that this belief is based on the perception that caring for the child is primarily the mother's responsibility, and that caregivers "always fear for the future of the person they care for." Furthermore, in our study, most caregivers believed they should do more for their family member—a finding in line with the aforementioned authors, who explained that caregivers often believe the child's illness resulted from inadequate care, and thus they must attend to them better, which is sometimes incongruent with the diagnosis and prognosis

The findings of this study revealed important aspects of the context in which this group of caregivers carried out their role and highlighted key points for dentists to consider. Among the study's limitations were a low participation rate from the invited institutions and caregivers; the impossibility of conducting in-person interviews due to the pandemic context, as CADs were not attending institutions; and caregivers' limited availability to connect remotely, partly because CADs were at home and caregivers often lacked time. Additionally, the oral hygiene habits of CADs were reported by caregivers, which could lead to information bias. Although the Zarit Burden Interview is a suitable tool, it was originally designed to assess caregiver burden among those caring for older adults with dementia. Therefore, it may not have been the most accurate instrument for evaluating the burden of caregivers of CADs. It would be advisable to adapt a version of this scale to specifically evaluate the burden of this type of caregiver; likewise, it would be interesting to create instruments that measure the barriers faced by caregivers when performing oral hygiene for CADs.

CONCLUSIONS

Most caregivers reported that CADs had oral hygiene practices and received assistance in performing them. Caregivers also reported multiple barriers and high levels of burden. Finally, most caregivers were women, primarily the mothers of the CADs.

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CAOH: conceptualization, data curation, formal analysis, research, methodology, visualization, writing – original draft, writing – review & editing.
LMOS: conceptualization, formal analysis, methodology, project administration, resources, supervision, writing – review & editing.
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REFERENCES

1. Fondo de Naciones Unidas para la Infancia. Reconocidos, contabilizados, incluidos. Utilizar los datos para arrojar luz sobre el bienestar de los niños y las niñas con discapacidad. Resumen [Internet]. Unicef; [n. d.]. Available from: https://www.unicef.org/nicaragua/media/8016/file/Reconocidos,%20contabilizados,%20incluidos.pdf
2. Ministerio de Desarrollo Social y Familia, Servicio Nacional de la Discapacidad (CL). III Estudio Nacional de la Discapacidad 2022 [Internet]. Santiago de Chile: MDSF; 2023. Available from: https://www.senadis.gob.cl/pag/693/2004/iii_estudio_nacional_de_la_discapacidad
3. Ley n.° 20.422, que Establece normas sobre igualdad de oportunidades e inclusión social de personas con discapacidad [Internet]. Santiago de Chile: Ministerio de Planificación; 2010, 3 de febrero. Available from: https://www.bcn.cl/leychile/navegar?idLey=20422
4. Islas NL, Ramos B, Aguilar MG, García ML. Perfil psicosocial del cuidador primario informal del paciente con EPOC. Rev Inst Nal Enf Resp Mex [Internet]. 2006; 19(4): 266-271. Available from: https://www.scielo.org.mx/pdf/iner/v19n4/v19n4a6.pdf
5. Swartz K, Collins LG. Caregiver care. Am Fam Physician [Internet]. 2019; 99(11): 699-706. Available from: https://www.aafp.org/pubs/afp/issues/2019/0601/p699.html
6. Barros AL, Gutierrez GM, Barros AO, Santos MT. Quality of life and burden of caregivers of children and adolescents with disabilities. Spec Care Dentist [Internet]. 2019; 39(4): 380-388. Available from: https://doi.org/10.1111/scd.12400
7. Bizarra MF, Ribeiro Graça S. Short-term impact of an oral health program for adults with cerebral palsy. Spec Care Dentist [Internet]. 2020; 40(1): 26-34. Available from: https://doi.org/10.1111/scd.12431
8. Philip P, Prasanna P, Vijaya Remi R, Samuel R, George WT, Joseph MS, et al. Prevalence of dental caries among children and adolescents with intellectual disability in India: a scoping review. J Appl Res Intellect Disabil [Internet]. 2024; 37(5): e13278. Available from: https://doi.org/10.1111/jar.13278
9. Silva EL, Góes PS, Vasconcelos MM, Jamelli SR, Eickmann SH, Melo MM, et al. Oral health care for children and adolescents with cerebral palsy: perceptions of parents and caregivers. Ciênc Saúde Coletiva [Internet]. 2020; 25(10): 3773-3784. Available from: https://doi.org/10.1590/1413-812320202510.27972018
10. Rizal RV, Suharsini M, Budiardjo SB, Sutadi H, Indiarti IS, Rizal MF, et al. Evaluation of oral hygiene in children with down syndrome using the busy book ayo sikat gigi as an educational toy. Pesqui Bras Odontopediatria Clín Integr [Internet]. 2019; 19: e5101. Available from: https://www.scielo.br/j/pboci/a/dL7dmsY9b6rKN6MtBmbG9hC/?lang=en
11. Zhou N, Wong HM, McGrath C. Oral health and associated factors among preschool children with special healthcare needs. Oral Dis [Internet]. 2019; 25(4): 1221-1228. Available from: https://doi.org/10.1111/odi.13057
12. Barrero CL, García S, Ojeda A. Índice de Barthel (IB): Un instrumento esencial para la evaluación funcional y la rehabilitación. Plast Rest Neurol [Internet]. 2005; 4(1-2): 81-85. Available from: https://www.medigraphic.com/pdfs/plasticidad/prn-2005/prn051_2l.pdf
13. Breinbauer H, Vásquez H, Mayanz S, Guerra C, Millán T. [Original and abbreviated Zarit caregiver burden scales. Validation in Chile]. Rev Med Chil [Internet]. 2009; 137(5): 657-665. Available from: http://dx.doi.org/10.4067/S0034-98872009000500009 Spanish.
14. Stensson M, Norderyd J, Van Riper M, Marks L, Bjork M. Parents' perceptions of oral health, general health and dental health care for children with Down syndrome in Sweden. Acta Odontol Scand [Internet]. 2021; 79(4): 248-255. Available from: https://doi.org/10.1080/00016357.2020.1824015
15. Floríndez LI, Como DH, Floríndez DC, Floríndez FM, Law E, Polido JC, et al. Toothbrushing and oral care activities of autistic and non-autistic latino children. Children (Basel) [Internet]. 2022; 9(5): 741. Available from: https://doi.org/10.3390/children9050741
16. 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. F1000Res [Internet]. 2022;

11: 374. Available from: https://doi.org/10.12688/f1000research.87848.2

17. Arias C, Muñoz-Quezada MT. [Quality of life and overload in caregivers of school children with intellectual disabilities]. Interdisciplinaria [Internet]. 2019; 36(1): 257-272. Available from: https://www.scielo.org.ar/scielo.php?script=sci_abstract&pid=S1668-70272019000100017 Spanish.
18. Montero X, Jurado S, Valencia A, Méndez J, Mora I. [Zarit Caregiver burden scale: evidence of validity in Mexico]. Psicooncología [Internet]. 2014; 11(1): 71-85. Available from: https://doi.org/10.5209/rev_PSIC.2014.v11.n1.44918 Spanish.
19. Qiao Y, Shi H, Wang H, Wang M, Chen F. Oral health status of Chinese children with autism spectrum disorders. Front Psychiatry [Internet]. 2020; 11: 398. Available from: https://doi.org/10.3389/fpsyt.2020.00398
20. Asencios-Ortiz RP, Pereyra-Zaldívar H. [Workload of caregiver according to functionality level of the person with disabilities in a district of Lima]. An Fac Med [Internet]. 2019; 80(4): 451-456. Available from: http://dx.doi.org/10.15381/anales.v80i4.16441 Spanish.
21. Chu CH, Lo EC. Oral health status of Chinese teenagers with cerebral palsy. Community Dent Health [Internet]. 2010; 27(4): 222-226. Available from: https://web.archive.org/web/20241005181610/https://www.cdhjournal.org/issues/27-4-december-2010/290-oral-health-status-of-chinese-teenagers-with-cerebral-palsy
22. Du RY, Yiu CK, King NM. Oral health behaviours of preschool children with autism spectrum disorders and their barriers to dental care. J Autism Dev Disord [Internet]. 2019; 49(2): 453-459. Available from: https://doi.org/10.1007/s10803-018-3708-5
23. Carvalho RB, Mendes RF, Prado RR, Moita JM. Oral health and oral motor function in children with cerebral palsy. Spec Care Dentist [Internet]. 2011; 31(2): 58-62. Available from: https://doi.org/10.1111/j.1754-4505.2011.00180.x
24. Deshpande AN, Naik K, Deshpande N, Joshi N, Jaiswal V, Raol RY. Safety and efficacy of plaque removal using manual and powered toothbrush in cerebral palsy children by parents/caregivers: a randomized control crossover trial. Int J Clin Pediatr Dent [Internet]. 2023; 16(2): 344-349. Available from: https://doi.org/10.5005/jp-journals-10005-2533
25. Moraes RB, Marques BB, Cocco DM, Knorst JK, Tomazoni F, Ardenghi TM. Effect of environmental and socioeconomic factors on the use of dental floss among children: a hierarchical approach. Braz Oral Res [Internet]. 2019; 33: e096. Available from: https://doi.org/10.1590/1807-3107bor-2019.vol33.0096
26. Quadri MF, Shubayr MA, Hattan AH, Wafi SA, Jafer AH. Oral hygiene practices among Saudi Arabian children and its relation to their dental caries status. Int J Dent [Internet]. 2018; 2018(1): 3234970. Available from: https://doi.org/10.1155/2018/3234970
27. Goodarzi A, Heidarnia A, Tavafian SS, Eslami M. Predicting oral health behaviors among Iranian students by using health belief model. J Educ Health Promot [Internet]. 2019; 8(1): 10. Available from: https://doi.org/10.4103/jehp.jehp_10_18
28. AlHumaid J, Gaffar B, AlYousef Y, Alshuraim F, Alhareky M, El Tantawi M. Oral health of children with autism: the influence of parental attitudes and willingness in providing care. Sci World J [Internet]. 2020; 2020(1): 8329426. Available from: https://doi.org/10.1155/2020/8329426
29. Subasi F, Mumcu G, Koksal L, Cimilli H, Bitlis D. Factors affecting oral health habits among children with cerebral palsy: pilot study. Pediatr Int [Internet]. 2007; 49(6): 853-857. Available from: https://doi.org/10.1111/j.1442-200x.2007.02445.x
30. Constance D, Subbiah R, Sukumaran A, Madankumar P. Barriers in maintaining oral health among the children with cerebral palsy – Parent/caregiver's perspective. J Indian Soc Pedod Prev Dent [Internet]. 2023; 41(3): 234-238. Available from: https://doi.org/10.4103/jisppd.jisppd_360_23
31. George SS, Elenjickal MG, Naik S, Thomas NG, Vellappally S, Varghese N, et al. Oral health status and dental treatment needs in children with autism spectrum disorder. Heliyon [Internet]. 2024; 10(18): e37728. Available from: https://doi.org/10.1016/j.heliyon.2024.e37728
32. Malta CP, Guerreiro GG, Dornelles NM, Marques CT, Martins JS, Westphalen Bento L. Caregivers' perceptions regarding oral health status of children and adolescents with cerebral palsy. J Clin Pediatr Dent [Internet]. 2020; 44(3): 161-167. Available from: https://www.jocpd.com/articles/10.17796/1053-4625-44.3.5
33. Kayadjanian N, Schwartz L, Farrar E, Comtois KA, Strong TV. High levels of caregiver burden in Prader-Willi syndrome. PLoS ONE [Internet]. 2018; 13(3): e0194655. Available from: https://doi.org/10.1371/journal.pone.0194655