

Universidade Estadual de Campinas Faculdade de Odontologia de Piracicaba

TAMIRIS CHRISTENSEN BUENO

PACIENTES COM NECESSIDADES ESPECIAIS DO OROCENTRO DA FACULDADE DE ODONTOLOGIA DE PIRACICABA

PATIENTS WITH SPECIAL NEEDS OF OROCENTRO OF THE PIRACICABA SCHOOL OF DENTISTRY

PIRACICABA 2021

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Orientador: Prof. Dr. Márcio Ajudarte Lopes

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Universidade Estadual de Campinas Faculdade de Odontologia de Piracicaba

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RESUMO

Esta tese é composta por três estudos distintos que serão apresentados: O primeiro estudo objetivou avaliar o nível de entendimento dos cuidadores de pacientes com necessidades especiais do OROCENTRO sobre saúde bucal e alimentação equilibrada e do uso de um vídeo educacional. Participaram do estudo 40 cuidadores, os quais foram divididos em dois grupos, os do grupo intervencionista assistiram um vídeo produzido para este estudo e em seguida, foi aplicado um questionário para os dois grupos. Não foram observadas diferenças significativas entre os grupos, no entanto, os cuidadores do grupo controle apresentaram menor porcentagem de acertos. Foi então concluído que embora as ferramentas educacionais possam contribuir para o conhecimento dos cuidadores, no presente estudo os resultados não foram estatisticamente significantes, o que pode ser atribuído ao fato dos dois grupos serem assistidos em um centro especializado, onde as informações sobre a saúde bucal e alimentação equilibrada são trabalhadas com os cuidadores em todas as consultas. O segundo estudo descreveu e abordou as medidas ambientais, individuais e da saúde bucal de 15 cuidadores de pacientes com Transtorno do Espectro Autista (n = 7) e Síndrome de Down (n = 8). A maioria teve como cuidador principal os pais, sendo a maioria mulheres (86,6%), com idades entre 40 e 59 anos (60,0%) e cursado até o ensino médio (53,3%). Um grande número de cuidadores relatou saúde bucal boa (33,3%) ou nem boa nem ruim (33,3%). Em relação às variáveis psicossociais as pontuações obtidas foram: senso de coerência (SOC) média de 48,9, suporte social média de 69,3 e para OHRQoL (Qualidade de vida relacionada a saúde bucal) a média foi de 10,9. O estudo mostrou que os cuidadores tinham um forte SOC, a maioria deles relatou alto suporte percebido e não relatou um alto impacto na OHRQoL. Além disso, este estudo mostrou a importância de se compreender os fatores de proteção e enfrentamento do cuidador frente ao desafio de cuidar de um paciente com necessidades especiais, a fim de promover uma melhor qualidade de vida a essa população. O terceiro estudo verificou a quantidade e o perfil dos pacientes que ficaram sem atendimento no OROCENTRO durante a pandemia do Coronavírus no ano de 2020. Foi identificado um total de 1.266 pacientes, sendo a maioria do sexo feminino, com idade entreas décadas de 50, 60 e 70, residentes na cidade de Piracicaba ou cidades próximas e estavam em tratamento há aproximadamente 1 ano. As doenças base por ordem de frequência observadas nos pacientes em tratamento odontológico foram HIV (Vírus da Imunodeficiência Humana), Carcinoma Espinocelular, Transtorno do Espectro Autista, Síndrome de Down, Deficiência Intelectual e Hepatite C. Em relação aos pacientes em acompanhamento de lesões e diagnóstico foram observadas com maior frequência Carcinoma Espinocelular, Queilite Actínica, Líquen Plano e Leucoplasia. Os dados apresentados mostraram que a suspensão das consultas poderá contribuir para o agravamento da condição bucal dos pacientes com necessidades especiais e o agravamento e / ou desenvolvimento de doenças bucais dos pacientes em acompanhamento. Os resultados também permitem conhecer melhor o perfil dos pacientes e contribuir para o planejamento do retorno ao atendimento clínico, estabelecendo critérios de prioridade.

Palavras-chaves: Pessoas com deficiência. Saúde bucal. Vídeo. Pandemia do Coronavírus.

ABSTRACT

This thesis is composed of three distinct studies that will be presented: The first study aimed to evaluate the level of understanding of caregivers of OROCENTRO special needs patients about oral health and balanced eating and the use of an educational video. Forty caregivers participated in the study and were divided into two groups, where those in the interventionist group watched a video produced for this study, and then a questionnaire was applied to both groups. No diferences were observed between groups, however, the caregivers in the control group had a lower percentage of correct answers. It was then concluded that although educational tools can contribute to the knowledge of caregivers, in this study the results were not statistically significant, which can be attributed to the fact that the two groups were assisted in a specialized center, where information on oral health and nutrition balanced are worked on with caregivers at in all appointments. The second study described and addressed the environmental, individual, and oral health measures of 15 caregivers of patients with Autism Spectrum Disorder (n = 7) and Down syndrome (n = 8). Most of them had their parents as their main caregiver, and most of them were women (86.6%), aged between 40 and 59 years (60.0%) and had completed high school (53.3%). A large number of caregivers reported good (33.3%) or neither good nor bad (33.3%) or al health. Regarding the psychosocial variables, the scores obtained were: sense of coherence (SOC) mean of 48.9, social support mean of 69.3, and for OHRQoL (oral health-related quality of life) the mean was of 10.9. The study showed that caregivers had a strong SOC, most of them reported high perceived support and did not report a high impact on OHRQoL. In addition, this study showed the importance of understanding the caregiver's protective and coping factors when faced with the challenge of caring for patient with special needs in order to promote a better quality of life for this population. The third study verified the amount and profile of patients who were not attended at OROCENTRO during the Coronavirus pandemicin the year 2020. It was identified a total of 1,266 patients, being most of them female, aged in the 50s, 60s, and 70s decades, living in the city of Piracicaba or nearby cities, and had been in treatment for approximately 1 year. The underlying diseases in order of frequency observed in patients undergoing dental treatment were HIV (Human Immunodeficiency Virus), Squamous Cell Carcinoma, Autism Spectrum Disorder, Down Syndrome, Intellectual Disability, and Hepatitis C. Regardingpatients in follow-up for oral lesion, Squamous Cell Carcinoma, Actinic Cheilitis, Lichen Planus and Leukoplakia were observed most frequently. The presented data showed that the suspension of appointments at OROCENTRO due to the pandemic could contribute to the worsening of the oral condition of patients with special needs as well as worsening and/or development of oral diseases of patients in follow-up. The results also allow a better understanding of the patients' profile and contribute to the planning of the return to clinical care, establishing priority criteria.

Keywords: Disabled persons. Oral health. Video. Coronavirus pandemic.

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1 INTRODUÇÃO

Os distúrbios de conduta e o comportamento antissocial são os problemas mentais e comportamentais mais comuns em crianças e jovens (NICE, 2013). Como exemplo podemos citar os pacientes com o transtorno do espectro autista (TEA), que tem tido alta prevalência ao longo dos últimos anos (Zablotsky et al., 2015).

Em relação as causas genéticas de deficiência intelectual e atraso de desenvolvimento, a Síndrome de Down é a mais prevalente (Kazemi et al., 2016). Segundo Bermudez et al. (2015), afeta 1 a cada 700 indivíduos nascidos vivos.

Pessoas com deficiência intelectual têm pior higiene bucal e maior prevalência e maior gravidade de doença periodontal. Com relação a cárie, curiosamente, a prevalência tem sido relatada com igual ou inferior à população em geral. No entanto, a prevalência de cárie não tratada tem sido reportada como mais elevada (Anders & Davis, 2010).

Desta forma, estas pessoas requerem cuidados familiares, médicos e odontológicos específicos direcionados a sua condição. Sendo assim, os profissionais da área da saúde devem estar preparados para oferecer um tratamento adequado e de qualidade(Resende et al., 2005).

Segundo Morales-Chávez et al. (2014), no caso de pacientes com necessidades especiais, os profissionais devem ter conhecimentos mais amplos, visto que algumas deficiências estão associadas a graves problemas dentários, como bruxismo, má oclusão, gengivite, cárie, entre outros. Muitas dessas doenças estão frequentemente relacionadas à dieta do paciente ou à dificuldade em realizar uma higiene bucal adequada.

Amaral et al. (2000) observaram que por meio de programas que visam a promoção de saúde bucal de pacientes com necessidades especiais, as noções de higiene transmitidas, além de propiciarem a manutenção da saúde, também possibilitam oestreitamento do vínculo família-paciente-equipe profissional.

Portanto, para se obter um resultado desejado nos cuidados com a saúde geral e bucal do paciente, devemos conseguir amparar, motivar e orientar o seu cuidador. Com isso, é recomendado que ocorra um contato regular com os cuidadores através das consultas aos pacientes, informando sobre melhoria de higiene oral e a necessidade de modificações da dieta, como foi descrito por Oredugba & Akindayomi (2008).

Sendo assim, diante da importância da inter-relação necessária entre os pacientes com necessidades especiais e o acompanhamento odontológico, o primeiro estudo se faz necessário, para evidenciar se recursos audiovisuais podem contribuir para melhorar a compreensão dos cuidadores de pacientes com necessidades especiais sobre saúde bucal.

Outro fator importante observado por Barros et al. (2019) é que na maioria das vezes, os cuidadores de pacientes com necessidades especiais são pessoas que possuem escolaridade e poder econômico baixo, possuem problemas de saúde e os mais velhos mostraram maior sobrecarga e maior impacto na qualidade de vida. Tuna et al. (2004) destacaram que a qualidade de vida dos cuidadores de crianças com paralisia cerebral é encontra-se diminuída nos domínios de função física, vitalidade, saúde geral e papel emocional.

Apesar da atenção aos pais e cuidadores de pessoas com necessidades especiais ter crescido nos últimos anos, são poucas as informações sobre indicadores subjetivos que podem impactar no bem-estar e na qualidade de vida dessa população (Nordahl-Hansen et al., 2018).

Assim, o segundo estudo teve como objetivo abordar as características sociodemográficas, do senso de coerência, suporte social e da qualidade de vida relacionada a saúde bucal dos cuidadores de pacientes com o Transtorno do Espectro Autista e Síndrome de Down.

Além das pessoas com necessidades especiais, outro grupo de pacientes quedevem estar em constante acompanhamento em centros especializados odontológicos são pessoas com doenças potencialmente malignas, bem como pacientes que foram tratados para malignidades orais (Alves et al., 2021).

O OROCENTRO é uma clínica de Estomatologia do Departamento de Diagnóstico Oral da Faculdade de Odontologia de Piracicaba – UNICAMP, que presta atendimento a este grupo de pessoas, realizando procedimentos visando o diagnóstico e tratamento de lesões bucais, além de tratamento odontológico aos pacientes com necessidadesespeciais.

Porém, diante do agravamento da pandemia do Coronavírus, no dia 13 março de 2020 os atendimentos presencias foram suspensos, seguindo as recomendações das normas da Organização Mundial da Saúde. Consequentemente, todas estas pessoas que tinham consultas agendadas e estavam em tratamento ficaram sem acompanhamento.

A pandemia da COVID-19 está causando alarmantes impactos na saúde individual e coletiva com consequências ainda obscuras (Pfefferbaum & North, 2020). Portanto, a realização do terceiro estudo desta tese objetivou identificar a quantidade e o perfil dos pacientes que ficaram sem atendimento, que poderão contribuir para estabelecer critérios para retomada dos atendimentos quando for possível.

2 ARTIGOS

2.1 ARTIGO: Knowledge of caregivers of patients with special needs about oral health CAPÍTULO 1 – Artigo submetido ao Journal of Dental Education

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ABSTRACT

Purpose/Objectives: This study aimed to evaluate the knowledge of caregivers of special needs patients about oral health and balanced diet using an educational video. **Methods:** From October to December 2020, forty caregivers of special needs patients whoare assisted at the Orocentro of FOP-UNICAMP participated in the study. The caregiverswere divided into two groups, 20 in the Control Group (without video) and 20 in the Interventionist Group (video group). The caregivers in the intervention group watched a video about oral health and balanced nutrition specially produced for this study. A questionnaire was then applied to all caregivers to assess the degree of understanding, and the results were compared between the two groups. Results: It was observed that, in general, the caregivers have a good level of knowledge about oral health and a balanced diet. Although no significant differences were observed between the groups, the caregivers in the control group had a lowerpercentage of correct answers, especially regarding tooth brushing and the type of toothpaste. In addition, the caregivers' education and age did not influence the variables studied. **Conclusions:** Although the educational tools can contribute to the knowledge of caregivers, in the present study the results were not statistically significant, which can be attributed to the fact that both groups were assisted in a specialized dental center, where information on oral health and balanced diet is given to the caregivers in all the patient's visits. However, future investigations are necessary to increase the number of participants and better understand the contribution of audiovisual tools in the population of caregivers of people with special needs.

Keywords: Disabled persons, Oral health, Oral hygiene.

INTRODUCTION

Patients with special needs are those "who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require healthcare and other services in addition to those normally required".¹

These people have a high degree of unmet dental need when compared to the general population.^{2, 3} In addition, there are numerous barriers to access the health care, as well as a lack of resources.⁴⁻⁶ Due to the complexity of the problem, these people need multiple visits to various services ^{7, 8} and often need transportation.^{4, 5} In addition, they face other difficulties, such as low reimbursement rates^{4, 5, 9}, awareness deficiency among caregivers, who mostly have a low level of understanding about health,⁴ lack of organizational support,¹⁰ lack of health professional with knowledge to care and the patient's lack of cooperation. ^{5, 9-12}

The most common dental problems in these patients are dental caries, gingivitis, periodontal problems, and consecutively fewer remaining teeth. ^{3, 13} The difficulty in maintaining adequate oral hygiene is enough to explain the high incidence of these problems, besides the fact that mouth breathing, malocclusion, macroglossia, bruxism, cariogenic diet, and side effects of medications, such as hyposalivation, may also be present.^{14, 15} In addition, some patients require specialized dental services with sedation in a hospital setting, which usually has long waiting lines.¹⁴

It has been proven that the most effective method for preventing caries, gingivitis, and periodontal disease is the mechanical removal of biofilm through brushing, coupled with fluoride dentifrice and proper nutrition. ^{4, 16, 17}

Another very important aspect that needs to be highlighted is that these special patients have motor, sensory, intellectual, and psychological deficiencies in performing their hygiene. Therefore, family members are responsible for their care, and consequently they must know and be aware of hygiene practices to preserve the oral health of these people. ^{18, 19}

However, this is not the scenario that has been observed. Many of these caregivers do not understand or are unaware of the importance of oral health care and do not choose an adequate diet.²⁰ One strategy that can contribute to change this panorama is interventions directed to caregivers in order to directly improve their knowledge of oral health, including hygiene, to reflect in the care of patients with special needs.^{21, 22} Studies show that oral health education to caregivers is effective in showing positive outcomes regarding dental care.²³⁻²⁵

Therefore, the regular participation of the dentist in this context is extremely important because he has an essential role in the necessary orientations to the caregivers for the

promotion of oral health and well-being of the patient. Besides acting regularly in the execution of hygienic procedures and rehabilitation of these patients. ^{15, 26}

By obtaining information on the treatment needs of special needs patients, it is possible to create guidelines and develop promotion and prevention strategies in this vulnerable class. In addition, seeking motivation and guidance can allow better retention of information by caregivers, in this way, caregivers who have assistance in specialized dental centers can have a good understanding about oral health and balanced nutrition. Thus, the objective of this study was to evaluate the knowledge of caregivers of patients with special needs about oral hygiene and balanced nutrition, using an educational video.

MATERIALS AND METHODS:

This cross-sectional observational was carried out from October to December 2020, at OROCENTRO (Service for the Diagnosis and Treatment of Oral Lesions) Semiology area of the Piracicaba School of Dentistry, UNICAMP.

The research project was prepared according to the Declaration of Helsinki and was approved by the Research Ethics Committee of the Piracicaba School of Dentistry (protocol: 31454720.0.0000.5418). Potential participants were recruited by message contact, where the research objectives were explained. Those who agreed accepted electronically the Informed Consent Form (ICF).

Eighty-six volunteers were invited to participate in the study, and forty volunteers over 18 years of age, of both genders, caregivers of people with special needs undergoing dental treatment at OROCENTRO agreed to participate and were included. Parents or caregivers of patients with unspecified needs were excluded from the study when completing the questionnaire.

The researchers sent the electronic survey through a Google system form, together with the Free and Informed Consent Form.

The participants (N = 40) were divided into two groups, the control group (N = 20), received the Google form with the questionnaire only, and the intervention group (N = 20), received the Google form questionnaire together with the educational video.

The electronic form consisted of socioeconomic data (gender, age, years of study of the caregiver), the relationship between caregiver and patient, and type of disability (Down Syndrome, Autism, Cerebral Palsy, or others), in addition to eleven multiple-choice questions about oral hygiene and balanced diet (Table1). The comprehension results were classified as high understanding (nine to eleven correct answers), intermediate (six to eight correct answers), and low understanding (zero to five correct answers).

Question	Options
1- Do you think it is important to establish oral hygiene and eating routine to prevent gingival inflammation and caries?	Yes. No.
2- Can mouth infections cause problems in other organs of the body?	Yes. No.
3- Should the food be as natural as possible?	Yes. No.
4- Which toothbrush is the most important for the prevention of oral diseases?	Morning. After meals. Before bed.
5- Which teeth should we start brushing?	From the front. From the bottom.
6- When should we floss?	Before brushing. After brushing.
7- How should the brushing be on the outside of the teeth?	Come and go. Circular.
8- Should we brush our tongue?	Yes. No.
9- Which way should the tongue be brushed?	From the front to the back. From the bottom to the front.
10- Which type of toothpaste should we use?	With fluoride Fluoride-free.
11- How much paste should we put on the brush?	Not much. A lot of quantity.

Table 1. Multiple choice questions about knowledge of oral hygiene and balanced diet.

The groups were compared regarding their understanding of the subject addressed and the results correlated with the caregiver's age and educational level.

Data were tabulated using Excel software, version 16.45 (Microsoft Excel, Microsoft Inc., Redmond, WA, USA) and analyzed with Stata SE 15.0 software. (StataCorp LP; College Station, TX, USA). Fisher's exact test and Mann-Whitney test were used to compare participants' sociodemographic and knowledge characteristics. The significance level was set at 5%.

RESULTS

In the Control Group (without video), there were caregivers of 5 patients with Down's Syndrome, of 8 patients with Autism Spectrum Disorder, and of 7 patients with other syndromes. In the Intervention Group (with video), there were caregivers of 4 patients with Down Syndrome, of 7 patients with Autism Spectrum Disorder, and of 9 patients with other syndromes. Most of these patients have their father or mother as their primary caregiver, corresponding to 90% in the Control Group and 85% in the Interventionist Group. The mean age of the caregivers of the Control Group was 46.05 years and of the Interventionist Group was 39.15 years. Most caregivers studied up to high school (40% in the control group and 50% in the intervention group). Only 6 caregivers had higher education (20% in the Control Group and 10% in the Intervention Group) (Table 2).

 Table 2 – Sociodemographic and socioeconomic of caregivers of patients with special needs.

VARIÁBLE	No Vídeo (n=20)	With Vídeo	p-value
SPECIAL NEED, N (%)		(11-20)	0.849 ^a
Down Syndrome	5 (25 %)	4 (20%)	01017
Autism Spectrum Disorder	8 (40 %)	7 (35%)	
Another	7 (35%)	9 (45%)	
SOCIODEMOGRAPHIC			1.000 ^a
KINSHIP OF CAREGIVER N (%)			
Father or Mother	18 (90%)	17 (85%)	
Brother or Sister	1 (5%)	2 (10%)	
Another	1 (5%)	1 (5%)	
AGE, MEAN (DP)	46.05 (13.23 %)	39.15 (8.41 %)	0.107 ^b
SOCIOECONOMIC STATUS			0.808 ^a
YEARS OF STUDY, N (%)			
Elementary School I	2 (10%)	1 (5%)	
Elementary School II	6 (30%)	7 (35%)	
High School	8 (40%)	10 (50%)	
Higher Education	4 (20%)	2 (10%)	

a - Fisher's exact test

b - Mann-Whitney

Data on caregivers' understanding and knowledge about oral health and a balanced diet are presented in Table 3. Questions 1 and 3 obtained a total of 100% of correct answers in both groups, showing that both groups understand the need to maintain a routine of oral hygiene and a balanced diet.

Question number 2, which approached the possibility of foci of infection in the mouth generating other health problems, such as infections in other organs, was answered 95% right

in the Control Group and 100% right in the Interventionist Group. Therefore, it was possible to observe that the caregivers know that oral health is very important for the patient's overall health.

Questions 4 and 5 had a lower hit rate compared to the previous questions. In question 4, the Control Group obtained only 50% correct answers. This means that in this group there are still uncertainties about which period of brushing is the most important for the promotion of oral health (after meal, before meals, or bedtime). In the Interventionist Group, the total number of correct answers was 75%. However, no statistically significant difference was observed between the groups (p=0.191).

Question 5 showed that 13 out of 40 caregivers (32.5%) could not identify the correct way to perform tooth brushing. The percentage of correct answers was lower in the control group compared to the video group, corresponding to 60% and 75% of correct answers, respectively.

Question 6 addressed the best time to floss, which should be before brushing. The percentage of correct answers was 80% in the Control Group and 75% in the Interventionist Group. The data showed that there are still uncertainties about the use of dental floss by caregivers.

Question 7, which verified tooth brushing technique, obtained the same percentage of correct answers in both groups, corresponding to 85%, showing that some caregivers still have doubts about which movements should be performed to brush the teeth. Question 8asked about the importance of brushing the tongue. All caregivers answered correctly, emphasizing that everyone knows the importance of this practice. In addition, question 9 mentioned how the tongue brushing should be, with a total of 100% correct answers in the Control Group and 95% in the Interventionist Group. It was possible to observe a low rate of uncertainties regarding tongue brushing.

Question 10, addressed the use of toothpaste, containing or not fluoride. The results showed 80% of correct answers in the first group, and a better performance in the Interventionist Group of 95%.

The last question, about the amount of paste that should be placed on the toothbrush, showed a total of 100% of correct answers in both groups, showing the understanding that only a small amount of toothpaste is necessary to perform tooth brushing.

According to the analysis of the answers presented in each group, it was possible to observe that there was no statistically significant difference concerning knowledge about oral health between the two groups studied.

	No Vídeo (n=20)	With Vídeo (n=20)	p-value
1 Do you think it is important to establish oral hygiene and eating routine to prevent gingival inflammation and caries?			-
- Yes - No	20 (100%)	20 (100%)	
2- Can mouth infections cause problems in other organs of the body?			1.000 ^a
- Yes - No	19 (95%) 1 (5%)	20 (100%)	
3- Should the food be as natural as possible?Yes	20 (100%)	20 (100%)	-
- No	-	-	
4 - Which toothbrushing is the most important for the prevention of oral diseases?	_	_	0.191 ^a
- After meals	10 (50%)	5 (25%)	
- Before bed.	10 (50%)	15 (75%)	
5- Which teeth should we start brushing?			0.501 ^a
From the front.From the bottom.	8 (40%) 12 (60%)	5 (25%) 15 (75%)	
6- When should we floss?			1.000 ^a
Before brushing.After brushing.	16 (80%) 4 (20%)	15 (75%) 5 (25%)	
7- How should the brushing be on the outside of the	2 (1 50()	2 (150()	1.000 ^a
- Come and go. - Circular.	3 (15%) 17 (85%)	3 (15%) 17 (85%)	
8- Should we brush our tongue?	20 (100%)	20 (100%)	-
- Yes - No	-	20 (100%) -	
9- Which way should the tongue be brushed?			1.000 ^a
From the front to the back.From the bottom to the front.	- 20 (100%)	1 (5%) 19 (95%)	
10- Which type of toothpaste should we use?			0,342 ^a
- With fluoride - Fluoride-free.	16 (80%) 4 (20%)	19 (95%) 1 (5%)	
11- How much paste should we put on the brush? - Not much.			-
- A lot of quantity.	20 (100%)	20 (100%)	

 Table 3 - Oral health knowledge of caregivers of patients with special needs.

a - Fisher's exact test. b - Mann-Whitney

Table 4 shows the level of education and the age of the caregivers regarding the understanding of the information provided by the dentist. Most participants in both groups studied (N=35) had a high level of comprehension. Another 5 caregivers presented an intermediate level of understanding. There was no statistically significant difference between the two groups. The data show that age did not influence the caregivers' level of comprehension. The data on education and age of the caregivers did not differ statistically between the groups studied (P > 0.05).

	LEVEL OF UNDERSTANDING						
	Intermediate			High			
LEVEL OF	With	No	P value*	With vídeo	No	P value*	
EDUCATION	vídeo	vídeo			vídeo		
Elementary School I	0	1		1	1		
Elementary School II	1	0	1 0000	6	6	0.0027	
High School	2	1	1.0000	8	7	0.9027	
Higher Education	0	0		2	4		
Total of participants	3	2		17	18		
AGE							
20 to 30 years old	2	0		1	2		
31 to 40 years old	0	1		10	5		
41 to 50 years old	1	0	0.4000	4	5	0 2704	
51 to 60 years old	0	0	0.4000	2	5	0.3784	
61 to 70 years old	0	1		0	0		
71 to 80 years old	0	0		0	1		
Total of participants	3	2		17	18		

Table 4 - Level of understanding as a function of educational level and age of caregivers of patients with special needs.

* Fisher's exact test.

DISCUSSION

Several factors can influence the quality of oral hygiene in patients with special needs. Mouth breathing, malocclusion, macroglossia, bruxism, cariogenic diet, and side effects of medications are highlighted in the literature,^{14, 15} in addition to age, the severity of the health condition, and the patient's living conditions.^{26, 27}

Patients with special needs may have impaired physical, intellectual, social, and emotional skills,¹ causing health care to be performed with the help of a caregiver.²⁸

Monitoring the oral health of these patients can be even more challenging for their caregivers when there is an association of other factors, such as the limited financial resources that some families may encounter.⁴⁻⁶

This scarcity of resources may be related to the level of education of the guardians /caregivers of patients with special needs, reflecting on the restriction of access to health systems, specifically those aimed at the promotion and preservation oral health.⁴

A recent study conducted with caregivers of special needs patients revealed that most are unemployed mothers with low educational attainment.²⁹ The present study reflects the same situation, mothers with low education. Only a small percentage (15%) presented educational level of higher education. In general, families with worse socioeconomic status, have fewer resources for health, which may reflect in health-related behaviors.^{30, 31}

The success of dental treatment in totally dependent patients is undoubtedly influenced by the motivation of their caregivers, since hygiene will be performed by them. Therefore, the more they understand the harmful effects of inadequate oral hygiene, the closer they will be to prevention.¹⁹

Investment in oral health education is effective because it shows positive results to dental care related to caregivers of patients with special needs. This occurs because these people may not understand or be aware of the importance of oral care. ²⁵

The best motivational technique for oral health education is direct guidance. Its association with an educational video has proven to be an efficient method for the prevention of oral diseases.³² Thus, this study used, in addition to verbal information of guidance on oral hygiene and a balanced diet, an educational video, directed to caregivers of people with special needs.

This educational video was created with a simplified and easy-to-understand language for caregivers containing information about eating habits, oral hygiene, the evolution of dental caries and periodontal disease, oral biofilm and fluoride use as previously described.³³

Although most of the participants in the Interventionist Group demonstrated greater comprehension, represented by a higher number of correct answers, there was no significant difference when compared to the Control group. We can hypothesize that the level of understanding of the caregivers was high, with no statistically significant difference between the groups. This may have happened because of the constant dental monitoring received by the two groups at a specialized center (OROCENTRO), where this information is frequently emphasized. As it is a health center aimed in assisting people with special needs, patients and caregivers are advised about oral hygiene and balanced diet in all clinical consultations, which may have contributed to a similar degree of understanding between the groups, regardless of access to the educational video. In addition, establishing relationships with family support groups to reach out the parents and other caregivers improves patients' oral health.²⁶

The teaching method of transmitting information through audiovisual tools has been effective in other populations. The effectiveness has already been observed in several fields of medicine³⁴⁻³⁶ and dentistry^{37, 38} in the environment outpatient, and are easy and inexpensive to incorporate in healthcare settings.³⁸

Caregivers' level of understanding and educational level was also analyzed. Most of the caregivers (n = 35) had a high level of comprehension, with no statistical difference between the groups (p = 0.9027). The other caregivers presented an intermediate level of understanding, with no difference between the groups (p = 1.0000). The data showed that although the educational level of the caregivers is low, the information provided in the dental consultations and in the video helps the caregivers in understanding oral health care. According to previous studies, a video is a useful tool, especially for people with loweducation.³⁸

Regarding age, there was no statistical difference between the groups in the high level of understanding (p = 0.3784) and also in the intermediate level (p = 0.4000). With this sample it is not possible to say that older people have greater difficulty in understanding, although this correlation has already been observed in previous study, which showed that videos are of greater relevance to older people than to younger people.³⁹

These data showed that regardless of the social class and the age group of the caregiver, the knowledge about oral health and balanced diet seems to be adequate when the population is assisted at a specialized center. The provision of information on oral health education can contribute to the improvement of the health systems that support these people, such as OROCENTRO, providing the caregiver with a high level of understanding that can reflect positively on the care of the patient who needs special care.

The results presented should be viewed with caution as they only consider caregivers who already receive care at a specialized center. Future investigations are needed to increase the number of participants and better understand the contribution of audiovisual tools in the population of caregivers of people with special needs.

CONCLUSION

Although educational tools can contribute to the knowledge of caregivers, in the present study the results were not statistically significant, which can be attributed to the fact that both groups were assisted in a specialized dental center, where information about oral health and balanced diet is given to caregivers at every patient visit. However, future research is needed to increase the number of participants and better understand the contribution of audiovisual tools in the population of caregivers of people with special needs.

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2.2 ARTIGO: Subjective oral health measures in caregivers of patients with autism and Down syndrome: a preliminary study

CAPÍTULO 2 – Artigo submetido ao International Journal of Developmental Disabilities

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ABSTRACT

This study aimed to address the sociodemographic characteristics, sense of coherence (SOC), social support and outcome measures of oral health of caregivers of patients with Autism Spectrum Disorder (ASD) and Down syndrome. A total of 15 caregiversof children with ASD (n = 7), and Down syndrome (n = 8) were evaluated. Sociodemographic, SOC, social support, oral health-related quality of life (OHRQoL) and self-rated oral health were collected. Most patients have their parents as their primary caregiver, being the majority females (86.6%), aged between 40 and 59 years old (60%), and predominantly had from 9 to 11 years of study (53.3%). Regarding oral health, 33.3% of the caregivers reported as good and 33.3% neither good nor bad. The average score for SOC was 48.9, 69.3 for social support and 10.9 for OHRQoL. It is concluded that caregivers of patients with ASD and Down syndrome had a strong SOC, most of them reported high perceived support and did not report a high impact on OHRQoL. Understanding the caregiver's protective and coping factors in the face of the challenge of caring for a patient with special needs should be deepened in order to better promote quality of life for this population.

Keywords: Caregivers, Down syndrome, Autism Spectrum Disorder, Sense of coherence, Social support, Quality of life.

INTRODUCTION

Attention to parents and caregivers of individuals with special needs has been growing in recent years (Nordahl-Hansen *et al.* 2018). Patients with special care needs are those "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that are required by children generally" (McPherson *et al.* 1998). Data from the National Survey of Children with Special Health Care Needs indicated that 15.1% of children in the USA have special health needs, which occurs in 23% of households (NICE 2013)

Among mental and behavioral problems, conduct disorders and antisocial behavior are the most common in children and youth (NICE 2017). Autism Spectrum Disorder (ASD) is characterized by the presence of restricted interests, repetitive behaviors, deficits in social interaction and reciprocal social complication (*American Psychiatric Association. DSM-5 Task Force*. 2013). It is a neurodevelopmental disorder and is usually diagnosed in childhood (Wang *et al.* 2012). As a developmental disorder, ASD patients have their health and functioning profoundly affected (Boulet *et al.* 2009), reflecting on quality of life (NICE 2017).

Regarding genetic anomalies, Down syndrome is the most prevalent, being the most common genetic cause of intellectual disability (Kazemi *et al.* 2016). Children with this condition have characteristics such as low ears, small teeth, flattened nose, stunted, atypical growth and hypotonia. They also have developmental delay and constitute the majority of dental patients with special needs (Wang *et al.* 2012).

Parents of children with intellectual disabilities experience greater psychological distress and lower quality of life (Staunton *et al.* 2020). A recent study conducted with caregivers of children and young adults with disabilities, including ASD and Down's syndrome, revealed that the majority of caregivers were unemployed married mothers, with low education and health problems. In addition, older caregivers showed greater burden and greater impact on quality of life (Barros *et al.* 2019). Furthermore, caregivers are often physically tired and mentally frustrated, anxious, helpless, and hopeless (Caicedo 2014). As such, we hypothesized that the psychosocial factor (Sense of Coherence) and coping factor (social support), may have protective effects on perceived oral health and oral health-related quality of life of caregivers of patients with autism spectrum disorder and Down syndrome. However, there is little information on subjective indicators that may have an impact on the well-being and quality of life of this population. Thus, the objective of this study is to address the sociodemographic characteristics, sense of coherence, social support and outcome measures of oral health of caregivers of patients with ASD and Down syndrome.

METHODS

Ethical aspects

The research was carried out in accordance with the Declaration of Helsinki and approved by the Ethics Committee of the Piracicaba Dental School (protocol n^o 31448820.2.0000.5418). Caregivers gave electronic informed consent to participate in the study.

Study design, setting and participants

This cross-sectional study included 15 family caregivers who take care of the daily activities of children with ASD (n = 7) and Down syndrome (n = 8). The study was conducted at the Service of Diagnosis and Treatment of Oral Injuries, from the Piracicaba Dental School, University of Campinas (UNICAMP), Brazil, for dental treatment, from October to December 2020.

Data collection and study variables

The invitation to participate in the survey was sent by cell phone message, together with the electronic link to access Google Forms and the free and informed consent term. The electronic form was composed of sociodemographic characteristics (sex, age, educational level and family income), sense of coherence, social support and self-reported oral health outcome measures (oral health-related quality of life [OHRQoL] and self-rated oral health).

To assess the sense of coherence (SOC), a version of the SOC 13-item scale (Antonovsky 1987) adapted cross-culturally to the Portuguese language (Bonanato *et al.* 2009) was used. SOC-13 consists of thirteen questions answered on a five-point Likert scale. The scores of the questions that are negative to the sense of coherence are inverted for the final score composition. The final score is obtained by adding the scores on each of the 13 items and the higher the score, the greater the SOC.

The assessment of social support was performed using the instrument adapted from the Sherbourne and Stewart questionnaire (Sherbourne *et al.* 1991), in the version adapted for Brazil (Chor *et al.* 2001). The questionnaire has 19 items, in five dimensions: materialsupport; affective support; emotional support; positive social interaction and information

support. The total score is calculated by the average of the dimensions' scores, which are calculated by adding the values of the items (Griep *et al.* 2003).

To assess the OHRQoL, the Oral Health Impact Profile (OHIP -14) questionnaire (Slade 1997) was used, in the translated and validated version in Brazil (Oliveira *et al.* 2005). The instrument assesses, through individual self-perception, the biopsychosocial consequences of oral problems in seven dimensions: functional limitation, physical pain, psychological discomfort, physical disability, psychological disability, social disability and disability. Higher scores indicate a worse OHRQoL (Oliveira *et al.* 2005).

Self-rated oral health was assessed on a 5-point Likert scale, in response to thequestion: "In general, how do you consider your oral health status (teeth and gums)?" (Atchison *et al.* 1998). The response options are "Very good", "Good", "Neither good nor bad", "Bad", "Very bad".

Data analysis

The data were tabulated using the software Microsoft Excel, version 16.45 (Microsoft Excel, Microsoft Inc., Redmond, WA, USA). Then, the data were imported and analyzed using descriptive statistics in the SPSS software, version 25.0 (IBM SPSS Statistics forWindows, Version 25.0. Armonk, NY: IBM Corp). Exploratory nonparametric correlation analyzes were also performed between subjective oral health outcomes and the other variables, using the Spearman correlation coefficient.

RESULTS

Fifteen caregivers of patients with special needs were evaluated, seven with ASD and eight with Down syndrome. In general, most patients with special needs have their mother or father as their primary caregiver (86.6%), being the majority females (93.3%), aged between 40 and 59 years old (60%), and predominantly had from 9 to 11 years of study (53.3%). Most caregivers reported good oral health (33.3%) or neither good nor bad (33.3%). Regarding psychosocial variables, the sense of coherence had an average score of 48.9. The average score for social support was 69.3 and for OHRQoL the mean score was 10.9. The descriptive analysis of the data presented by the caregivers according to the type of special need is shown in the Table 1.

The correlation analyzes showed that the higher the family income, the better the OHRQoL (rs = -0.62, p = 0.014). The SOC also correlated to the score of the Emotional Support domain of the Social Support scale (rs = 0.54, p = 0.039). The OHIP -14 score was not associated with SOC (rs = -0.44, p = 0.097) or with social support (rs = 0.09, p = 0.737).

Table 1. Sociodemographic characteristics, psychosocial factors, social support, quality of life related to oral health and self-perceived oral health of caregivers of patients with ASD and Down syndrome.

VARIABLES	ASD N=7	Down syndrome N=8	Total N=15
Female	7 (100.0)	7 (87.5)	14 (93.3)
Male	-	1 (12.5)	1 (6.7)
Caregiver-patient			
relationship N (%)			
Father or mother	7 (100.0)	6 (75.0)	13 (86.6)
Brother or sister	-	1 (12.5)	1 (6.7)
Uncle or aunt	-	1 (12.5)	1 (6.7)
Age, N (%)			
Between 18 and 25 years	1 (14.2)	-	1 (6.7)
Between 26 and 39 years	3 (42.9)	2 (25.0)	5 (33.3)
Between 40 and 59 years	3 (42.9)	6 (75.0)	9 (60.0)
Socioeconomic level			
Years of schooling, N			
(%) 1 - 8	2(29.6)	1 (12 5)	F (22 2)
1 - 8 years	2 (28.6)	1(12.5)	5(33.3)
9 - 11 years	4(57.2) 1(14.3)	2 (25.0) 5 (62.5)	8 (55.5) 2 (13.4)
> 12 years	1 (14.3)	5 (02.5)	2 (13.4)
Family income/month, N			
(%)	4 (57.2)	1 (12 5)	5 (22 2)
	4(57.2)	1(12.3)	5(33.3)
>1 BMW ≤ 2 BMW	1(14.3)	3 (37.3) 4 (50.0)	4 (20.7)
>2 BMW \leq 5 BMW	1 (14.3)	4 (50.0)	5 (33.3)
>5 BMW ≤ 10 BMW	1 (14.3)	-	1 (6.7)
Psychosocial factors,			
mean (SD)			
Sense of coherence	48.9 (5.7)	49.4 (6.0)	48.9 (6.0)
Social support, mean (SD)			
Total	68.8(20.4)	70.9 (20.5)	69.3 (20.7)
Material Support	14.6(4.7)	15.0(4.7)	14.7 (4.7)
Affective Support	11.9 (3.6)	12.1 (3.2)	11.9 (3.2)
Emotional Support	13.8 (4.1)	14.3 (4.2)	14.0 (4.7)
Information support	14.2 (4.7)	14.8 (4.5)	14.3 (4.7)

				34
Social interaction support	14.4 (5.0)	14.6 (5.1)	14.5 (5.0)	
OHRQoL - OHIP-14,				
MEAN (SD)	11.1 (10.1)	11.6 (9.5)	10.9 (9.5)	
Functional limitations	0.9 (1.1)	1.0 (1.4)	0.9 (1.2)	
Physical pain	2.9 (2.2)	2.1 (1.6)	2.5 (1.9)	
Psychological discomfort	3.7 (2.9)	3.0 (2.1)	3.3 (2.4)	
Physical disability	0.9 (1.6	0.6 (0.9)	0.7 (1.2)	
Psychological disability	2.3 (3.4)	1.0 (0.9)	1.6 (2.4)	
Social disability	1.4 (2.5)	1.1 (1.5)	1.3 (1.9)	
Handicap	1.1 (1.3)	0.1 (0.4)	0.6 (1.4)	
-				
Self-rated oral health, N				
(%)				
Very good	2 (28.6)	1 (12.5)	3 (20.0)	
Good	1 (14.3)	4 (50.0)	5 (33.3)	
Neither good nor bad	3 (42.8)	2 (25.0)	5 (33.3)	
Bad	1 (14.3)	-	1 (6.7)	
Very bad	-	1 (12.5)	1 (6.7)	

ASD= Autism Spectrum Syndrome, SD=Standard Deviation, BMW= Brazilian Minimal Wage (One BMW was USD 186.28 in the study period.

DISCUSSION

Social determinants of health include the factors that influence, affect, or determine the health of individuals (WHO 2008). The literature has demonstrated the influence of social factors on health with evidence that they are powerful determinants of health (Braveman *et al.* 2014). Thus, income, education and employment can influence health-related behaviors (Stringhini *et al.* 2010).

The population of caregivers of patients with special needs, especially ASD and Down syndrome, has been characterized by low-educated mothers (Barros *et al.* 2019), as observed in the cases presented in the current study. It was also observed that the families of patients with ASD had a mensal income of less than one BMW, in addition to not having attended higher education. Unfortunately, this may reflect on access to health services, as previously reported. It has been reported that socioeconomic factors can be stressors that lead to delayed access for caregivers of patients with special needs (Donley *et al.* 2018).

In addition to knowledge of the impact of social determinants on health, the interest of the effect of psychosocial factors on the individual's health and consequently on the impact on quality of life is growing. The perception that strictly physiological measures are not sufficient to determine the health status of individuals is not new (Guyatt *et al.* 1994).Currently, health is also a reflection of the experiences of each individual, considering social

determinants, psychosocial factors, social support, behavior, among others (Guyatt *et al.* 1994; Braveman *et al.* 2014; Vettore *et al.* 2016).

The literature has shown that parents of children with intellectual disabilities experience increased psychological distress and worse quality of life (Caicedo 2014; Staunton*et al.* 2020). However, the mediators of this observation in this population have been little studied. The literature has already demonstrated in other populations, the protective effect of psychosocial factors (Li *et al.* 2002; Baker *et al.* 2010) and social support (Ong *et al.* 2018).

Antonovsky's salutogenic theory focuses on factors that support human health and wellbeing and not on the factors that cause the disease. Therefore, the theory seeks reasons that keep the individual healthy, considering that stressors are inherent to the human condition. In this context, the idea of the Sense of Coherence arises, defined as the individual's ability to adapt to a situation of adversity (Antonovsky 1979; Antonovsky 1987). The sense of coherence has been presented as an important determinant of the caregiver's well-being and can protect caregivers from high levels of psychological distress and burden (Del-Pino-Casado *et al.* 2019). The current study showed that the caregivers of patients with ASD and Down syndrome had a strong SOC, which ranged from 39 to 57, with an average of 48.9 for caregivers of patients with ASD and 49.4 for caregivers of patients with Down syndrome.

Another important aspect that can have a favorable impact on an individual's health and emotional well-being is social support. The social support scale aims to assess the extent to which a person has the support of others to face different situations in their life (Sherbourne*et al.* 1991), consequently, social support brings many benefits to caregivers when raising a child with a disability (Mantri-Langeveldt *et al.* 2019). A study with caregivers of elderly people diagnosed with physical and / or mental illness showed that the perceived social support mediates the association between resilience and caregiver burden among caregivers (Ong *et al.* 2018). In the current study, the social support received by caregivers varied widely, showing that some have material support, affective support, emotional support, positive social interaction and information support, while others do not. It was also observed that the emotional support received is related to the SOC, emphasizing the importance of strengthening the psychosocial variables in health care.

The family's quality of life has recently emerged, both to improve the living conditions of families of people with special needs and to evaluate the results in the services and support they receive (Balcells-Balcells *et al.* 2019). Conduct disorders almost alwayshave a significant impact on quality of life (NICE 2017). Parents of children with intellectual

disabilities experience greater psychological distress and lower quality of life (Staunton *et al.* 2020). OHRQoL represents the subjective experience of symptoms related to oral conditions that impact psychosocial well-being (Sischo *et al.* 2011). The literature has presented the perception of caregivers of patients with special needs regarding OHRQoL (Nqcobo *et al.* 2019; Faria Carrada *et al.* 2020; Wall *et al.* 2020). However, what attention has been paid to caregivers' self-rated oral health and OHRQoL? Little data is presented so far. A recent study reported that most caregivers of children with special needs have a negative impact on their OHRQoL (Cancio *et al.* 2018). Interestingly that the current study did not report a high impact on OHRQoL. Caregivers, particularly of patients with Down syndrome, reported a good state of oral health. However, the evidence for this observation needs to be investigated more comprehensively in this population.

The study has limitations and the data presented must be analyzed with caution as it is a preliminary study. Future investigations are needed to increase the number of cases and strengthen the observed evidence.

CONCLUSION

In summary, the current study showed that the caregivers of patients with ASD and Down syndrome had a strong SOC, most of them reported high perceived support and did not report a high impact on OHRQoL. In addition, this preliminary study showed the importance of understanding the caregiver's protection and coping factors in the face of the challenge of caring for a patient with special needs.
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2.3 ARTIGO: Profile of patients with dental treatment suspended in 2020 due to the Coronavirus pandemic: OROCENTRO report

CAPÍTULO 3 – Artigo submetido ao Jornal Brazilian Oral Research

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ABSTRACT

The objective of this study was to evaluate the number and profile of patients who were left without care at OROCENTRO during the Coronavirus pandemic in 2020. Allpatients who were scheduled for consultation between March 13 to December 2020 were included. Age, gender, city of origin, as well as base diagnosis and time, in years, in attendance were collected from electronic medical records. In total, 1,266 patients were left unattended during this period. Most were female (52,21%), predominantly aged in the 50s, 60s, and 70s, residing in the city of Piracicaba or nearby cities and the majority had been undergoing treatment for approximately 1 year. The basic disease, in order of frequency, observed in patients undergoing dental treatment was HIV, Squamous Cell Carcinoma, Autism, Down's Syndrome, Intellectual Disability and Hepatitis C. Among patients following oral lesions, the most frequent were Squamous Cell Carcinoma, Cheilitis Actinic, Lichen Planus, and Leukoplakia. The present study showed that a significant number of patients with diseases that need follow-up are no longer attended, which could have cause important impacts on oral health. In addition, these data can contribute to planning the return of clinical care by establishing priority criteria for appointments.

Keywords: Pandemic, Coronavirus, Oral Health, Diagnosis, Disabled persons.

INTRODUCTION

OROCENTRO is a stomatology clinic of the Department of Oral Diagnosis of the Piracicaba School of Dentistry - UNICAMP, which is a reference for public and private services and has been providing specialized care to the population of Piracicaba and the entire region for approximately 40 years. In this clinic, procedures are performed to diagnose and treat oral lesions, in addition to dental treatment forpatients with special needs. Within this group of patients with special needs, they include patients with infectious diseases, such as HIV and viral hepatitis B and C, cancer patients, patients with syndromes, patients with neurological and cognitive disabilities, among others.

As OROCENTRO has become a reference in its area of activity, it carries out approximately 1,000 monthly consultations, and approximately 100 new patients are registered per month. However, in the year 2020, it was not possible to carry out the consultations due to the pandemic of the Coronavirus and its worsening declared on March 11th, 2020, by the general director of the World Health Organization ¹ and by the measures established by UNICAMP.

With the worsening of the pandemic and a large number of cases and, consequently, deaths, there was a need to adopt restrictive measures to contain the contagion. Healthsystems around the world have suffered important, and in many cases, dramatic impacts. Consequently, innumerable restrictions were imposed, and healthcare services were forced to prioritize patients affected by this new disease.^{2, 3}

Regarding universities, it was no different, and all face-to-face activities were interrupted throughout Brazil. In addition to the damage to education and training of human resources, numerous health care services were also affected. In this context, services for the diagnosis of oral diseases are included, which in most cases are linked to the faculties of dentistry at universities throughout the country.⁴

With the impediment of face-to-face assistance, new biosafety protocols are being created by health agencies, in addition to creating and improving new care alternatives such as telehealth, which consists of online patient care.⁵⁻⁸ However, these alternatives may not be sufficient, since, especially in cases of oral lesions, clinical monitoring and, in many cases, biopsy for diagnosis is necessary.

In the spectrum of lesions that can occur in the oral cavity, malignant tumors and potentially malignant disorders deserve special attention. Patients with potentially malignant disorders, particularly patients with leukoplakia, erythroplasia, and actinic cheilitis, as well as patients who have been treated for oral malignancies and whose clinical follow-up was interrupted during the pandemic, may suffer important consequences. Consequently, these patients may experience a malignant transformation of these lesions, the development of recurrence or a second primary tumor, and lose the possibility of early diagnosis.⁹ It is known that early diagnosis is essential for successful treatment with a great impact on prognosis.²

As a consequence, a large number of patients may have a late diagnosis. In addition, patients who have already been diagnosed, those undergoing treatment, and those already treated for oral cancer need follow-up, as they may develop conditions that require evaluation and treatment, such as infections, radiation cavities, and osteonecrosis.

Patients with special needs, on the other hand, have a high degree of dental needs when compared to the general population. ^{10, 11} The most common dental problems in these patients are dental caries, periodontal disease, and consecutively fewer remaining teeth.^{11, 12}

Due to the motor, sensory, intellectual, or psychological disabilities, patients with special needs have difficulty performing their hygiene. Therefore, family members or caregivers are responsible for personal care. The difficulty in maintaining adequate oral hygiene is sufficient to explain the high incidence of oral diseases, in addition to other complications such as mouth breathing, malocclusion, macroglossia, bruxism, cariogenic diet, and side effects of medications, particularly hyposalivation. ^{13, 14}

To preserve and promote oral health, OROCENTRO performs procedures for the diagnosis of oral diseases and dental treatments in patients with special needs and guides and motivates caregivers regarding oral hygiene. However, due to the Coronavirus pandemic, these visits were interrupted, hypothetically, many people were left without care and could have damage to their oral health. Therefore, this survey will make it possible to identify patients in greatest need and establish strategies to return from clinical care, minimizing greaterdamage to oral health, caused by the interruption of activities imposed by the Coronavirus pandemic. Thus, the objective of the study was to evaluate the number and profile of patients who were left without care at OROCENTRO during the pandemic Coronavirus in 2020.

METHODOLOGY

Study design and population

The research was carried out from April to June 2021, at OROCENTRO (Service of Diagnosis and Treatment of Oral Injuries) Semiology Area, Faculty of Dentistry, UNICAMP, located in the city of Piracicaba, in the state of São Paulo, Brazil.

Ethical considerations

The research project was prepared according to the Declaration of Helsinki and approved by the Research Ethics Committee of the Faculty of Dentistry of Piracicaba (CAEE: 43608921.3.0000.5418).

Data collect

The data were collected in the OROCENTRO scheduling system. All patients who were scheduled for consultation from March 13, 2020, to December 2020, a period with suspended care due to the Coronavirus pandemic, were identified.

The time, in years, when patients are linked to the OROCENTRO, gender, age, city of origin, and base diagnosis were collected.

Statistical analysis

The data were tabulated and divided into two groups, one group of patients who were scheduled for diagnosis and monitoring of oral lesions and the other group of patients who were scheduled for dental treatment, and a descriptive statistic was performed.

The data obtained were tabulated using the Excel program, version 16.45 (Microsoft Excel, Microsoft Inc., Redmond, WA, USA).

RESULTS

A total of 1,266 patients were identified, of whom 196 were undergoing dental treatment and 1,070 were being monitored for oral lesions.

Among the patients undergoing dental treatment, the majority were male (60.71%) and aged between 51 and 60 years old (26.02%) (Table 1). Most of these patients (18.88%) had undergone dental treatment for 1 year, 11.7% had been followed between 10 and 20 years (Table 2).

The vast majority of these patients lived in the city of Piracicaba (68.88%), followed by nearby cities such as Rio Claro (5.10%) and Limeira (4.59%). However, patients from seventeen other cities were identified (Table 3). Concerning clinical profile related to the underlying disease, the majority of patients who were undergoing dental treatment were HIV + (24.49%), followed by Squamous Cell Carcinoma (13.78%), and by patients with autism spectrum disorder (5.10%), and Down's syndrome (4.59%) (Table 4).

Regarding patients following oral lesions, 54.58% were female and between 61 and 70 years old (28.13%). It is interesting to highlight those 7 patients (0.65%) were over 90 years old, and 21 patients (1.96%) were under 10 years old (Table 1). The majority (31.96%) were also being treated at OROCENTRO for 1 year, 11.9% had been in follow-up between 10 and 20 years. (Table 2).

It was observed that 51.40% lived in the city of Piracicaba, 5.98% in Rio Claro, and 5.42% in Limeira. Another 68 municipalities were listed (Table 5).

Most patients were being followed up due to the diagnosis of Squamous Cell Carcinoma (14.3%), followed by Actinic Cheilitis (9.53%), Lichen Planus (7.94%), and Leukoplakia (6.17%). Another 67 patients were scheduled for the first consultation. Table 6 shows the list of all oral diseases, corresponding to a total of 148 diagnoses.

VARIABLES	Patients in dental treatment		Patients in follow-up for oral lesions		
	N=196	%	N=1,070	%	
Gender					
Female	77	39.29	584	54.58	
Male	119	60.71	486	45.42	
Age in years					
< 10 years	18	9.18	21	1.96	
11 - 20	13	6.63	49	4.58	
21 - 30	13	6.63	44	4.11	
31 - 40	24	12.24	59	5.51	
41 - 50	34	17.35	121	11.31	
51 - 60	51	26.02	271	25.33	
61 - 70	32	16.33	301	28.13	
71 - 80	10	5.1	154	14.39	
81 - 90	1	0.51	43	4.02	
> 90	-	-	7	0.65	

Table 1. Sociodemographic characteristics of patients in dental treatment and those in followup for oral lesions.

	Patients in dental treatment		Patients in follow-up for oral lesions		
Time in years	N=196	%	N=1,070	%	
Less than 1 year	18	9.18	127	11.87	
1	37	18.88	342	31.96	
2	17	8.67	113	10.56	
3	20	10.20	92	8.6	
4	13	6.63	59	5.51	
5	20	10.20	51	4.77	
6	11	5.61	48	4.49	
7	8	4.08	34	3.18	
8	11	5.61	30	2.80	
9	5	2.55	29	2.71	
10	5	2.55	20	1.87	
11	1	0.51	18	1.68	
12	1	0.51	15	1.40	
13	3	1.53	14	1.31	
14	2	1.02	10	0.93	
15	2	1.02	11	1.03	
16	2	1.02	13	1.21	
17	3	1.53	11	1.03	
18	2	1.02	8	0.75	
19	2	1.02	8	0.75	
20	4	2.04	4	0.37	
21	1	0.51	2	0.19	
22	2	1.02	2	0.19	
23	1	0.51	3	0.28	
24	1	0.51	2	0.19	
25	1	0.51	1	0.09	
26	1	0.51	2	0.19	
27	1	0.51	1	0.09	
28	-	-	2	0.19	
29	1	0.51	1	0.09	

Table 2. Distribution of patients in dental treatment and those in follow-up for oral lesions

 according to the time they have been under treatment at the Orocentro.

City	n	%
Piracicaba	135	68.88
Rio Claro	10	5.10
Limeira	9	4.59
São Pedro	7	3.57
Americana	6	3.06
Capivari	6	3.06
Rio das Pedras	6	3.06
Charqueada	3	1.53
Iracemápolis	2	1.02
Tietê	2	1.02
Águas de São Pedro	1	0.51
Anhembi	1	0.51
Brotas	1	0.51
Elias Fausto	1	0.51
Mombuca	1	0.51
Nova Odessa	1	0.51
Pirassununga	1	0.51
Rafard	1	0.51
Santa Bárbara d'Oeste	1	0.51
Santa Gertrudes	1	0.51

Table 3. Distribution of patients undergoing dental treatment at OROCENTRO according to the city of origin (n=196).

Table 4. Distribution of patients undergoing dental treatment at OROCENTRO accordingIADH classification (n=196).

DISEASE	IADH CLASSIFICATION	Ν	DISTRIBUTION
Deviations Of Intelligence	Mental retardation.	8	7 Intellectual Handicapped 1 Early dementia
Physical Defects	Central nervous system: cerebral palsy; stroke; Parkinson's disease; neuromuscular system: progressive muscular dystrophy; myasthenia gravis; musculoskeletal system: arthritis; scoliosis; osteogenesis imperfecta; congenital malformations: myelomeningocele or spina bífida.	17	5 Cerebral Palsy 4 Hypoxia in labor 3 Osteoradionecrosis 2 Hydrocephalus 2 Bone changes 1 Parkinson's
Congenital Defects	Disorders arising from chromosomal abnormalities; genetic mutations.	13	9 Down Syndrome 1 Ectodermic dysplasia 1 Moebius S. 1 Prader Willi S. 1 Sjőgren S.
Behavioural Deviations	Brain dysfunction; fear; anxiety; tantrums; shyness; aggressiveness; autismo.	10	10 Autism Spectrum Desorden
Psychic Deviations	Neuroses; psychoses; schizophrenia.	1	1 Schizophrenia
Chronic Systemic Diseases	Hemopathies; cardiopathies; nephropathies; pneumopathies; convulsive disorders; neoplasms; AIDS.	118	 48 HIV+ 27 Cancer treatment support 6 Hepatitis C 4 Actinic cheilitis 4 Chronic renal failure 4 Hemophiliac 3 Anticoagulated 3 Lupus 2 Von Willebrand's disease 1 Hematologic alteration 1 Arthritis 1 AVC 1 Cardipathy 1 Colorectal tumor 1 Degenerative Optic 1 HBV + 1 Idiopathic 1 Linear Epidermal Nevus 1 Metastatic breast câncer 1 Multiple sclerosis 1 Neurofibromatosis 1 Neuropathy 1 Pemphigus 1 Pemphiguid 1 Sickle cell anaemia 1 TB/ MIH 1 Thrombocytopenia
Other	Oral diseases and occlusal alteration transplanted and undiagnosed.	29	4 Transplanted 1 Adult Gingival Cyst 1 Florid Cemento-osseous Dysplasia 1 Hereditary Gingival Fibromatosis 1 Inflammatory Gingival Hyperplasia 1 Inflammatory Periapical Cyst 1 Leukoplakia 1 Ortal ulcerations 1 Ortodonthic 1 Periapical Bone Dysplasia 1 Peripheral Giant Cell Lesion 15 No Diagnosis

City	n	n % City		n	%
Piracicaba	550	51.40	Mogi Mirim	2	0.19
Rio Claro	64	5.98	Porto Feliz	2	0.19
Limeira	58	5.42	Salto	2	0.19
			Santa Cruz das		
Rio das Pedras	38	3.55	Palmeiras	2	0.19
São Pedro	35	3.27	São José do Rio Pardo	2	0.19
Capivari	30	2.80	Águas de Santa Barbara	1	0.09
Americana	27	2.52	Alpinópolis	1	0.09
Santa Barbara D'Oeste	24	2.24	Arthur Nogueira	1	0.09
Saltinho	24	2.24	Boituva	1	0.09
Tietê	24	2.24	Caconde	1	0.09
Charqueada	17	1.59	Casa Branca	1	0.09
Iracemápolis	17	1.59	Cesário Lange	1	0.09
Itatinga	11	1.03	Conchal	1	0.09
Cerquilho	10	0.93	Conchas	1	0.09
Vinhedo	9	0.84	Corumbataí	1	0.09
Elias Fausto	8	0.75	Divinolândia	1	0.09
Rafard	8	0.75	Holambra	1	0.09
Vargem Grande do Sul	8	0.75	Indaiatuba	1	0.09
Águas de São Pedro	7	0.65	Ipeúna	1	0.09
Nova Odessa	7	0.65	Itapetinga	1	0.09
Campinas	5	0.47	Itapira	1	0.09
Leme	5	0.47	Itu	1	0.09
Laranjal Paulista	4	0.37	Junqueirópolis	1	0.09
Pirassununga	4	0.37	Jumirim	1	0.09
Santa Maria da Serra	4	0.37	Louveira	1	0.09
São João da Boa Vista	4	0.37	Mombuca	1	0.09
Sumaré	4	0.37	Mogi Guaçu	1	0.09
Tambaú	4	0.37	Porto Ferreira	1	0.09
Araras	3	0.28	Praia Grande	1	0.09
Cordeirópolis	3	0.28	Ribeirão Preto	1	0.09
			Santa R. do Passa		
Jundiai	3	0.28	Quatro	1	0.09
Santa Gertrudes	3	0.28	Tapiratiba	1	0.09
Cosmópolis	2	0.19	Tatuí	1	0.09
Engenheiro Coelho	2	0.19	Valinhos	1	0.09
Hortolândia	2	0.19	Várzea Paulista	1	0.09
Monte Sião	2	0.19			

Table 5. Distribution of patients in follow-up for oral lesions according to the city of origin inOROCENTRO (n=1,070).

Squamous cell carcinoma15314.30Metastasis20.19Actinic Cheilitis1029.53Exfoliative Cheilitis20.19Lichen planus857.94Cherubism20.19Leukoplakia666.17Paresthesia20.19Fibrous hyperplasia454.21Cowden Syndrome20.19Proliferative Verrucous Leukoplakia343.18Gorlin Goltz Syndrome20.19Periapical Cyst262.43Amalgam Tattooing20.19Reactive Hyperkeratosis252.34Periapical abscess10.09Periapical Cemento-Osseous Dysplasia211.96Follow-up after RXT10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications10.09	Disease	n	%	Disease	n	%
Actinic Cheilitis1029.53Exfoliative Cheilitis20.19Lichen planus857.94Cherubism20.19Leukoplakia666.17Paresthesia20.19Fibrous hyperplasia454.21Cowden Syndrome20.19Proliferative Verrucous Leukoplakia343.18Gorlin Goltz Syndrome20.19Periapical Cyst262.43Amalgam Tattooing20.19Reactive Hyperkeratosis252.34Periapical abscess10.09Periapical Cemento-Osseous Dysplasia211.96Follow-up after RXT Hypoplastic10.09Burning mouth syndrome161.5Imperfecta10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications Calcification10.09	Squamous cell carcinoma	153	14.30	Metastasis	2	0.19
Lichen planus857.94Cherubism20.19Leukoplakia666.17Paresthesia20.19Fibrous hyperplasia454.21Cowden Syndrome20.19Proliferative Verrucous Leukoplakia343.18Gorlin Goltz Syndrome20.19Periapical Cyst262.43Amalgam Tattooing20.19Reactive Hyperkeratosis252.34Periapical abscess10.09Periapical Cemento-Osseous Dysplasia211.96Follow-up after RXT Hypoplastic Amelogenesis10.09Burning mouth syndrome161.5Imperfecta10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications Calcification10.09	Actinic Cheilitis	102	9.53	Exfoliative Cheilitis	2	0.19
Leukoplakia666.17Paresthesia20.19Fibrous hyperplasia454.21Cowden Syndrome20.19Proliferative Verrucous Leukoplakia343.18Gorlin Goltz Syndrome20.19Periapical Cyst262.43Amalgam Tattooing20.19Reactive Hyperkeratosis252.34Periapical abscess10.09Periapical Cemento-Osseous Dysplasia211.96Follow-up after RXT Hypoplastic10.09Burning mouth syndrome161.5Imperfecta10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications Calcification10.09	Lichen planus	85	7.94	Cherubism	2	0.19
Fibrous hyperplasia454.21Cowden Syndrome20.19Proliferative Verrucous Leukoplakia343.18Gorlin Goltz Syndrome20.19Periapical Cyst262.43Amalgam Tattooing20.19Reactive Hyperkeratosis252.34Periapical abscess10.09Periapical Cemento-Osseous Dysplasia211.96Follow-up after RXT Hypoplastic10.09Burning mouth syndrome161.5Imperfecta10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications Calcification10.09	Leukoplakia	66	6.17	Paresthesia	2	0.19
Proliferative Verrucous Leukoplakia343.18Gorlin Goltz Syndrome20.19Periapical Cyst262.43Amalgam Tattooing20.19Reactive Hyperkeratosis252.34Periapical abscess10.09Periapical Cemento-Osseous Dysplasia211.96Follow-up after RXT10.09Burning mouth syndrome161.5Imperfecta10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications10.09	Fibrous hyperplasia	45	4.21	Cowden Syndrome	2	0.19
Periapical Cyst262.43Amalgam Tattooing20.19Reactive Hyperkeratosis252.34Periapical abscess10.09Periapical Cemento-Osseous Dysplasia211.96Follow-up after RXT10.09Burning mouth syndrome161.5Imperfecta10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications10.09	Proliferative Verrucous Leukoplakia	34	3.18	Gorlin Goltz Syndrome	2	0.19
Reactive Hyperkeratosis252.34Periapical abscess10.09Periapical Cemento-Osseous Dysplasia211.96Follow-up after RXT Hypoplastic10.09Burning mouth syndrome161.5Imperfecta10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications Calcification10.09	Periapical Cyst	26	2.43	Amalgam Tattooing	2	0.19
Periapical Cemento-Osseous Dysplasia211.96Follow-up after RXT Hypoplastic10.09Burning mouth syndrome161.5Imperfecta10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications Calcification10.09	Reactive Hyperkeratosis	25	2.34	Periapical abscess	1	0.09
Burning mouth syndrome161.5Imperfecta10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications10.09CalcificationoftheStyle-	Periapical Cemento-Osseous Dysplasia	21	1.96	Follow-up after RXT	1	0.09
Burning mouth syndrome161.5Imperfecta10.09Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications10.09CalcificationoftheStyle-	During month and damage	16	15	Hypoplastic Amelogenesis	1	0.00
Frictional Keratosis111.03Bone marrow aplasia10.09Mucocele111.03Lymph node calcifications10.09CalcificationoftheStyle-	Burning mouth syndrome	10	1.5	Imperfecta	1	0.09
Calcification of the Style-	Frictional Keratosis	11	1.03	Bone marrow aplasta	1	0.09
	Mucocele	11	1.05	Calcification of the Style-	1	0.09
Pleomorphic adenoma 10 0.93 Hyoid Ligament 1 0.09	Pleomorphic adenoma	10	0.93	Hyoid Ligament	1	0.09
Florida Cemento-Bone Dysplasia 10 0.93 Cementoblastoma 1 0.09	Florida Cemento-Bone Dysplasia	10	0.93	Cementoblastoma	1	0.09
Osteonecrosis 10 0.93 Actinic keratosis 1 0.09	Osteonecrosis	10	0.93	Actinic keratosis	1	0.09
Fibrous Scar from				Fibrous Scar from		
Keratocyst100.93Odontogenic Cyst10.09	Keratocyst	10	0.93	Odontogenic Cyst	1	0.09
Varicose vein100.93Epidermoid Cyst10.09	Varicose vein	10	0.93	Epidermoid Cyst	1	0.09
Reactive Lymph Node100.93Eruption Cyst10.09	Reactive Lymph Node	10	0.93	Eruption Cyst	1	0.09
Idiopathic Osteosclerosis100.93Parotid Cyst10.09	Idiopathic Osteosclerosis	10	0.93	Parotid Cyst	1	0.09
Paracoccidioidomycosis90.84Gingival Cyst of the Adult10.09	Paracoccidioidomycosis	9	0.84	Gingival Cyst of the Adult	1	0.09
Candidiasis80.75Gingival Cyst of the Newborn10.09	Candidiasis	8	0.75	Gingival Cyst of the Newborn	1	0.09
Hemangioma80.75Calcifying Odontogenic Cyst10.09	Hemangioma	8	0.75	Calcifying Odontogenic Cyst	1	0.09
Lichenoid reaction80.75Lateral Periodontal Cyst10.09	Lichenoid reaction	8	0.75	Lateral Periodontal Cyst	1	0.09
Torus/ Exostosis80.75Osteoporotic Jaw Defect10.09	Torus/ Exostosis	8	0.75	Osteoporotic Jaw Defect	1	0.09
Traumatic Ulcer80.75Tooth without eruption10.09	Traumatic Ulcer	8	0.75	Tooth without eruption	1	0.09
Stomatitis70.65Supernumerary teeth10.09	Stomatitis	7	0.65	Supernumerary teeth	1	0.09
Multiple Myeloma70.65Cleidocranial Dysplasia10.09	Multiple Myeloma	7	0.65	Cleidocranial Dysplasia	1	0.09
Prosthetic mucositis70.65Intense Dysplasia10.09	Prosthetic mucositis	7	0.65	Intense Dysplasia	1	0.09
Osteoradionecrosis 7 0.65 Edema on Face 1 0.09	Osteoradionecrosis	7	0.65	Edema on Face	1	0.09
Papiloma 7 0.65 Lip Edema 1 0.09	Papiloma	7	0.65	Lip Edema	1	0.09
Ranula 7 0.65 Exostosis 1 0.09	Ranula	7	0.65	Exostosis	1	0.09
Lymphoepithelial Cyst60.56Congenital Epulid10.09	Lymphoepithelial Cyst	6	0.56	Congenital Epulid	1	0.09
Erythroleukoplakia60.56Gingival Fibromatosis10.09	Erythroleukoplakia	6	0.56	Gingival Fibromatosis	1	0.09
Melanotic macula60.56Gingivitis10.09	Melanotic macula	6	0.56	Gingivitis	1	0.09
Eibro Bone Lesion 6 0.56 Cincivitia 1 0.00	Fibro Bone Lesion	6	0.56	Localized Juvenile Spongiotic	1	0.00
Linoma 6 0.56 Perianical Granuloma 1 0.09	Lipoma	6	0.50	Oligivius Perianical Granuloma	1 1	0.09
Nonspecific Ulcer60.56Fordyce granules10.09	Nonspecific Ulcer	6	0.56	Fordyce granules	1	0.09

Table 6. Distribution of patients in follow-up for oral lesions according to the underlying disease at OROCENTRO (n=1,070).

Dentigerous Cyst	5	0.47	Hepatitis C	1	0.09
Mucus Retention Cyst in Maxillary Sinus	5	0.47	Hyperplasia Epithenai	1	0.09
Nasopalatine Duct Cyst	5	0.47	Lingual tonsil hypertrophy	1	0.09
Ossifying fibroma	5	0.47	Radiolucent Image	1	0.09
Fistula	5	0.47	Incidentaloma	1	0.09
Lymphoma	5	0.47	Local Infection	1	0.09
Odontoma	5	0.47	Leishmaniasis	1	0.09
Pemphigoid	5	0.47	Leukoedema	1	0.09
Sialodenitis	5	0.47	Geographic Language	1	0.09
Trauma	5	0.47	Port Wine Stains	1	0.09
Simple bone cyst	5	0.47	Melanoma	1	0.09
Nonspecific/myofascial pain	4	0.37	Morsicatio Buccarum	1	0.09
Glossitis	4	0.37	Salivary Gland Neoplasia	1	0.09
Pyogenic Granuloma	4	0.37	Neurofibroma	1	0.09
Gingival hyperplasia	4	0.37	Neurofibromatosis	1	0.09
Giant Cell Lesion	4	0.37	Linear Epidermal Nevus	1	0.09
Vascular Malformation	4	0.37	Oligodontia	1	0.09
Pemphigus Vulgaris	4	0.37	Odonto - Hypophosphatasia	1	0.09
Angular Cheilitis	4	0.37	Peri - Implantitis	1	0.09
Temporomandibular Dysfunction	3	0.28	Racial pigmentation	1	0.09
Focal Bone Dysplasia	3	0.28	Antral Pseudocyst	1	0.09
Hemangiolymphagioma	3	0.28	Foreign Body Reaction	1	0.09
Periapical Radiolucent Lesion	3	0.28	Lip dryness	1	0.09
Condensing Osteitis	3	0.28	Sarcoidosis	1	0.09
No lesion	3	0.28	Proteus Syndrome	1	0.09
Eosinophilic ulcer	3	0.28	Drug Reaction Syndrome	1	0.09
Xerostomia/ Hypossalivation	3	0.28	Sjogren's Syndrome	1	0.09
Stafne Bone Defect	2	0.19	Sturge Weber Syndrome	1	0.09
	-		Mentonian Nerve		
Epithelial Dysplasia	2	0.19	Superficialization	1	0.09
Ameloblastoma	2	0.19	Salivary Gland Tumor	1	0.09
Residual cyst	2	0.19	Hyperparathyroidism	1	0.09
Monostotic Fibrous Dysplasia	2	0.19	Benign Mesenchymal Tumor	1	0.09
Bone Lesion	2	0.19	Warthin Tumor	1	0.09
			Melanocytic Neuroectodermal		
Vesiculobullous Lesion	2	0.19	Tumor	1	0.09
Cervical Lymphadenopathy	2	0.19	Medication Ulcer	1	0.09
Supraclavicular lymphadapopathy	r	0.10	Bone Abnormality in the	1	0.00
Systemic lupus erythematosus	2	0.17	wianulute	1	0.09
	2	0.19	First consultation	67	6.26

DISCUSSION

Due to the rapid spread of COVID-19 throughout the country, dentists had to postpone elective dental procedures, mainly due to the production of aerosol that can be a significant source of disease transmission in the community.¹⁵ Consequently, they only had to perform urgent and emergency care, according to recommendations from the Ministry of Health.¹ Following the norms, OROCENTRO of the Faculty of Dentistry of Piracicaba canceled on March 13, 2020, all the presential activities and started to postpone the dental treatment of patients with special needs as well as the care of patients who were scheduled for diagnosis and monitoring of injuries buccal. The Coronavirus pandemic led to changes in care, exposed significant gaps in the collective response of global health systems to a public health emergency.¹⁶

These factors may reflect, over time, a large number of people in the country in need of dental treatment. In the present study, it was observed that the majority of patients with suspended appointments had started dental treatment or were being followed up by oral lions between 1 and 2 years old. It is worth mentioning that 23 (11.7%) patients undergoing dental treatment and 128 (11.9%) of the patients undergoing oral lesions were being monitored at OROCENTRO for over 10 years, respectively. In addition, 13 (6.6%) and 17 (1.5%) had been followed up for over 20 years. These data show that the dental treatment of patients with special needs and patients following oral lesions is a long process and often these patients are cared for and monitored throughout their lives.

The profile of patients undergoing treatments showed a predominance of the male gender (60.71%). On the other hand, there was a higher frequency of women among patients undergoing oral lesions (44.42%). Previous studies have shown that the presence of men in primary health care services is lower than that of women¹⁷ and that they suffer more from severe and chronic health conditions than women.^{18, 19}

Regarding the age of the patients, it was possible to observe that OROCENTRO has a wide age group, from children to the elderly. Among patients with special needs, those aged between 50 and 60 years old predominated, while for patients with oral lesions, the predominant age was between 60 and 70 years old. It is worth mentioning that among patients

with special needs, 9.18% were younger than 10 years old and 5.61% were older than 70 years. On the other hand, 1.96% and 19.06% of patients diagnosed with oral lesions were under 10 years old and over 70 years old, respectively. These data showed that, in general, diagnostic patients are older than patients with special needs.

As reported before, the risk of developing oral cancer increases with age and most cases occur in people aged 50 or over.²⁰ In addition, with increasing age, changes in the organic system may occur, the immune system becomes less potent, the use of medications is more common and may lead to the development of dry mouth, altered taste, decreased motor coordination, low self-esteem, and several factors that contribute to an increase in oral diseases.²¹ These data may justify higher ages in patients with oral lesions.

The distribution of patients according to the city of origin showed that although OROCENTRO serves patients from several cities, the vast majority lived in the city of Piracicaba itself, corresponding to 68.88% of patients undergoing dental treatment and 51.04% of patients following oral lesions. Another 20 and 71 cities were identified, respectively for these groups. In addition to being composed of patients from different municipalities, patient care for the diagnosis of oral lesions was also composed of more distant cities, showing that OROCENTRO, for decades, has been a reference service in this type of care, also evidencing the scarcity of service for the same purpose in the region.

Regarding the clinical profile of patients undergoing dental treatment, the majority was composed of HIV patients (24.49%), followed by patients who had oral squamous cell carcinoma (13.78%), patients with autism spectrum disorder (5.10%), and with Down Syndrome (4.59%). Other underlying diseases were intellectual disability, hepatitis, and cerebral palsy.

In addition, oral health care can improve the health-related quality of life of patients with HIV / AIDS.²² Since these patients have a higher DMFT index, associated with a worse quality of life-related to oral health.²³

Patients with infection by the hepatitis C virus may also have important oral changes such as lichen planus and xerostomia.²⁴ Therefore, they are people who need more effective health education and constant monitoring with the dentist.

People with special needs such as autism, Down syndrome, intellectual disability, and cerebral palsy are a group of people who also have a high degree of unmet dental needs when compared to the general population.^{10, 11}

In the oncology field, therapeutic approaches for the treatment of the tumor usually result in side effects and an impact on the quality of life.^{25, 26} In general, patients with tumors

in the oral cavity are among the worst quality of life rates when compared to patients with tumors in other regions.²⁷ Specifically, OHRQoL represents the subjective experience of symptoms related to oral conditions that impact psychosocial well-being.²⁸

Concerning patients who were being monitored for oral lesions, squamous cell carcinoma was the most frequent, corresponding to 153 patients (14.3%). Potentially malignant disorders were the second most common group. Adding the patients with actinic cheilitis (9.53%), lichen planus (7.94%), and leukoplakia (6.17%), a total of 253 (23.64%) were identified. The follow-up of these patients is mandatory since they present an increased risk of developing squamous cell carcinoma ²⁹. Furthermore, it was reported that the highest mortality and morbidity rates of oral mucosa neoplasms are due to late diagnosis.²⁹

CONCLUSION

In conclusion, the data presented showed that the suspension of patient care at OROCENTRO during 2020, due to the Coronavirus pandemic, could contribute to the worsening of the oral condition of patients with special needs and the aggravation and/or development of oral diseases. The data also allows us to better understand the profile of patients who have not been seen, and to contribute to the planning of return to clinical care by establishing priority criteria.

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3 DISCUSSÃO

O estudo de Hinrichsen & Niederehe (1994) evidenciou que a função de cuidar de pessoas com necessidades especiais comumente é exercida por um membro da família. O cuidador é o principal responsável pelas condições de saúde bucal do paciente, sendo importante que esta pessoa tenha clareza da importância da prevenção e da educação odontológica (Khanagar et al., 2014).

Através do primeiro e segundo estudos apresentados, foi possível observar o perfil dos cuidadores dos pacientes com necessidades especiais que são atendidos no OROCENTRO. No primeiro estudo a maioria dos pacientes com necessidades especiais tinham como cuidador principal os pais, sendo 90% no Grupo Controle e 85% no Grupo Intervencionista. No segundo estudo 86.6% dos cuidadores eram os pais sendo a maioria do sexo feminino. Resultados semelhantes foram observados nos estudos de Petrova et al. (2014) e de Barros et al. (2019) em que a maioria dos cuidadores eram as mães.

Outra informação destacada foi em relação ao nível de escolaridade dos cuidadores, nos dois estudos a maioria tinha completado o ensino médio, sendo 40% no Grupo Controle, 50% no Grupo Intervencionista e 53,3 % no segundo estudo. Shah et al. (2018) também demonstrou que a maioria concluiu até o ensino médio, sendo 80% dos cuidadores. Já em Barros et al. (2019) a maioria possuia somente o ensino fundamental completo. Desta forma, épossível notar que geralmente estas pessoas não possuem um alto nível de escolaridade.

Em relação à idade dos cuidadores foram observadas no primeiro estudo médias de 46,05 anos no Grupo Controle e de 39,15 anos no Grupo Intervencionista. No segundo estudo 60% possuíam entre 40 e 59 anos de idade. Estes resultados foram semelhantes aos observados por Petrova et al. (2014), em que a média das idades dos cuidadores foi de 41,8 anos e dos estudos de Shah et al. (2018) e Barros et al. (2019) em que a maioria dos cuidadores tinham entre 26 a 35 anos e 21 a 40 anos, respectivamente. Esses resultados ressaltam que em geral a idade dos cuidadores dos pacientes com necessidades especiais está próxima ou acima dos 40 anos de idade.

Considerando o conhecimento sobre saúde bucal dos cuidadores, o primeiro estudo demonstrou que os recursos audiovisuais podem ser utilizados como ferramenta educativa para contribuir no conhecimento dos cuidadores sobre a saúde bucal. Outros estudos como o de González-Arriagada et al. (2013) e Fernandes et al. (2020) também demonstraram aeficácia dessa ferramenta em relação a melhora da compreensão dos pacientes e cuidadores diante das informações dadas pelo profissional de saúde.

Os cuidadores dos pacientes analisados no primeiro estudo e que assistiram o vídeo (grupo intervencionista) tiveram maior taxa de respostas certas que os cuidadores do grupo controle. Entretanto, a diferença não foi estatisticamente significante. Podemos supor que não foi possível observar diferença, devido ao amparo a todos os cuidadores em um centro especializado como o OROCENTRO, possibilitando assim um conhecimento adequado sobre saúde bucal e alimentação equilibrada. Por outro lado, Stiefel (2002), observou deficiência na conscientização entre os cuidadores, os quais na maioria das vezes têm baixo nível de compreensão sobre saúde bucal.

Como o cuidador principal é a pessoa que despende um tempo maior com os cuidados do indivíduo com necessidades especiais, ela pode estar exposta a uma série deconsequências, podendo assim, vir a ter desgastes físicos, psicológicos ou emocionais devidoà sobrecarga a que está submetido (Braccialli et., 2012). Desta forma, estas pessoas acabam tendo um impacto negativo na qualidade de vida.

O segundo estudo apresentado mostrou que a maioria dos cuidadores de pacientes com Transtorno do Espectro Autista e Síndrome de Down relataram ter uma boa saúde (33,3%) ou uma saúde nem boa e nem ruim (33,3%). Em relação às variáveis psicossociais as pontuações foram: Senso de Coerência média de 48,9, suporte social média de 69,3 e para OHRQoL média de 10,9. A avaliação subjetiva de OHRQoL reflete o conforto das pessoas ao comer, dormir e se envolverem interação social, e sua satisfação com relação à saúde bucal (Kleinman, 2002), sendo o resultado de uma interação entre as condições de saúde bucal, fatores sociais e contextuais (Locker et al., 2005) e o resto do corpo (Atchison et al., 2006).

Sendo assim, é interessante notar que neste estudo a maioria dos cuidadores relataram um senso de coerência forte, a maioria deles relatou um elevado apoio percebido e não relatou um impacto elevado na qualidade de vida relacionada a saúde bucal. Já um estudo semelhante de Cancio et al. (2018) demostrou que a maioria dos cuidadores de crianças com necessidades especiais relataram um impacto negativo em sua OHRQoL. Neste contexto, são necessárias investigações futuras que poderão medir o impacto das disparidades de saúde bucal na saúde geral e na qualidade de vida dos cuidadores de pacientes com necessidades especiais (Sischo & Broder, 2011).

Os últimos dados a serem discutidos se encontram no terceiro estudo, onde foi observado que devido a Pandemia do Coronavírus, 1.266 pacientes que estavam em tratamento odontológico ou em acompanhamento de lesões bucais no OROCENTRO ficaram sem atendimento no ano de 2020.

É importante destacar que muitos pacientes que possuem lesões bucais precisam de um acompanhamento clínico contínuo, particularmente os pacientes com desordens potencialmente malignas e pacientes que foram tratados de alguma malignidade, visto que estas lesões podem apresentar recorrência ou transformação maligna. Além disso, os pacientes podem também desenvolver um segundo tumor primário, e o diagnóstico precoce é essencial para um melhor prognóstico (Da Cunha et al., 2020).

Os especialistas em medicina oral desempenham um papel importante no alívio dos efeitos colaterais orais do tratamento oncológico, garantindo que os pacientes sejam capazes de manter a saúde e função bucal adequadas, bem como manter seu tratamento programado sem interrupção (Lalla et al., 2017). Portanto, pacientes que estão passando por tratamento oncológico também requerem visitas regulares ao dentista para receber cuidados e serem avaliados quanto aos efeitos colaterais decorrentes do tratamento (Alves et al., 2021).

A quarentena forçada de pacientes com câncer pode resultar em atrasos indesejáveis associados ao próprio tratamento do câncer e na exacerbação dos efeitos colaterais orais, o que pode piorar o prognóstico da doença (Werner, et al.,2020).

Outra preocupação é em relação aos pacientes que estão predispostos aos fatores de riscos das doenças bucais. Segundo o estudo de Watt & Sheiham (2012) os fatores de risco comuns para desenvolver doenças bucais incluem estresse, dieta pobre, uso de álcool etabaco, uso indevido de substâncias, problemas de saúde comportamental, violência doméstica e pobreza. Sendo assim, os pacientes com necessidades especiais se enquadram no grupo de risco para desenvolver doenças bucais, como cárie e doença periodontal (Anders & Davis, 2010). O grau de limitação física e/ou mental, a dificuldade da realização da higiene bucal, a dieta alimentar, geralmente rica em carboidratos e alimentos pastosos, são fatores que favorecem o acúmulo de placa bacteriana e, consequentemente, o aparecimento dessas patologias (Resende et al., 2007).

Dessa maneira é possível pressupor que o não atendimento odontológico durante este período pode contribuir para a piora da condição bucal dos pacientes com necessidades especiais. Visto que a participação regular do cirurgião dentista neste contexto é extremamente importante porque tem papel essencial nas orientações necessárias aos cuidadores para a promoção de saúde bucal e bem-estar do paciente, além de atuar regularmente na execução de procedimentos de higienização e reabilitação (Oredugba & Akindayomi, 2008; Pini et al., 2016).

Os resultados destes estudos possibilitaram conhecer melhor os cuidadores dos pacientes com necessidades especiais, assim como o perfil dos pacientes que não foram

atendidos durante a pandemia. Estas informações serão extremamente úteis para planejar o retorno ao atendimento clínico estabelecendo critérios de prioridade.

4 CONCLUSÃO:

• A maioria dos pacientes com necessidades especiais do OROCENTRO tem como cuidador principalmente os pais, sendo a maioria do sexo feminino, com idade entre 40 e 60 anos e com estudo até o ensino médio;

• Independente da classe social e da idade do cuidador, o conhecimento em relação a saúde bucal e alimentação equilibrada parece ser adequado quando a população é atendida em um centro de referência;

• Embora as ferramentas educacionais possam contribuir para o conhecimento dos cuidadores, no presente estudo os resultados não foram estatisticamente significantes, o que pode ser atribuído ao fato dos dois grupos serem assistidos em um centro especializado, onde as informações sobre a saúde bucal e alimentação equilibrada são trabalhadas com os cuidadores em todas as consultas. Sendo necessários novos estudos para investigar melhor a contribuição das ferramentas audiovisuais na população de cuidadores de pessoas com necessidades especiais.

• Cuidadores de pacientes com Transtorno do Espectro Autista e Síndrome de Down tiveram um forte Senso de Coerência, a maioria relatou alto apoio social percebido e não relatou um alto impacto na OHRQoL;

• A compreensão dos fatores de enfrentamento do cuidador frente ao desafio de cuidar de um paciente com necessidades especiais deve ser aprofundada, a fim de melhor promover a qualidade de vida dessa população;

• Um total de 1.266 pacientes ficaram sem atendimento no OROCENTRO durante a pandemia do Coronavírus no ano de 2020;

• A maioria dos pacientes que ficaram sem atendimento são do sexo feminino, com idade entre as décadas de 50, 60 e 70, residentes na cidade de Piracicaba ou cidades próximas e estavam em tratamento há aproximadamente 1 ano;

• As doenças base desses pacientes que ficaram sem atendimento por ordem de frequência foram HIV (Vírus da Imunodeficiência Humana), Carcinoma Espinocelular, Autismo, Síndrome de Down, Deficiência Intelectual e Hepatite C. Em relação aos pacientes em acompanhamento de lesões e diagnóstico foram observadas com maior frequência Carcinoma Espinocelular, Queilite Actínica, Líquen Plano e Leucoplasia;

• A suspensão do atendimento aos pacientes no OROCENTRO devido a pandemia do Coronavírus poderá contribuir para o agravamento da condição bucal e ou desenvolvimento de doenças bucais;

• Os dados do perfil dos pacientes podem contribuir para o planejamento do retorno ao atendimento clínico, estabelecendo critérios de prioridade.

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ANEXOS ANEXO 1 - Comprovante de submissão artigo 2.1

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Sincerely, Journal of Dental Education Editorial Office

ANEXO 2 - Comprovante de submissão artigo 2.2

------ Forwarded message ------De: <<u>rpsupport@tandf.co.uk</u>> Date: sex., 30 de abr. de 2021 às 10:17 Subject: Submission received for International Journal of Developmental Disabilities (Submission ID: 217540659) To: <<u>juvpereira@ufam.edu.br</u>>

Dear Juliana Vianna Pereira,

Thank you for your submission. Please see the details below.

Submission
ID217540659Manuscript
TitleSubjective oral health measures in caregivers of patients with autism and
Down syndrome: a preliminary study
International Journal of Developmental Disabilities

You can always check the progress of your submission <u>here</u> (we now offer multiple options to sign in to your account. To log in with your ORCID please click on the 'with ORCID' box on the bottom right of the log in area).

If you have any queries, please get in touch with YJDD-peerreview@journals.tandf.co.uk.

Thank you for submitting your work to our journal.

Kind Regards, International Journal of Developmental Disabilities Editorial Office

ANEXO 3 - Comprovante de submissão artigo 2.3

Cristina Leitão <onbehalfof@manuscriptcentral.com> Qui, 27/05/2021 13:09 Para: Você Cc: Você; juvpereira@ufam.edu.br; mirlenamansur@uol.com.b; lemecardia.milena@gmail.com; marcioajudartelopes@gmail.com

27-May-2021

Dear Miss Bueno:

Your manuscript entitled "Profile of patients with dental treatment suspended in 2020 due to the Coronavirus pandemic: OROCENTRO report" has been successfully submitted online and is presently being given full consideration for publication in the Brazilian Oral Research.

Your manuscript ID is BOR-2021-0570.

Please mention the above manuscript ID in all future correspondence or when calling the office for questions. If there are any changes in your street address or e-mail address, please log in to ScholarOne Manuscripts at https://mc04.manuscriptcentral.com/bor-scielo and edit your user information as appropriate.

You can also view the status of your manuscript at any time by checking your Author Center after logging in to https://mc04.manuscriptcentral.com/bor-scielo.

Thank you for submitting your manuscript to the Brazilian Oral Research.

Sincerely, Brazilian Oral Research Editorial Office ANEXO 4 - Relatório de verificação de originalidade e prevenção de plágio

PACIENTES COM NECESSIDADES ESPECIAIS DO OROCENTRO DA FACULDADE DE ODONTOLOGIA DE PIRACICABA



ANEXO 5 - Certificado de aprovação do Comitê de Ética



PARECER CONSUBSTANCIADO DO CEP

DADOS DA EMENDA

Título da Pesquisa: Análise clínica e laboratorial de pacientes com necessidades especiais do OROCENTRO da FOP-UNICAMP

Pesquisador: Tamiris Christensen Bueno

Área Temática:

Versão: 5

CAAE: 31454720.0.0000.5418

Instituição Proponente: Faculdade de Odontologia de Piracicaba - Unicamp

Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

Número do Parecer: 4.537.080

ANEXO 6 - Certificado de aprovação do Comitê de Ética



PARECER CONSUBSTANCIADO DO CEP

DADOS DA EMENDA

Título da Pesquisa: Influência do senso de coerência e do apoio social na saúde bucal e qualidade de vida relacionada à saúde bucal de pais/cuidadores de pacientes com necessidades especiais

Pesquisador: Tamiris Christensen Bueno

Área Temática:

Versão: 5

CAAE: 31448820.2.0000.5418

Instituição Proponente: Faculdade de Odontologia de Piracicaba - Unicamp Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

Número do Parecer: 4.536.420
ANEXO 7 - Certificado de aprovação do Comitê de Ética



PARECER CONSUBSTANCIADO DO CEP

DADOS DO PROJETO DE PESQUISA

Título da Pesquisa: Análise do perfil dos pacientes que não foram atendidos no OROCENTRO no ano de 2020 devido a pandemia do Coronavírus.

Pesquisador: Tamiris Christensen Bueno Área Temática: Versão: 3 CAAE: 43608921.3.0000.5418 Instituição Proponente: Faculdade de Odontologia de Piracicaba - Unicamp Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

Número do Parecer: 4.610.508