

CAREGIVERS' PERCEPTIONS OF ACCESS TO DENTAL CARE FOR CHILDREN WITH DOWN SYNDROME

Madrid-Canales C^{1,2}; Verdugo-Ahumada J¹; Paz-Venegas C¹; Carreño-Henriquez D.^{1,3}

1 School of Dentistry, Pontificia Universidad Católica de Chile, Chile

2 Institute of Epidemiology and Health Care, University College London, UK

3 Pedro Aguirre Cerda National Rehabilitation Institute, East Metropolitan Health Service, Ministry of Health, Chile

BASCD #27

BACKGROUND

17% of Chileans live with a disability (>2 years old) (2,836,818 people)

People with disabilities are 15% of the world's population and 17% of Chileans (1). They are affected by social and health inequalities, with greater inequalities in oral health explained by greater poverty and fewer options for access to education, employment and independence at the individual and family level (2,3).

Chile has the highest Down Syndrome (DS) prevalence in Latin America, with a rate of 2.2 DS births per 1000 births (4). People with DS have a greater level of dental care needs and present a higher prevalence of oral diseases (2,5,6).

Moreover, other countries have observed the difficulty of access to dental care for this group, which results in an emotional, economic and care-specific impact on individuals and caregivers (3,6,7). However, there are no studies in Chile that report barriers to access dental care focused on children with DS.

Objective: To identify the perceptions that caregivers have about barriers to accessing dental care for children with DS in Chile.

METHODS

A cross-sectional study was developed based on a validated online survey designed by the research team in 2020. The Bioethics Committee of Pontificia Universidad Católica de Chile approved the study.

THE SURVEY: Microsoft Forms was used as online platform

- 28 Likert-scale questions: About oral health knowledge
- 2 open-ended questions: 1 Related to access to dental care and 1 oral health knowledge
- 5 questions about socio-demographic data.



PARTICIPANTS

Caregivers of people with DS aged 2-18 years living in Chile

A convenience sample was used and the link to the survey was sent via email to Chilean organisations working with families of children with DS. Caregivers were also invited to participate via social media.

- Responses were collected from October 2021 to February 2022

Responses to the open-ended question "What are the barriers or difficulties your child with DS has had in accessing dental care?" were analysed qualitatively and individually by the research team.

The individual findings were then discussed and grouped into domains in a descriptive matrix in Excel.

RESULTS

CHARACTERISTICS OF THE SAMPLE

A total of 155 correctly answered questionnaires were received

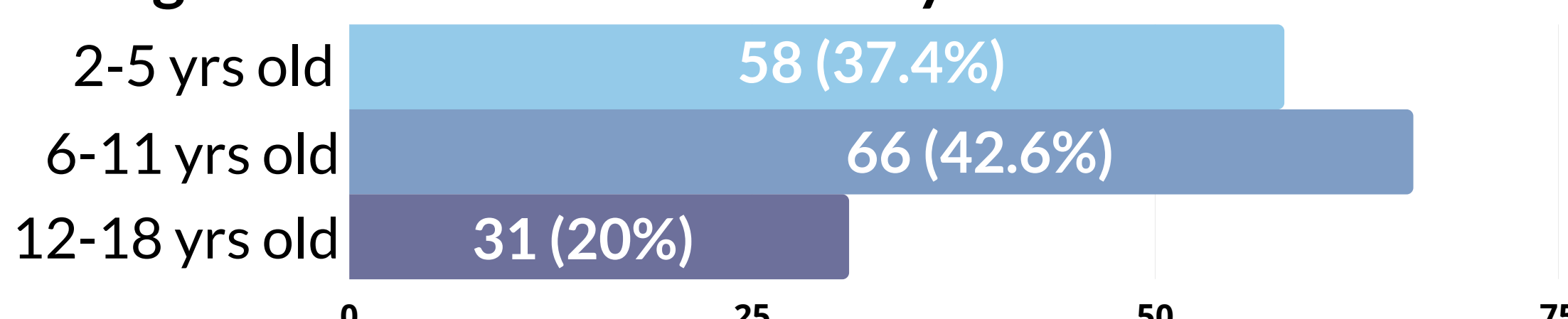
95.4% of them were mothers

Between 20-64 years old (Mean= 43.64; SD= 7.2)

59.4% Others Regions

40.6% Metropolitana Region (Capital of Chile)

Age of children with Down Syndrome



DOMAINS

- Perceptions of access to dental care were grouped in 6 main domains:

Barriers related to:

No barriers Professionals DS Costs Distance COVID

REFERENCES:

1. II National Study of Disabilities, 2015. Department of Studies, National Disability Service, Government of Chile.
2. Faulks D, Freedman L, Thompson S, Sagheri D, Dougall A. 2012. The value of education in special care dentistry as a means of reducing inequalities in oral health. Eur J Dent Educ 16(4):195-201.
3. Watt R, Listl S, Peres M, Heilmann A. 2015. Social inequalities in oral health: from evidence to action. International Centre for Oral Health Inequalities Research & Policy
4. Julio Nazer H, Lucía Cifuentes O. Estudio epidemiológico global del síndrome de down. Rev Chil Pediatr. 2011;82(2):105-12.
5. Mubayrik A Bin. The Dental Needs and Treatment of Patients with Down Syndrome. Dent Clin North Am. 2016;60(3):613-26.
6. Allison PJ, Hennequin M, Faulks D. Dental care access among individuals with Down syndrome in France. Spec Care Dentist. 2000 Jan-Feb;20(1):28-34
7. Casamassimo PS, Seale NS, Ruehs K. General dentists' perceptions of educational and treatment issues affecting access to care for children with special health care needs. J Dent Educ. 2004 Jan;68(1):23-8.
8. Dougall, A., Fiske, J. Access to special care dentistry, part 4. Education. Br Dent J 205, 119-130 (2008).

NO BARRIERS

*(Relationship to child, age of child)

A number of caregivers reported no barriers, saying that their children are regularly cared for without distinction between the Public and Private Health System

Fortunately, in the case of our daughter, we have never had any difficulties in the Public System, in the CESFAMs." (Father, 15 yrs old)*

"None, in fact he goes every 6 months for a dental check-up and we cap his permanent molars to avoid cavities." (Mother, 7 yrs old)

BARRIERS

1 Barriers related to health professionals

Parents recognise the shortage of trained professionals in DS as the main barrier to accessing dental care

"There are few paediatric dentists with the knowledge, experience and expertise to treat a children with DS, and even more if they have a cardiopathie" (Mother, 6 yrs old)

Caregivers believe that patient behaviour management, patience and up-to-date knowledge are the major characteristics that dentists often lack

"They don't attend to them out of fear because they say they are aggressive"(Mother, 3 yrs old)

"We can not find a health professionals who understand her condition, who have the patience and competence to be able to carry out the relevant procedures" (Mother, 9 yrs old)

The public system was mostly mentioned due to the short time available for the dentist to adapt, waiting lists and poor knowledge about the management of DS

"...it has been impossible to get an hour in the public system... and there are no dentists with experience with children with DS there... it is stressful for both you and the child, you are helpless because you can't afford to pay for a private attention" (Mother, 9 yrs old)

"There are few dental appointments availables and a long waiting list" (Mother, 4 yrs old)

2 Barriers related to Down Syndrome

Children's behaviour also could acts as a barrier when they are fearful, sensory hypersensitive or uncooperative with the treatment.

"He has hypersensitivity in the face and we have to fight to brush his teeth" (Mother, 2 yrs old)

"His bad disposition to everything medical due to experiences of hospitalisations when he was younger...it is really impossible for him to be examined by a dentist...he cries and screams from the beginning to the end." (Mother, 6 yrs old)

3 Barriers related to costs of dental treatment

The caregivers perceive the costs of dental care to be too high to afford. Also, access to nitrous oxide sedation is perceived as a decisive factor in the care of children with DS, however, it is difficult to afford due to the cost.

"The high cost of dentists here in Chile, many times the budget is not enough" (Mother, 18 yrs old)

"...and it is impossible to treat him without sedation, as he will not allow it... but it is very expensive" (Mother, 10 yrs old)

4 Barriers related to distance to health centers

Parents mention that living in remote areas of Chile is a barrier to accessing a qualified professional. They often have to travel to the capital to access them.

"The distance to access good dentists, as we are from Los Andes and for important treatments we have had to go to Santiago" (Mother, 14 yrs old)

5 Barriers related to COVID pandemic

Some parents report that the pandemic caused the suspension of dental treatment in the Public System. This made it difficult for them to go to the dentist because of the high costs of the private system.

"So for the moment it has been attended to in the Hospital and the only difficulty has been the suspension of the appointment due to the pandemic" (Mother, 7 yrs old)

CONCLUSIONS AND RECOMMENDATIONS

- Caregivers of children with DS perceive economic, geographic, DS-related and professional-related barriers, the latter being the most frequent.
- Professionals in primary dental care settings should respond to the dental care needs of people with disabilities. Appropriate education and training at both undergraduate and postgraduate levels are key points to addressing the professional-related barrier (2, 8).
- In Chile, only 6 out of 32 dental schools include Special Care Dentistry at the undergraduate level. Restructuring the dental curriculum is crucial to addressing oral health inequality in people with disabilities (2,8)
- In September 2022, free care was extended to all levels of the Chilean Public Health Service. This measure is expected to decrease the associated dental costs, especially for children in Secondary and Tertiary Care. However, waiting times and workforce training need to be addressed so that people with DS can be effectively cared for with this benefit.

SOURCE OF FUNDING:

ODO UC Funding, School of Dentistry, Faculty of Medicine, Pontificia Universidad Católica de Chile
Correspondence to: Carla Madrid-Canales Email: carla.madrid.22@ucl.ac.uk