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Accessibility to the oral health of people with Intellectual Disabilities from the caregiver's perspective: a qualitative evaluation

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ABSTRACT

Objective: to access and identify barriers to oral health care of people with intellectual disabilities (ID), from the caregivers' perspective. **Material and Methods:** the random sample was composed of 55 caregivers of people with ID and an interview script with a qualitative approach was applied to deepen the understanding of this group about oral health services accessibility. The qualitative analysis was performed through the Discourse of the Collective Subject Method. **Results:** we observed some barriers to access and care to oral health to patients with disabilities, such as: lack of structure and organization of the service, deficient training of professionals for attendance, among others. In addition, the health care within a practice little paid in and weakly based on health promotion were other factors that compromised the access of people with ID. **Conclusion:** the access evaluation is extremely important, because it allows the reordering of actions and services according to the users' needs. However, despite the advances, the patient with ID still has been facing barriers, basically to the accessibility to treatment performed by professionals, to reception and low management.

Keywords: Health services accessibility; Oral Health; Intellectual disabilities.

Introduction

According to the 2010 Census, considering Brazil's population, 23.9% of people have at least one of the disabilities being investigated: visual, auditory, motor and mental or intellectual, and of these people, 1.40% present mental or intellectual disability.[1]

According to the American Association on Mental Retardation (AAMR) and to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), the person with Intellectual Disability presents a limitation on the ability of learning and on daily life skills, and their intellectual functioning is below the average.[2,3]

The Convention on the Rights of Persons with Disabilities of the United Nations (UN) guarantees the right to health access to those with disabilities, without any discrimination.[4] In Brazil, the Unified Health System (SUS) establishes the National Policy for Persons with Disabilities (PNSPPD) and the Living Without Limits Plan proposes the insertion of people with disabilities in the various programs of the Ministry of Health and the creation of a healthcare network. In addition, PNSPPD provides for liaison with the National Coordination of Oral Health with the security of a dental care network and qualified to all people with disabilities, from primary to hospital care.[5]

However, studies have reported many times a negative perception of the users on the quality of oral health services in Brazil[6,7] and point out flaws related basically to accessibility, to the treatment performed by professionals, to reception and to low management. At the same time, we observed that people with disabilities have levels of general and oral health lower than the general population.[8-10] This fact is attributed mainly to the barriers that still exist in health care,[11-13] which increases the risk of compromising even more the oral and general health and quality of life.

Accessibility is not restricted to the use of services, but also includes the adequacy of professionals, enabling individuals with disabilities to have the same opportunities as the entire population.[14]

In addition, the majority of informal caregivers in Brazil still have no support as to the information and guidance needed to assist people with disabilities. This fact reflects directly on the oral health levels of individuals with ID, which leads to a more complex clinical practice.[15]

In an attempt to unravel which components have hampered accessibility and use of services, studies aimed at improving access and reducing variability in the practice have been conducted. Considering the scarcity of studies that address this issue, the purpose of this one was to assess accessibility and identify barriers to oral health care of people with ID, from the caregivers' perspective.

Material and Methods

Research Design

Epidemiological, transversal, descriptive exploratory study of qualitative character; was approved by the Ethics and Research Committee (CAAE no. 0045.0.258.000-09. Those who needed dental care received treatment at the public university that serves this audience. This study was carried out in a municipality in the state of Rio de Janeiro that has governmental and non-governmental institutions, non-profit organizations, psychosocial care for people with disabilities and their families.

Sample Definition

There is an estimate, based on prior survey, about the types of disabilities present in the special individuals of these institutions, which receive 200 individuals with intellectual disabilities.[16,17] Sample calculation was based on this population of 200 people with ID in the age group from 11 to 29 years.[16,17] Considering a sampling error of 5%, significance level of 95% and an additional of 20% for possible sampling losses. Therefore, the sample number surveyed was 55 individuals; they were proportionally and randomly selected from the four institutions.

Due to variability in the available classifications of age (adolescent, young adult, adult) and, especially, to the diversity of biological and psychosocial parameters that occur mainly on people with intellectual disabilities, the age range chosen for this study was from 11 to 29 years, since generally from 11 years (early teens) the permanent dentition is formed.[18,19]

Inclusion criteria comprised voluntary and consented participation of individuals with intellectual disabilities and their guardians or individuals with ID associated with other conditions, such as attention deficit and behavioral disorder, who presented the report or a physician's opinion, aged between 11 and 29 years, of both sexes.

Data Collection

The interviews with the guardians were conducted by a trained interviewer, in a reserved environment.

The study was conducted in two phases:

I) Preparatory phase: training of interviewers and pilot study

The pilot study was conducted to test and assess the understanding of the questions by the respondents and, if necessary, to adjust the semi-structured script. In this phase, a researcher with prior experience in this type of research tool applied the script, through interviews, to ten caregivers of patients with ID. The objective of the pilot study was to enhance the interview scripts, making them more accurate and clear, allowing changes in quantity, approach or a sequence of questions.

The training consisted in the preparation of interviewers (n=3) to apply the interview script. This preparation was performed by AVA, a researcher with prior experience in this type of research, and it ended with the practical training of the interviewers, from the application of a few interview scripts to the caregivers of people with ID attended in the last six months in the university.

II) Application of the interview script to the guardians

The instrument used to assess the access under the qualitative approach consisted of a interview with eleven discursive questions, as shown in the following chart, directed to the caregivers of people with ID, for further development on the access of these individuals to oral health care. The adapted script (Chart 1)[12,20] refers to the perception and description of the access of people with ID to dental service, according to the guardians' perspective. All the interviews were transcribed with the permission of the interviewees. The duration of the interviews was about 15 minutes to half an hour.

Chart 1. Interview script applied to the caregivers of the study, adapted from Cardoso *et al.*[12] and Azevedo[20]

INTERVIEW SCRIPT:

1) Has your child ever received dental care? If yes, have you had any problem for him/her to receive it? Which one(s)?
2) Why have you decided to seek dental care for your child?
3) What kind of treatment has he/she received, hospital treatment with general anesthesia or from traditional clinic? Did you participate in this decision? What do you have to say about this kind of treatment he/she received?
4) Were there difficulties to get him/her to the attendance place? Which ones? Do you think it would be better to treat him/her at home?
5) In your opinion, your child's deficiency was a problematic factor for the attendance? Report which aspects interfered.
6) Has any dentist already refused to attend your child? What was the justification? Do you think it would take an expert to attend him/her?
7) Did the dentist who attended your child hold the entire dental treatment or only solved the problem that he/she had at the moment?
8) Did the dentist who attended your child give guidelines on how to take care of his/her teeth? How are these guidelines? Is your child called by the dentist periodically for maintenance appointments?
9) How is your relationship with the professionals that attend your child? Do you know the name of the dentist?
10) Which means of transport do you use to take him/her to the attendance place?
11) In your opinion, what could be done to improve the oral health care that he/she receives?

Results Analysis

Initially, descriptive quantitative analyses were carried out to characterize the patient's caregivers. For the qualitative analysis of open questions regarding the interviews applied to caregivers, we used the process of transcription and analysis "Discourse of the Collective Subject" (DSC). DSC is a set of different testimonies related to the same subject in one homogeneous discourse, written in the first-person singular, but promoting ideas that a social group has to express. Thus, despite being written in the first-person singular, DSC seeks to express a collective thinking.[21]

The qualitative data passed through a content analysis using DSC, for the interpretation of the interviewees' answers. Two researchers read, transcribed and identified the themes that emerged from the data analysis of each interview, based on the selection of the key-expressions contained in the answers of the interviewees and their respective classifications according to the central ideas. When disagreements occur, a third researcher was consulted to reach a consensus. All the central ideas (CI) identified were codified in positive and negative.

Results

The characterization of the sample appears in annex Table 1. The discourses showed central ideas of several natures, from the perspective of the 55 caregivers participating in the study (Chart 2).

Table 1. Characterization of the sample, 55 caregivers of patients with intellectual disabilities

Variables	N(%)
Age	Mean 47.69 years (standard deviation of 12.95)
Sex	55 (100%)
Female	49 (89.09%)
Male	6 (10.9%)
Income	55 (100%)
≤3 minimum wages;	43 (78.18%)
>3 minimum wages	12 (21.81%)
Education level	55 (100%)
≤5 years	33 (60%)
>5 years	22 (40%)

Chart 2. Central ideas (CI) and discourse of the collective subject (DSC) collected through interviews with caregivers

CI: Access and organization of services
DSC: "It would be better if it were nearer to my house, and if appointments were more close to each other, more follow-ups too. One of the things is the speed issue because he gets agitated. I think a suggestion to everyone is the periodic examination to avoid complications or something serious. To be attended on the first timetable would make a lot easier for him not to have to wait; more vacancies would also be very good. She has a lot to do, she needs braces, but can't get it."
CI: Lack of structure of the service
DSC: "It was very difficult for us to get a professional because the hospital did not take x-rays."
CI: Professional competence
DSC: "It was good because she felt a lot of pain and cannot use any kind of medicine, the dentist attended her and was very good. At the hospital, in order to pull out the tooth, the dentist put her to sleep, it was great and fast. When she woke up he had already pulled it out."
CI: Level of professional competence
DSC: "When he felt pain, I took him straight into the dentists' clinic, but the dentist couldn't give a diagnosis and even examined the tooth that wasn't causing the problem. They don't have the course needed for her teeth. Her tooth requires more resources." On the institution the dentist didn't want to attend her, she was traumatized and didn't want to go back. Sometimes there wasn't any problem, but I also couldn't get care.
CI: Need for humanized care
DSC: "The dentist has to be careful, sensitive. The dentist needs to be patient because he feels pain and doesn't complain. He is fearful, has mood swings and needs to be convinced to do the treatment."
CI: Humanized care
DSC: "The dentists were lovely and earned her trust."
CI: Non-collaborating behavior of the individual with ID:
DSC: "The problem is that he doesn't let the dentist work, sometimes we have to hold him. He even bit the finger of the dentist once, he is afraid of the little engine. He cries a lot sometimes, doesn't accept and gets agitated. Sometimes he's alright, but sometimes it's difficult."
CI: Case management
DSC: "In the clinic he behaves well, he likes going there. This time he needed to extract a tooth that he had gnawed. He didn't let we extract in the clinic, but in the hospital he was wonderful."
CI: Lack of case management
DSC: "The treatment didn't continue and no procedure, obturation, nothing was done in the clinic. It is such a pity that it was interrupted by the difficulty of waiting for treatment."

Discussion

The assessment is extremely important, because it allows the reordering of activities and services and contributes to the development of practices more compatible with the users' needs.[22] It must also identify problems as well as assess the incorporation of new health practices in work processes and measure the impact of actions implemented for the population using the system.[23]

The analysis of the caregivers' perception regarding the access to oral health care of the individual with ID was objective of this study, similar to previous studies.[24,25] The focus on the caregiver is a relevant item, since in most cases, individuals with ID are not fully independent, and parents/caregivers are mainly responsible for their health.

We noticed that the oral health of many people with disabilities is precarious. Studies have shown that people with disabilities have lower levels of general and oral health among the general population.[8-10] Castro *et al.*[26] cite several risk factors related to oral diseases in this population.

Access to attendance is important when priority to health care is given and becomes of high value to this public.[27] Given this context and corroborating with this study, we observed in the literature the presence of distinct barriers that generate a low accessibility to general and oral health services.[28]

In this study, the difficulties for the dental care were reported by caregivers, among them, the lack of structure and organization of the service. Some people raised issues about the delay in scheduling, characteristic also presented in previous studies.[22,23] Authors mention that the treatment with general anesthesia, for example, takes up to 12 months, and 3-4 months for treatments with sedation. All this waiting can aggravate the existing conditions, making them more difficult to treat. Thus, we suggest a better organization of services to provide a more efficient scheduling system for individuals with disabilities.[23]

The guardians indicated the need for more frequent appointments to solve the cases as a collective discourse. However, they critically stressed a trend to provide appointments focusing more on assistance and less on prevention or maintenance. However, Cardoso[12] considered that the need for preventive measures and professional control, focused on health promotion, can favor the improvement of oral health and its posterior maintenance through home oral health care at a satisfactory level.

According to Rocha,[29] one of the ways to improve the oral health care of patients with disabilities is to organize health systems, as well as their actions and services, to receive them, eliminating access barriers, be they architectural, geographical, communicational or attitudinal. Some caregivers showed a relevant geographical issue, criticizing the difficulty of access, given the distance in relation to the households, a result that is contrary to the one by the National Policy for Persons with Disabilities, which establishes Basic Health Unit as the prime place of care to the person with disabilities, given his/her geographical and sociocultural proximity with the surrounding community.[30,31]

Regarding professional competence, we highlight the following discourse of the caregiver: "When he felt pain, I took him straight into the dentists' clinic, but the dentist couldn't give a diagnosis and even examined the tooth that wasn't causing the problem. They don't have the course needed for her teeth. Her tooth requires more resources." The oral health of the patient with ID is usually compromised. This initial commitment (caused by intrinsic issues of some of these patients), is added to the fact that a few dental surgeons are not interested in treating them.[32]

The qualification of professionals must permeate the theoretical-practical conception about the care to the patient with disabilities because they need to be sensitive to integral health care. The low supply of dentists to take care of these individuals can be related to the academic qualification that professionals acquire.[22,23]

In Dentistry, there is the field of expertise called *Dentistry for Patients with Special Needs*. However, the health professional, expert or not, must be prepared to treat patients with special needs, understanding the disease and the methodology recommended for the service.[33] The training must include, in addition to clinic training for the care, aspects related to the reception, to the humanized care and integrality of care.[34]

According to Machado *et al.*,[35] the discussion on integrality includes professional training and education, encouraging teamwork and dialogue between health professionals and caregivers.

According to the DSC captured in this study, regarding the humanized care, the professional needs to be careful, sensitive and patient, because individuals with ID may feel pain and not not know how to express it. This issue is discussed in a study by Resende *et al.*,[36] where it is considered that the design of a differentiated look permeates the clinic itself, being more efficiently when the professionals know the reality of the population and of the role that they play in the integrality of care, in addition to its professional importance to the strengthening of the public health care model.

The development of interpersonal relationships is fundamental to establish a better understanding between the assisted person and the professional. Therefore, it is necessary to give a more humanistic significance to the dental practice, because the more the dentist understands the people who seek his/her service, the more positive will be the treatment.[37]

It is noteworthy that behavioral aspects must also be considered during treatment. In this study, we observed reports that, at some point, the patient does not cooperate during dental care, does not accept it and gets agitated, and, in such cases, general anesthesia is the only option for efficient dental care. The predominance of hospital care in patients in adulthood may be linked to the fact that the patient with ID, at this stage, increases in size and physical strength to a point that the implementation of behavioral management techniques do not promote the control the dentist needs to perform his/her job, or even by greater interference of involuntary movements.[38] This fact raises difficulties in the management of the patient for dental treatment.[39] There is a clear commitment related to the demands of this population, which may generate a complex and challenging picture to be won by the public health care system.[40]

As to case management, we observed in this study that most dentists perform physical examinations, oral hygiene or possible and or immediate treatment in this population, result that corroborates with the study by Lawrence *et al.*[34] Despite being a seemingly positive data, it is necessary to discuss what "possible treatment" means, as it may be a prophylaxis or application of fluoride, not performing more complex procedures or only these, such as restorations, scraping and/or tooth extractions as needed by the patient. Then we have a population that needs attention and continues with accumulated dental needs, sometimes even by difficulty of waiting for the full treatment, despite having already been "assisted" by a professional.

This way, some caregivers aim at a greater satisfaction in hospitals, which could mean that the municipalities do not offer a resolutive primary care for this group, or that they do not guarantee the integrality of care, being in a situation of deficiency in the organization of access. According to a study, the referrals were made in acute conditions of oral diseases and there was no timely intervention by primary care.[41]

While seeking care only in emergency, the user aims at the management of the problem, which can reduce or give little emphasis to the full service, based on oral health promotion and prevention.[42] Therefore, we assume that the demand for urgent appointments can represent so many difficulties in accessing treatment, as well as lack of information on the part of users.

We also suggest that families' low priority to early dental care may be caused by challenges on the part of the guardians, because of possible health conditions of these patients who demanding continuous care for the maintenance of life, do not have easy access to oral health care,[38] leading thus to a high number of adults giving priority to treatment under sedation and/or to general anesthesia.

This study has some limitations, as it is about a universe that has relatively homogeneous behavior from institutions. The determination of the ID degree was not possible because the reports and/or opinions of ID in most cases do not specify the ID degree. The construction of the discourse of the collective subject in some cases is hindered due to some caregivers' difficulty with argumentation during the interview, generating a loss in the final sample of individuals who created the discourses, which is hardly quantified. However, the strengths of this study overlap to the limitations thereof, in addition to its originality, for correlating access and caregiver to this type of population with intellectual disabilities.

In short, with the results of this study, difficulties in the access to oral health for the people with disabilities persist, consistent with other studies.[13,43] However, studies that did not indicate difficulties in the access of people with disabilities to oral health services show that, in these cases, access is more related to emergency treatments.[23] In addition, access can often be guaranteed, but the case management may be compromised, as it is also shown by Lawrence *et al.*[34] People with disabilities, due to their peculiarities, should be welcomed by health units; however, there must be an effort on everyone's part to resolve their demands.

Conclusion

Some thoughts from the caregivers' perception were identified on the situation of access to oral health care to individuals with intellectual disabilities. We conclude that, despite the advances and the mobilizations for the recognition of potentialities and needs of this group, individuals with ID still have been facing major barriers that compromise oral health access, especially as regards lack of structure and organization of the service, poor training of professionals for the care, and the lack of case management of the service offered.

Thus, we see that knowledge of the existing access barriers can generate important information for oral health care policy, ensuring, in each context, a quality standard and efficiency within the possible viabilities of the management process.

However, there is still a long way to go in the scope of policies, of planning and oral health care, until the demands are minimized, not only regarding assistance but, especially, care, from a change in the conceptions of caregivers and, above all, of dentists, focused on integrality and oral health promotion.

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Mini Curriculum and Author's Contribution

1. Tiago Martins – graduate student. Contribution: effective scientific participation in the study and data collection.
2. Victor Gavina – DDS and MSc. Contribution: data collection, data interpretation and manuscript preparation.
3. Flávia Maia Silveira – DDS and PhD. Contribution: effective scientific and intellectual participation in the study; critical review.
4. Nayara Silva Alves – DDS and MSc. Contribution: effective scientific and intellectual participation in the study; data collection.
5. Andrea Videira Assaf – DDS and PhD. Contribution: study conception and design; data interpretation; manuscript preparation; manuscript writing; critical review and final approval.
6. Francielle Ribeiro Alves – DDS and MSc. Contribution: worked on the entire research participated in the original idea of the topic, coordinated the calibration process and in writing the final article.

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