

## Level of Satisfaction and Quality of Life of Caregivers of People with Disabilities in Secondary Dental Care

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### ABSTRACT

**Objective:** To assess the level of satisfaction and quality of life (QOL) of caregivers of Patients with Special Needs seen at the Dental Specialties Center in Aracaju, Brazil. **Material and Methods:** The Program for Primary Care Access and Quality Improvement (PMAQ – DSC) and the World Health Organization's Quality of Life - Brief (WHOQOL-BREF) questionnaires were applied to PSN and caregivers. **Results:** The PMAQ questionnaire was applied to 31 patients or caregivers; 97% had no paid work and 61% used public transportation to reach the Dental Specialties Center. The WHOQOL-BREF questionnaire was applied to 20 caregivers; 60% considered their life to be good; however, 60% had practically no leisure time. Correlation tests (Pearson's coefficient) showed a statistically significant correlation between the physical and psychological domain ( $p=0.02$ ;  $r=0.64$ ), the psychological and social domain ( $p=0.033$ ;  $r=0.48$ ), and the psychological and environment domain ( $p<0.001$ ;  $r=0.80$ ). **Conclusion:** The caregivers and patients with special needs felt satisfied with the specialized oral health service offered by the municipality. Concerning the quality of life of caregivers, the majority stated they had a good quality of life, despite not having the opportunity to participate in leisure-oriented activities and often having negative feelings.

**Keywords:** Quality of Life; Patient Satisfaction; Caregivers; Disabled Persons.

## Introduction

The consolidation of the National Oral Health Policy (NOHP) – *Brasil Sorridente* is associated with specialized outpatient care characterized by services provided at Dental Specialties Centers (DSCs). The NOHP guidelines aim to ensure actions to promote, prevent, recover, and maintain the oral health of Brazilians who are represented in the evolution of public oral health policies in Brazil in the phase that aims to ensure health and quality of life [1,2].

Brasil Sorridente consists of an oral health policy with several actions that are developed within the Ministry of Health (MOH), as well as actions articulated with other ministries, such as the Ministry of Education, of Women, of Family, and of Human Rights [2]. These actions aim to guarantee access to the vulnerable population, for example, through the articulation with the Living without Limits - National Plan for the Rights of People with Disabilities [3].

Thus, Ordinance n° 1,570 of the Minister's Office (MO)/Ministry of Health (MOH) [4] establishes that for the DSC to operate, the following minimum number and type of specialties must be offered to the population: oral diagnosis, with emphasis on diagnosis and detection of oral cancer; specialized periodontics; minor oral surgery of soft and hard tissues; endodontics; and care for people with disabilities. In addition, the DSCs that joined the Care Network for People with Disabilities, such as the one based in the municipality of Aracaju, capital of the state of Sergipe, receive an additional financial incentive to qualify the assistance to people with special needs (PSN), as stated in Ordinance n° 835 of the MOH/MO [5].

In the structuring of secondary dental care, there was a lack of qualitative and quantitative indicators, so the MOH directed the Program for Primary Care Access and Quality Improvement (PMAQ – DSC) to carry out a survey of these indicators. One of the phases of this program is external evaluation, and one of the modules that constitute this phase is composed of a questionnaire that aims to listen to DSC's users as to their level of satisfaction; this is an important component of the health evaluation process of the Unified Health System (SUS) [6].

Knowing the level of satisfaction of users who attend DSCs is necessary for the reorganization of health services and for decision-making, and, ultimately, improving the quality and surveillance of oral health [7]. Studies show that caregivers suffer from an overload of stress, which can affect their psychological, physical and emotional health. In addition, the caregiver often does not have access to appropriate support to meet the needs of the person who needs care so that they can become a patient within the health system [8-10].

In the last Census conducted in 2010 by the Brazilian Institute of Geography and Statistics (IBGE) [11], 23.9% of Brazilians reported having some hearing, physical, visual and/or intellectual disability. The Brazilian Law n° 13,146 of July 6, 2015, on inclusion of people with disabilities defines a person with a disability as “one who has a long-term impairment of a physical, mental, intellectual or sensory nature, which, associated with one or more barriers, can obstruct their full and effective participation in society on equal terms with other people” [12].

In 1993, the World Health Organization (WHO) conceptualized quality of life (QOL) as “the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concern” [13]. In this context, verifying the QOL through methodological contributions from different knowledge areas can help improve the quality and comprehensiveness of care from the perspective of health as a right of citizenship [14].

Some problems faced by caregivers such as tiredness, sleep disturbance, headache, weight loss, hypertension and dissatisfaction in social life, social exclusion, affective and social isolation, depression, erosion in relationships, loss of life perspective, sleep disorders, greater use of psychotropic drugs can restrict the possibilities of the caregiver to have a better quality of life [9,15]. In addition, the caregiver burden can reduce the quality of care provided and, consequently, can affect the health of the person receiving care [16].

The investigation of the QOL of caregivers of patients with special needs (PSN) is composed of the analysis of positive and negative, objective and subjective aspects of individuals who are formally or informally responsible for the care of dependent persons to carry out their daily activities [17]. Given the above, the present study aimed to assess the level of satisfaction and QOL of caregivers of PSN treated at the DSC based in Aracaju, Brazil.

## Material and Methods

### Study Design and Ethical Clearance

This is an observational and cross-sectional study approved by the Research Ethics Committee of the Federal University of Sergipe (CAAE: 91726818.8.0000.5546). All the PSN with preserved cognitive function and/or legal guardians who accepted the invitation to participate in the research signed and received a copy of the informed consent form.

### Research Scenery and Data Collection

The survey was conducted at the municipal DSC based in Aracaju, capital of the state of Sergipe. It is a type III DSC, offering the five minimally required specialties, with more than seven dental chairs operating 40 hours a week [18].

To verify the satisfaction of DSC's users, an adapted version of the questionnaire developed by the PMAQ - DSC was applied. The questionnaire was organized in the following dimensions: user identification; access to the DSC services; scheduling of consultations in the DSC; embracement; assistance provided at consultations; bond and accountability; inputs, equipment and ambience; and mechanism for user participation and interaction. Each dimension was composed of subdimensions; for example, in the dimension of inputs, equipment and ambience, the user was asked about their satisfaction with the general service received in the DSC of Aracaju, as well as with the attention received from dentists and clerks [18,19].

The number of new patients seen annually was counted for the application of the questionnaire. From June 2018 to June 2019, 51 first consultations were held. Of the 51 patients attending first consultations in 2019, 31 were interviewed. The sample size was based on population size equal to 51, expected frequency equal to 50%, error 5%, design effect 0.76, clusters 1, and confidence level equal to 80%.

Thus, a convenience sample was used based on the number of patients attending first consultations in 2019. These 31 caregivers or patients without cognitive problems (who were able to answer the questionnaire) answered the adapted version of the PMAQ - DSC questionnaire.

Among the 31 volunteers, a selection was made of caregivers of patients with special needs (PSN) who needed an active caregiver, as in cases of syndromes, disabilities, etc. At the end of this selection, 20 caregivers answered the adapted version of the PMAQ - DSC questionnaire and the World Health Organization Quality of Life (WHOQOL-BREF) questionnaire [15,20]; Eleven responded only to the adapted version of the PMAQ - DSC questionnaire. The application of the questionnaires was carried out individually through interviews.

The WHOQOL-BREF [15,20] consists of 26 questions with the following structure: the first two questions are related to overall quality of life, and the following 24 are related to the analysis of four domains, namely: physical, psychological, social relationships, and environment, as detailed in Table 1 [20,21].

**Table 1. Domains and facets of the WHOQOL-BREF [20,21].**

Domains	Facets
I Overall	Perception of quality of life; satisfaction with health.
II Physical	Pain and discomfort; energy and fatigue; sleep and rest; mobility; activities of daily living; dependence on medication or treatments; work capacity.
III Psychological	Positive feelings; thinking, learning, memory and concentration; self-esteem; bodily image and appearance; negative feelings; spirituality/religion/personal beliefs.
IV Social relationships	Personal relationships; sexual activity; social support.
V Environment	Physical safety and protection; home environment; financial resources; health and social care: accessibility and quality; opportunities for acquiring new information and skills; participation in recreation/leisure opportunities; physical environment: pollution/noise/climate; transport

### Data Analysis

Databases referring to the adapted version of the PMAQ - DSC questionnaire were tabulated in the Microsoft Office Excel software version 2007 and presented in tables, descriptively. To compare domains of the WHOQOL-BREF [15,17], correlation tests (Pearson's coefficient) were performed in the statistical software SPSS 21.0. To calculate the sample, the Epi Info 7.0 program (Centers for Disease Control and Prevention, Atlanta, GA, USA) was used.

### Results

The average age of the PSN informed by the 31 interviewees was 24 ( $\pm 17$ ) years; 18 of the PSN were male; 54% self-declared to be brown skinned, 96% lived in Aracaju and in the urban area, 58% lived in places with 4-6 people, and 100% lived in a region covered by the Family Health Strategy program. Regarding the educational level, 42% had an incomplete elementary school, and 35% were illiterate. Regarding socioeconomic status, 97% had no paid work, 71% had a family income of 1 to 2 minimum wages, and 13% received Family Grant (*Bolsa Família in Portuguese*).

The needs observed among patients were: cerebral palsy + epilepsy + hypothyroidism, cerebral palsy, schizophrenia, hydrocephaly, schizophrenia + epilepsy, mental disorder, severe autism, trisomy of chromosome 12p, bipolar affective disorder and multiple deficiencies.

Concerning the dimension of access to the DSC services, as shown in Table 2, 61% of the interviewees reported using collective means of transportation to reach the DSC; 22.5% took around 30 minutes to arrive; 90% said that the DSC's road signs make it easy to find the service; and 100% stated that the DSC's opening hours met their needs.

Regarding the scheduling of consultations, 71% said they called the DSC; 45% said they waited from one week to one month to be seen at the DSC; and 74% said they were consulted about the best time and day to schedule the service, as shown in Table 2.

When analyzing the dimension of embracement, 61% of users stated it was very good and, 94% said they felt respected by the professionals from the DSC in relation to their cultural habits, customs, and religion.

In the dimension of assistance provided at consultations, 61% reported that until the time of the interview, they had not completed their treatment at the DSC; 52% felt comfortable during the service in the office; and 87% stated that they were always guided by the professionals about the care measures they should take to recover, such as need for rest, adequate food, use of medicines, and others.

Regarding the dimension of bond and accountability, 93% said that professionals from the DSC of Aracaju called them by name and that during the consultation, the dentist provided an explanation about the treatment plan; 71% reported that when they need to clarify doubts after the consultation, they can easily talk to the professionals who see them; and 71% stated that they never abandoned or missed the treatment.

Regarding the input, equipment and ambience, 100% of the interviewees thought that the facilities of the DSC of Aracaju were in good condition; 97% stated that their service was never interrupted due to lack of material or equipment; 90% attributed a score of 10 for their satisfaction with the care provided by the dental surgeon; 81% attributed a score of 10 for their satisfaction with the service provided by the clerk(s); and 55% rated as very good the service, in general, that is provided at the DSC, as shown in Table 2.

Regarding the mechanism for user participation and interaction, 90% of the participants said they never had to make a complaint or suggestion regarding the service offered at the DSC of Aracaju; and 67% said they knew about the ombudsman or complaint channels of the Municipality, the state, or the Ministry of Health (Table 2).

**Table 2. Evaluation of users of the DSC of Aracaju regarding the care provided for patients with special needs.**

Questions	Answer	%
How long do you take to reach DSC?	Up to 30 minutes	22.5
How did you come to DSC?	Public transportation	61
Do you think the DSC's road signs make it easy to find the service?	Yes	90
Do the opening hours of this DSC meet your needs?	Yes	100
How did you make an appointment at this DSC?	Phone call	71
How long did you wait to start treatment at the DSC?	1 week to 1 month	45
Were you consulted about the best time and day to schedule your consultation?	Yes	74
How were you received when you sought service at the DSC?	Very good	61
Do you feel respected by the professionals in relation to your cultural habits, customs, and religion?	Yes, always	94
With regard to comfort, how do you feel during the consultation at the office?	Very good	52
During your treatment, how often are you advised by professionals about the care measures you must take to recover, such as need for rest, adequate food, use of medications and others?	Always	87
When you interrupt the treatment for any reason or do not come to the consultation, do the professionals seek you to find out what happened and resume the treatment?	Never abandoned or missed the treatment	71
Have you ever had the service interrupted due to lack of material or equipment?	Never	97
How do you evaluate the facilities of this DSC?	Good	55
In your opinion, in general, the service you receive in this DSC is...	Very good	55
From zero to ten, what score do you give for your satisfaction with the care received from the dentist?	10	90
From zero to ten, what score do you give to your satisfaction with the service received from the clerk(s)?	10	81
When you want to make a complaint or suggestion, do you succeed?	Never needed	90
Do you know about the existence of a telephone number of the ombudsman or complaint center in the municipality, the state, or the Ministry of Health?	Yes	67

Twenty caregivers, who received the WHOQOL-BREF [15], were responsible for the care of patients diagnosed with autism spectrum disorder, cerebral palsy, mental disorder, hydrocephalus, schizophrenia, multiple disabilities, epilepsy, bipolar disorder, trisomy 12P chromosome, and in the case of some patients, multiple disabilities.

The average age of the interviewees regarding the quality of life was 45.3 years ( $\pm 14$ ), with the oldest caregiver being 72 years old and the youngest 19 years old; 100% declared to be female and 25% of the interviewees took care of patients diagnosed with behavioral disorders.

The analysis of the quality of life according to domains showed that 60% of the respondents considered their quality of life to be good, 45% reported having little money to meet their needs, 60% stated that they had practically no leisure time, and 60% said they sometimes had negative feelings.

Table 3 presents the analysis of the domains of the quality-of-life instrument. On average, values were above 3, considered good, considering that the instrument classifies the quality of life from 1 to 5. Correlation tests (Pearson's correlation) showed a statistically significant correlation between the physical and psychological domain ( $p=0.02$ ;  $r=0.64$ ), the psychological and social domain ( $p=0.033$ ;  $r=0.48$ ), and the psychological and environment domain ( $p<0.001$ ;  $r=0.80$ ).

**Table 3. Quality of life assessment (WHOQOL-BREF) of caregivers according to domains.**

Domains	Mean	SD	Maximum	Minimum
I Overall	3.85	0.86	5	2
II Physical	3.52	1.29	5	1
III Psychological	3.59	1.41	5	1
IV Social relationships	3.58	1.21	5	1
V Environment	3.15	1.34	5	1

## Discussion

The oral health care network in the state of Sergipe is characterized by dental care coverage by oral health teams linked to the Family Health Strategy, characterizing primary oral health care in 100% of the municipalities. With regard to secondary care coverage, the state of Sergipe has seven regional DSCs strategically distributed across the state's health regions, five municipal DSCs, including the type III municipal DSC in Aracaju, and one Unit of Oral Diagnosis and Dentistry for Patients with Special Needs (UODPSN) based at the University Hospital (UH) of the Federal University of Sergipe (UFS) [22,23].

Patients with special needs in dentistry can be pregnant, hypertensive and elderly, so not all PSN need caregivers. Thus, the number of respondents in this research as caregivers was 20. The CEO of Aracaju has few calls for PNE, and it was found that in 2018, the CEO reached the goal of care in 9 months and, in 2019 only four months [24]. Therefore, the low number of respondents is a limitation of the study.

More than half of the interviewees reported that they used public transportation to travel to the DSC of Aracaju. This is similar to the information presented in a study carried out by Souza [25], in which it is stated that the way of commuting may hinder or facilitate the access to the reference center and social transportation linked to the public power should be ideally provided as a way to ensure that users do not miss scheduled consultations in secondary care.

In this survey, many interviewees stated that they called the DSC of Aracaju to schedule consultations. This differs from the study by Costa et al. [6] in 2018, in which a large part of the users went through the regulation of the booking center that allows organizing access through the ordering of users, taking into account the doctrinal principles of the Unified Health System (SUS), and thus hindering the facilitated access by third parties. Therefore, it is important to set up a scheduling center to regulate users to be assisted at DSCs.

In the interviews with users (PSN or guardians), the majority gave a score of 10 for the care provided by the dental surgeon of the DSC of Aracaju, which may be related to humanized reception, explanation of the treatment plan, guidance when necessary to caregivers about the functioning of points that make up the care network, and provision of care with resoluteness and accountability, which is equivalent to the findings of the study conducted by Souza [25]. However, a large part of the interviewees declared low income and low

schooling, and these make them often fail to recognize failures such as poor assistance, lack of social transportation, among others, generating a system of gratitude for the service provided because it is free of charge, as shown in the literature [6].

Interviewees of this study declared that they were satisfied with the service that is offered to PSN at the DSC of Aracaju. This was also seen in the study carried out by Rosendo et al. [26], in 2020, in which 93.1% of the interviewees said they were satisfied with the service offered in a DSC in Paraiba; they recognized the service as resolute and therefore said it met their expectations.

Thus, knowing the level of satisfaction of users assisted by a given health service is extremely important, as it allows monitoring what is being offered to guarantee quality care, as says Souza [25]. This is because, according to findings in the literature researched by Bracciali et al. [27] and Kitamura et al. [7], users' satisfaction allows them to evaluate the quality of health care, making it possible to suggest public policies to improve health and social inclusion.

In this research, a little more than half of the interviewees reported knowing about the existence of a telephone number of the ombudsman or complaint center in the municipality, the state or the Ministry of Health. Contrary to that, in the study by Carvalho and Paes [28], most respondents had never heard of an ombudsman channel. These researchers stressed that it is very important that users know the mechanisms of participation and interaction linked to SUS because it allows qualified listening to improve the service offered.

Another point addressed in the present study was the quality of life of caregivers, who were all female. These findings corroborate the study by Gomes [29], which portrayed the profile of caregivers of PSN in Brazil, who, in most cases, were women, mothers or close relatives who, out of love or obligation, assumed this role even knowing that they would experience restrictions in the activities of their daily living, mainly those related to social life and leisure.

In the present study, a higher mean for the quality of life of caregivers for overall and a lower for the environment was observed. In the study carried out in Pelotas, Brazil. The greatest impact was in the physical domain, and the least was on social relationships [10].

The environment and psychological domain were statistically correlated since the respondents claimed a good quality of life despite not having enough money to satisfy their needs or leisure opportunities. Similarly, Gonçalves et al. [30] concluded that limitations in the caregivers' professional life are one of the consequences of the task of caring for older adults, reducing the amount of daily working hours and even leading to the abandonment of work. In addition, caregivers also express a lack of time for self-care, leisure activities, and permanent tiredness.

According to data from the present research, more than half of the participants answered that they sometimes had negative feelings such as bad moods, despair, anxiety, and depression. This is in line with what was stated by Floriani [31], who mentions problems faced by caregivers such as social exclusion, depression, erosion of relationships, emotional and social isolation, sleep disorders, and greater use of psychotropic drugs. The researcher also reinforces the need for planning and implementing public policies that guarantee support for caregivers.

Given the above, it is evident that the study of the degree of user satisfaction allows for assessing the quality of health care, as indicated by the findings in the research carried out by Kitamura et al. [7], emphasizing that the study of the quality of life makes it possible to suggest public policies that lead to improved health, as well as social inclusion, as mentioned in the study by Bracciali et al. [27], in 2012.

## Conclusion

The analysis of the level of satisfaction shows that caregivers feel satisfied with the care provided. However, displacement seems to be a negative factor for access, as most users depend on public transport. Regarding the caregivers' quality of life, most respondents reported having a good quality of life despite not having the opportunity to participate in leisure activities and often developing negative feelings.

## Authors' Contributions

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RCA		<a href="https://orcid.org/0000-0002-9191-0960">https://orcid.org/0000-0002-9191-0960</a>	Conceptualization, Methodology, Formal Analysis and Writing - Review and Editing.

All authors declare that they contributed to critical review of intellectual content and approval of the final version to be published.

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## Conflict of Interest

The authors declare no conflicts of interest.

## Data Availability

The data used to support the findings of this study can be made available upon request to the corresponding author.

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