

Artículo de investigación

Use of P-CPQ to measure the impact of oral health on the quality of life of children with special health care needs

Uso de la P-CPQ para medir el impacto de la salud oral en la calidad de vida de los niños con necesidades especiales de atención médica

Uso do P-CPQ para mensuração do impacto da saúde bucal na qualidade de vida de crianças com necessidades especiais de saúde

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Abstract

Introduction and objective: the WHO defined the concept of quality of life as the self-perception that the individual has about his position in the social, cultural and ideological context, being these factors the main responsible for denoting the worst parameters regarding oral health care during the dental clinical examination performed by the dentist. To evaluate the impact of oral health on the quality of life of children with special health care needs aged 7 to 14 years old and the influence of different types of specialties on the quality of life, in the view of parents/caregivers in the Brazil southeast region. **Materials and methods:** the sample was composed of 62 children enrolled in municipal public schools and the Association of Parents and Friends of the Exceptional. The validated Parental- Caregivers Perception Questionnaire (P-CPQ) was used as an instrument for

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data collection, applied in the home environment and answered by the main responsible. The relation between demographic factors, type of special need and P-CPQ was evaluated with alpha of 0.05. **Results:** the worst parameters in Family Impact Scale were observed when the mother and father was responsible for data transmission ($p= 0.004$). Oral health was associated with the worst parameters of oral symptoms on quality of life in the view of parents ($p = 0.012$). There was no statistically significant difference regarding the impact of the child's type of specialty on quality of life. **Conclusion:** the variables caregiver and oral health status child are related to the worst indicators regarding the impact of oral health on quality of life.

Keywords: quality of life; oral health; dental care for disabled.

Resumen

Introducción y objetivo: la OMS definió el concepto de calidad de vida como la autopercepción que tiene el individuo sobre su posición en el contexto social, cultural e ideológico, siendo estos factores los principales responsables de denotar los peores parámetros en cuanto al cuidado de la salud bucal durante el examen clínico dental realizado por el dentista. Evaluar el impacto de la salud bucal en la calidad de vida de los niños con necesidades especiales de atención de la salud de 7 a 14 años de edad y la influencia de los diferentes tipos de especialidades en la calidad de vida, en opinión de los padres/cuidadores de la región sudoriental del Brasil.

Materiales y métodos: la muestra se compuso de 62 niños matriculados en escuelas públicas municipales y en la Asociación de Padres y Amigos de los Excepcionales. Se utilizó el cuestionario validado *Parental-Caregivers Perception Questionnaire (P-CPQ)* como instrumento para la reunión de datos, aplicado en el entorno doméstico y contestado por el principal responsable. La relación entre los factores demográficos, el tipo de necesidad especial y el P-CPQ se evaluó con un alfa de 0,05. **Resultados:** los peores parámetros en la Escala de Impacto Familiar se observaron cuando la madre y el padre fueron los responsables de la transmisión de datos ($p= 0,004$). La salud oral se asoció con los peores parámetros de los síntomas orales sobre la calidad de vida a juicio de los padres ($p = 0,012$). No hubo diferencias estadísticamente significativas en cuanto al impacto del tipo de especialidad del niño en la calidad de vida.

Conclusión: las variables "cuidador" y "estado de salud bucal del niño" se relacionan con los peores indicadores relativos al impacto de la salud bucal en la calidad de vida.

Palabras clave: calidad de vida; salud bucal; atención dental para personas con discapacidades.

Resumo

Introdução e objetivo: a OMS definiu o conceito de qualidade de vida como a autopercepção que o indivíduo tem sobre sua posição no contexto social, cultural e ideológico, sendo esses fatores os principais responsáveis por denotar os piores parâmetros quanto aos cuidados com a saúde bucal durante o exame clínico odontológico realizada pelo dentista. Avaliar o impacto da saúde bucal na qualidade de vida de crianças com necessidades especiais de cuidados de saúde de 7 a 14 anos de idade e a influência de diferentes tipos de especialidades na qualidade de vida, na visão dos pais/cuidadores na região sudeste do Brasil. **Materiais e métodos:** a amostra foi composta por 62 crianças matriculadas nas escolas públicas municipais e na Associação de Pais e Amigos dos Excepcionais. Foi utilizado o *Parental- Caregivers Perception Questionnaire (P-CPQ)* como um instrumento de mensuração, aplicado no ambiente familiar e respondido pelo responsável principal. A relação entre fatores demográficos, tipo de necessidade especial e o *P-CPQ* foi avaliada com alfa de 0,05. **Resultados:** os piores parâmetros em relação à qualidade de vida foram observados quando a mãe foi a responsável pela transmissão dos dados ($p= 0,004$). A variável estado de saúde bucal ($p= 0,012$) apresentou resultados relevantes quando relacionadas com os piores parâmetros na percepção do impacto da saúde bucal na qualidade de vida na percepção dos cuidadores sobre suas crianças. Não houve diferença estatisticamente significativa com relação ao impacto do tipo de especialidade da criança na qualidade de vida. **Conclusão:** as variáveis cuidador e estado de saúde oral da criança estão relacionadas com os piores indicadores relativos ao impacto da saúde oral sobre a qualidade de vida.

Palavras-chave: qualidade de vida; saúde bucal; assistência odontológica para pessoas com deficiências.

Introduction

Individuals with special health care needs (SHCN) are individuals who present modifications that require special approaches in all fields of health for a period of their life or indefinitely ⁽¹⁾. Currently, according to the World Health Organization (WHO), about one billion people live with some form of disability, which corresponds to one in seven people in the world ⁽²⁾. It was estimated that approximately 24% of the Brazilian population had some intellectual, motor, hearing and/or visual disability ⁽³⁾.

The WHO (1995) defined the concept of quality of life as the self-perception that the individual has about his position in the social, cultural and ideological context, being these factors the main responsible for denoting the worst parameters regarding oral health care during the dental clinical examination performed by the dentist ⁽⁴⁾. In recent years, the literature has turned its attention to the influence of comorbidities on the quality of life of SHCN patients ⁽⁵⁻⁸⁾. Diseases such as caries, periodontal disease and malocclusions, often present in this population, are related to a worsening in quality of life ⁽⁸⁻¹¹⁾.

Faced with the limitations imposed by deficiency, caregivers are the main protagonists in decision-making regarding the dental treatment plan and the state of health of these children⁽¹²⁻¹⁴⁾. The literature shows some instruments of measures to evaluate the quality of life from the children's perspective and also from the caregivers' perspective, considering the psychological, social and economic indicators for oral health⁽¹⁵⁻¹⁷⁾. The development of these instruments present a positive and growing perspective in dental research since clinical criteria do not allow determining the real impact of oral health needs^(18, 19). Thus, the data obtained by these questionnaires allow the adoption of public policies in oral health for both individual and collective treatment, in addition to optimizing time for decision making regarding clinical, social and oral health promotion interventions^(19, 20). Moreover, there are no reports that the most varied types of syndromes lead to differences in parents' perception regarding changes in quality of life.

Therefore, the objectives of this study were: 1) to evaluate the impact of oral health on the quality of life of children with SHCN between 7 and 14 years and 2) the influence of different types of specialties on the quality of life, in the view of caregivers in a mid-sized municipality in the Brazil southeast region.

Materials and methods

The guidelines STROBE Statement (Strengthening the Reporting of Observational studies in Epidemiology) was followed for this study⁽²¹⁾.

Ethical Approval

The study followed the norms determined by the Brazilian resolution 466 (2012) for research with Human Beings. The study was protocolled and approved by the Committee on Ethics in Research Involving Human Beings of Federal University of Alfenas (UNIFAL), under the report number (2.717.792/2018). The study was attended by parents and caregivers who agreed with the terms of the research and signed the Informed Consent Term.

Study Location

This study was developed in Alfenas-MG, Brazil. This municipality is located in the South of state of Minas Gerais, with a total area of 850,446 km², having a population of 79,996 inhabitants and a demographic density of 84.75 (inhabitants/km²) having predominantly the population in the urban perimeter⁽²²⁾. In Alfenas, a national institution, the Association of Parents and Friends of the Exceptional (APAE), acts in attention psychosocial, educational and health care of the SHCN patients, and the municipal schools that also include these patients⁽²³⁾.

Study Sample

For this descriptive and cross-sectional study, a convenience sample was obtained from a list of all children with SHCN enrolled in public schools or attending APAE-Alfenas, Brazil. All children

between 7 and 14 years of age were included; with any kind of special need and willing to receive the researcher in home environment.

The initial sample was 132 children. The children's parents were first approached by telephone and informed about the study in order to be invited to participate in the survey. Afterwards, home visits were made to apply the instrument. 56 could not be contacted or changed addresses and 15 did not want to participate in the study. Thus, the final sample of the study was 62 children and their respective caregivers.

Characterization of the speciality of children

The children and adolescents in the sample were allocated to groups according to the criteria determined by the Chilean Society of Pediatrics, which characterizes SHCN according to their medical, dental, nutritional and educational needs ⁽²⁴⁾.

Calibration of Researchers

The evaluators were two graduates in Dentistry from UNIFAL (FIDC and LBO), previously trained and calibrated. For calibration, the questionnaire was in different periods with the same caregiver to verify the understanding of the questions contained in the instrument. At the end, a Kappa= 0.91 was obtained.

P-CPQ instrument

The instrument used in the study was the brazilian version of the *Parental Caregiver Perceptions- questionnaire* (P-CPQ) composed of 33 questions distributed in four domains: oral symptoms, functional limitations, emotional well-being and social well-being, taking into account that the events assessed should have occurred frequently in the last three months. For each answer, the Likert Scale was used: (never = 0, once or twice = 1, sometimes = 2, often = 3, every day or almost every day = 4). The answer "Don't know" was also inserted in order not to lose valuable data regarding the oral health status of the studied group, being scored as 5 points. After the application of the instrument, the sum of each domain was performed, with a higher score denoting a greater impact on the quality of life conditions in oral health of children with special needs ⁽¹⁵⁾.

Application of P-CPQ

Data were collected from home visits to caregivers of children with SHCN. The interviewers read each question in the questionnaire and filled in each field with the caregiver's answer.

Statistical analysis

In the evaluation of the relation of demographic factors and special needs of patients, Mann-Whitney, Kruskal-Wallis and Post hoc de Dunn tests were used by the statistical program SPSS for Windows (Version 17.0; SPSS Inc. Chicago, IL, USA), with a significance level of 5%.

Results

Of the 132 caregivers consulted, 62 were interviewed, leading to a response rate of 46.96%. The characterization of the population is described in [Table 1](#). The sample consisted of 44 male (71%) and 18 female (29%) individuals. The mother was the main transmitter of the data (n=41- 66.1%) when evaluating who was the caregiver or responsible for the child transmitting the information. Patients with service needs and special education (Autism, HASD, intellectual disability and hyperactivity syndrome) was the type of special need more prevalent in this study (n=43- 69.4%).

Table 1. Description of sample. Alfenas, MG, Brazil, 2020.

Variable	Category	n (%)
Age (years)	7-10	35 (56.45)
	11-14	27 (43.55)
Sex	Female	18 (29)
	Male	44 (71)
Caregiver	Mother	41 (66.1)
	Dad	6 (9.7)
	Others	15 (24.2)
CSHCN	Special Education Service	43 (69.4)
	Rehabilitation therapy for functional limitation	8 (12.9)
	Special medical care	6 (9.7)
	Use or need for medication prescription	4 (6.5)
	Special nutrition	1 (1.6)
Oral health	Excellent	7 (11.3)
	Very good	10 (16.1)
	Good	24 (38.7)
	Regular	16 (25.8)
	Bad	5 (8.1)
Welfare	Excellent	23 (37.1)
	Very good	14 (22.6)
	Good	10 (16.1)
	Regular	6 (9.7)
	Bad	9 (14.5)

SHCN: Special Health Care Needs.

Table 2 shows the results of the analysis of the P-CPQ questionnaire domains. The scores "Emotional Well-Being" and "Family Impact Scale" were higher than the other domains. When the P-CPQ base factors were evaluated 13 individuals (20.96%) obtained the lowest scores (0 points) and no individual obtained the highest score (125 points).

Table 2. P-CPQ according to total scale and domains. Alfenas, MG, Brazil, 2020.

P-CPQ domains	Median	Mean (SD)	Floor effects ¹ / ceiling effects ²	Possibility of variation in score
Total score	1	9.62 (6.8)	20.96/0.00	0-125
Oral symptoms (6)	6	5.85 (3.16)	8.06/3.22	1-13
Functional limitations (8)	10	9.82 (4.89)	3.22/4.83	1-22
Emotional well being (8)	10	11.34 (5.82)	4.83/1.61	0-22
Social well being (11)	6.5	8.29 (7.52)	11.29/ 1.61	0-32
Family impact scale (14)	11	12.82 (8.91)	4.83/1.61	0-36

¹ Proportion with 0 score.

² Proportion with maximum score.

In the bivariate analysis, the worst states in relation to quality of life were obtained when the mother and father were the transmitters of the information ($p=0.004$). The variable Oral health of the child ($p = 0.012$) were related to the worst parameters of perception on quality of life from the perspective of symptoms or oral disorders that the special children had (**Table 3**).

In **Table 4**, there was no association between the type of special need of the child and the values obtained in P-CPQ.

Table 3. Bivariate analysis of association between demographic status with oral health-related quality of life in the domains median scores of P-CPQ Alfenas, MG, Brazil, 2020.

Variable	Category	n (%)	Oral symptoms			Functional limitations			Emotional well being			Social well being			Family impact scale		
			Med	Mean (SD)	P-value	Med	Mean (SD)	P-value	Med	Mean (SD)	P-value	Med	Mean (SD)	P-value	Med	Mean (SD)	P-value
Sex	Male	44 (71)	6.0	5.48 (3.11)	0.147	10.0	10.80 (5.22)	0.400	10.5	11.61 (6.08)	0.646	6.5	8.52 (7.30)	0.539	11.0	13.55 (9.71)	0.699
	Female	18 (29)	6.0	6.78 (3.17)		9.0	8.94 (4.34)		10.0	10.67 (5.23)		6.0	7.72 (8.23)		10.0	11.06 (6.46)	
Age	7_10	35 (56.45)	6.0	6.40 (3.17)	0.130	10.0	10.14 (4.81)	0.623	11.0	11.57 (4.84)	0.608	6.0	7.14 (5.51)	0.545	11.0	14.00 (9.94)	0.438
	11_14	27 (43.55)	5.0	5.15 (3.06)		10.0	9.14 (5.25)		9.0	11.04 (6.97)		7.0	9.78 (9.43)		11.0	11.30 (7.25)	
Caregiver	Mother	41 (66.1)	6.0	6.44 (3.00) ^A	0.076	10.0	10.71 (4.66)	0.105	10.0	11.15 (5.50)	0.128	6.0	8.68 (8.56)	0.631	14.0	15.39 (9.62)	0.004 *
	Dad	6 (9.7)	5.5	5.00 (1.78) ^A		9.0	8.67 (3.98)		8.5	7.83 (3.06)		4.5	5.67 (4.27)		7.5	6.66 (4.36)	
	Others	15 (24.2)	4.0	4.60 (3.69) ^B		6.0	7.87 (5.76)		12.0	13.27 (6.96)		11.0	8.27 (5.21)		7.0	8.27 (4.13)	
Oral health	Excellent	7 (11.3)	3.0	4.00 (1.82) ^B	0.012 *	11.0	12.14 (5.24)	0.578	7.2	9.29 (7.54)	0.609	5.0	4.43 (2.82)	0.92	11.0	11.86 (6.91)	0.825
	Very good	10 (16.1)	8.0	6.80 (3.15) ^A		12.0	12.50 (4.08)		10.0	10.10 (6.57)		7.5	10.70 (9.22)		13.0	15.90 (11.32)	
	Good	24 (38.7)	4.0	4.67 (2.71) ^B		8.0	7.54 (4.46)		12.0	12.38 (5.60)		7.5	8.63 (7.12)		8.0	11.04 (8.49)	
	Regular	16 (25.8)	7.5	6.94 (3.23) ^A		10.0	9.63 (4.20)		10.5	11.56 (5.16)		6.0	9.25 (8.75)		12.5	13.00 (7.94)	
	Bad	5 (8.1)	9.0	8.80 (3.34) ^A		12.0	12.80 (6.97)		9.0	11.00 (5.95)		6.0	4.20 (3.89)		13.0	16.00 (11.93)	
Welfare	Excellent	23 (37.1)	4.0	4.70 (3.11)	0.061	10.0	9.87 (5.30)	0.99	10.0	11.00 (7.07)	0.867	7.0	7.11 (6.315)	0.901	8.0	10.00 (7.47)	0.166
	Very good	14 (22.6)	6.0	5.71 (3.22)		10.0	9.86 (3.84)		13.5	13.43 (5.17)		7.0	12.00 (10.47)		13.5	14.50 (7.49)	
	Good	10 (16.1)	7.0	7.00 (3.55)		8.0	7.90 (4.53)		9.0	8.40 (3.37)		4.0	5.80 (6.26)		12.5	13.60 (8.94)	
	Regular	6 (9.7)	8.5	8.33 (2.16)		10.0	10.50 (3.01)		9.5	11.60 (6.06)		7.0	10.50 (8.93)		16.0	17.33 (14.58)	
	Bad	9 (14.5)	5.0	6.11 (2.31)		10.0	11.23 (7.17)		12.0	12.44 (4.61)		6.0	6.67 (2.78)		8.0	13.56 (9.67)	

Med= Median; *Different overwritten bold letters indicate the statistic significant differences in comparison between groups (Dunn's Post-test; p<0,05).

Table 4. Bivariate analysis of association between Children with special health care needs with oral health-related quality of life in the domains median scores of P-CPQ Alfenas, MG, Brazil, 2020.

Variable	Category	n (%)	Oral symptoms			Functional limitations			Emotional well being			Social well being			Family impact scale		
			Med	Mean (SD)	P-value	Med	Mean (SD)	P-value	Med	Mean (SD)	P-value	Med	Mean (SD)	P-value	Med	Mean (SD)	P-value
SHCN	Special Education Service	43 (69.4)	6.0	5.24 (3.16)	0.199	10.0	9.26 (4.75)	0.538	11.0	12.07 (5.25)	0.497	7.0	8.42 (7.16)	0.649	12.0	13.91 (9.28)	0.197
	Rehabilitation therapy for functional limitation	8 (12.9)	5.0	5.25 (3.45)		11.0	12.25 (6.79)		9.5	10.00 (6.90)		5.5	7.75 (8.13)		8.0	11.50 (9.11)	
	Special medical care	6 (9.7)	4.0	4.67 (2.58)		10.0	9.33 (4.88)		7.5	8.50 (7.45)		4.5	7.83 (9.15)		6.0	6.50 (5.75)	
	Use or need for medication prescription	4 (6.5)	8.0	9.00 (2.70)		12.0	11.75 (3.77)		12.0	12.25 (7.13)		4.5	4.25 (3.30)		12.5	14.75 (6.39)	
	Special nutrition	1 (1.6)	-	-		-	-		-	-		-	-		-	-	

SHCN: Special Health Care Needs; Med= Median; * Significant statistical results $p < 0.05$.

Discussion

Patients with SHCN have several comorbidities that may negatively influence their quality of life ^(18, 20). Poor oral health conditions are not rare in this segment of the population due to the difficulties and limitations in achieving adequate standards of oral hygiene and diet control ^(13, 14). Therefore, this cross-sectional study had as main axis to evaluate the impact of oral health conditions of patients with SHCN on quality of life, from the caregivers' point of view.

In this context, the main caregiver of the child with SHCN is the one who can provide the best insight into the perception of oral health status and how much it influences the life of the child/adolescent in a positive or negative way ^(25, 26). This statement is directly related to the importance he attaches to good oral health conditions ^(27, 28). The literature shows that good oral hygiene practices were correlated with the caregiver and/or the child's primary caregiver ⁽²⁹⁾. For Silva et al., 2018 the caregiver factor, in 81.5% of cases, is the main responsible for the initial awareness of primary oral health care of their children with SHCN ⁽³⁰⁾.

Our results show that the worst parameters in relation to quality of life were observed when the mother and father were responsible for transmitting the data. This can be endorsed by the findings of Locker et al., 2007; Piovesan et al., 2010; Paula et al., 2012 and dePaula et al., 2013 that show that parents showed a more acute self-perception in relation to oral health care, this factor being influenced by the demographic and socioeconomic aspects in which they live ^(19, 31-33).

From this perspective, the quality of life questionnaires have shown positive results regarding the measurement of oral health impacts ^(17, 34, 35). When analyzed the scores, studies involving children with SHCN showed a greater tendency to obtain higher scores for oral symptoms, emotional well-being and functional limitations. The justification for the higher score is that oral diseases directly and negatively interfere with child welfare ^(7, 36, 37).

The mean values of the P-CPQ domains Oral Health Status was statistically significant in negatively influencing quality of life. In this sense, it is important to highlight that children with SHCN present high rates of caries, periodontal disease and malocclusions, which, identified by caregivers, justify their self-perception and association between a poor oral health status and a drop in quality of life ^(19, 20, 32). Hence the importance of this study in demonstrating the importance of the caregiver's role, especially for parents as our results show in the perception of the oral health status of their children with SHCN ^(32, 33).

Still regarding oral health status, evidence reinforces these findings, as demonstrated by Abanto et al., 2012 that associated poor oral health conditions to clinical examination with poor quality of life results in the application of P-CPQ in patients with cerebral palsy ⁽⁷⁾. Similarly, Baens-Ferrer et al., 2004 showed that oral diseases significantly compromise the exercise of daily

functions in children with SHCN, before and after oral rehabilitation under general anesthesia and Alves et al., 2016 in children with intellectual disabilities^(5, 20).

Our results showed that the largest number of SHCN that composed the sample belonged to the group of patients with service needs and special education and that there was no association between the type of special need of SHCN and the values obtained in P-CPQ. It was not possible to associate these data with those in the literature, since to our understanding there are no studies evaluating the relationship between the type of specialty of the individual and its impact on quality of life.

Finally, the number of patients interviewed is a partial limitation of this study. The constant change of telephone and address of the participants was the main responsible for the reduction of the sample. We talked about partial limitation, since, even with the reduction, statistically significant results were obtained.

From this study it is possible to infer that the caregiver is the key factor to add better oral health conditions for the children as they are responsible for the changes regarding preventive behavior and good oral health practices of their special children.

Conclusion

The factors "Caregiver" and "Oral Health Status" of the child are related to the worst indicators regarding the impact of oral health on quality of life. There is no difference in quality of life for the different specialties evaluated.

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Conflict of interest statement

The authors declare that they have no conflict of interest.

Ethics statement

This manuscript was submitted to the Human Ethical Committee beings of Federal University of Alfenas (UNIFAL-MG), having the favorable opinion of N° 2.717.792/2018.

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