Impact of untreated dental caries on oral health-related quality of life of children with special health care needs

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Abstract: The oral health status of children with special health care needs (SHCN) can affect their quality of life wich domains of the Brazilian version of the Early Childhood Oral Health Impact Scale (B-ECOHIS). A cross-sectional study was conducted in children with SHCN (aged 1 to 9 years), who underwent an oral examination for the assessment of dental caries severity. Parents/caregivers answered two questionnaires, one on oral health-related quality of life (OHRQoL) - B-ECOHIS, and one on socioeconomic characteristics. Statistical analyses were performed using the Kolmogorov-Smirnov test, Mann-Whitney U-test, Poisson regression, Point-biserial correlation coefficient, and Cronbach's alpha. A total of 128 children participated in the study and OHRQoL was affected in 68.75% of them. The function domain in the Child Impact Section (CIS) had a higher mean value. Caries severity was associated with worse quality of life (p=0.001). Severe dental caries was associated with a negative impact on the OHRQoL of disabled children and of their families. The impact of untreated dental caries and severity of dental caries was associated with the CIS domains (except for the self-image/social interaction domain).

Keywords: Dental Caries; Disabled Children; Pediatric Dentistry; Oral Health; Quality of Life.

Introduction

Patients with special health care needs (SHCN) have significant limitations in both intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills.[1] Twenty-four percent of the Brazilian population is composed of people who have some kind of disability (auditory, visual, physical, and/or intellectual). According to the Census of the Brazilian Institute of Geography and Statistics (IBGE), 45 million people in Brazil have SHCN.[2]

Studies have shown that the oral health of disabled individuals is poor and that they badly need oral treatment, leading to an increased caries risk/susceptibility.[3,4] A high caries prevalence has been reported among people with SHCN.[5,6,7,8] In Brazilian people with SHCN, the higher prevalence of caries is associated with a negative impact.[5,8,9] Investigations in healthy children have shown that health problems such as dental caries can affect a person functionally, psychologically, and socially, in addition

to causing pain and discomfort.[10,11,12,13] The assessment of oral health-related quality of life (OHRQoL) is more difficult in children with SHCN due to their limited understanding of what is being evaluated. Parents' perception of dental caries in intellectually disabled children has been examined, and the results have shown a significant impact of dental caries on parents' perception of the OHRQoL of children with intellectual disabilities.[4,5,8,9] Untreated dental caries represents a real clinical problem and it is associated with poor quality of life;[14,15] however, there is a paucity of research studies involving individuals with SHCN.

In dentistry, specific sociodental indicators have been used to measure the extent to which oral changes affect quality of life and well-being.[11,16,17] The Early Childhood Oral Health Impact Scale (ECOHIS) was designed to assess the OHRQoL of preschool children, where parents/caregivers answer the questionnaire as children lack the necessary cognitive skills to assess their own quality of life.[16] Dental caries has been associated with specific quality of life domains, such as the impact on parents' distress[15] and on children's social, functional, and psychological well-being.[14,15]

The prevalence of any impact on OHRQoL has been higher for intellectually disabled children with both low and high caries severity when compared with their caries-free counterparts.[4] However, the relation between OHRQoL in children with SHCN and presence of untreated dental caries has not been described in the literature. There are some limitations that need to be addressed, such as the use of a convenience sample and a sample of subjects with higher prevalence of potential risk factors for poor oral health than the general population.[18] Therefore, the purpose of this study was to identify which domains of the ECOHIS (symptoms, function, psychological well-being, and self-image/social interaction) are affected by the presence of untreated dental caries in a sample of Brazilian children with SHCN. In this study, we hypothesized that untreated dental caries severity, measured by the number of caries, is associated with worse OHRQoL. In addition, another objective was to determine sociodemographic factors that may influence the quality of life of children and of their parents/caregivers.

Methodology

Study population

This cross-sectional study was conducted in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement,[19] which was adapted to our study design. A convenience sample was selected for this cross-sectional study conducted with children with SHCN enrolled in the Acolher Project at the *Fluminense Federal University*, in Niterói, a town located in the metropolitan area of Rio de Janeiro, in southeastern Brazil, between August 2016 and December 2017. The inclusion criteria were age between 1 and 9 years and diagnosis of systemic disease, intellectual disability, congenital malformation, or other incapacitating disorders, such as Down syndrome, autistic spectrum disorder, cerebral palsy, sensory and communication disorders, HIV, and cancer, among others. No selection criteria were applied to these conditions. Subjects who were not able to cooperate due to their medical conditions, those children whose parents refused to give consent, and incomplete questionnaires (parents who failed to answer more than two items related to their children and one item related to the family[11]) were excluded from the study. Subjects whose legal guardians consented to their participation and those who gave consent themselves were eligible for the study.

A sample with 134 individuals is sufficient for the pre-calculated sample of 114 caregiver-child pairs, assuming a prevalence of child and family impact scores of 70.2% (pilot study) and 54%,[4] a 5% margin of error, and a 95% power. Another 17.5% was added to the sample size to account for missing answers or uncooperative children. A pilot study was carried out for the data collection of the main investigation to test the methodology and the understanding of the questionnaires. The pilot study was conducted in 57 children with SHCN (aged 1 to 9 years) and their parents/caregivers, who were randomly selected from a database and not included in the main study. This pilot study allowed observing an impact on 70.2% of the sample and higher mean values in the Child Impact Section (CIS) function domain.

Data collection – Impact on children's OHRQoL and sociodemographic information

Parents/caregivers were asked to answer the Brazilian version of the ECOHIS[17,20] and fill out a form for collection of socioeconomic information, such as gender (male or female), child's age (< 6 and ≥ 6),[11] parent's/caregiver's schooling (years of study: ≤ 8 years, > 8 years)[8], and household income based on the Brazilian minimum wage (approximately US$ 284.80 per month; categorized into < 2 Brazilian minimum wages [BMW] and ≥2BMW).[13] The B-ECOHIS was used to assess the negative impact of the presence and severity of caries on the quality of life of children with SHCN. This questionnaire is composed of 13 items distributed between the CIS and the Family Impact Section (FIS). The CIS has four domains: symptoms, function, psychological well-being, and self-image/social interaction. The FIS has two domains: parental distress and family function. The scale has five answer options (0 = 'never', 1 = 'hardly ever', 2 = 'occasionally', 3 = 'often', 4 = 'very often', 5 = 'don't know') for recording how often an event has occurred in the child's life.[16,17 20] The 'don't know' answers are not counted.[12] The score for each domain is calculated through a simple sum of the scores of each item. The CIS and FIS scores are calculated through a simple sum of the scores of all items in each section, ranging from 0 to 36 (CIS) and from 0 to 16 (FIS). The total score ranges from 0 to 52, with higher scores denoting greater oral health impact and poorer OHRQoL. The primary outcome in the present study was the occurrence of any impact on OHRQoL (B-ECOHIS>0).[4,13]

Data collection – Child's oral examination

The clinical oral examination was conducted by two experienced examiners (KF – examiner 1 and VC – examiner 2) who had undergone a calibration exercise during which inter-examiner and intra-examiner kappa values were 0.87 to 0.96 and 0.89 to 0.92 for examiners 1 and 2, respectively.[18] A visual examination was carried out with the assistance of a mouth mirror (PRISMA, São Paulo, Brazil) and a probe (Golgran, São Paulo, Brazil) in a dental chair under the light of a reflector.

The main explanatory variable in our study was the presence of untreated dental caries measured by the DMFT index (decayed, missing, and filled teeth), but only the component 'decayed – d/D' was used.[14,15,21] Likewise, caries prevalence was calculated using untreated dental caries data.

The patients were classified based on severity of caries and presence of untreated dental caries, which considers the decayed (d/D) teeth. After that, the participants were categorized into two groups: children without untreated dental caries (d + D = 0) and children with untreated dental caries (d + D > 0). Severity was classified according to the number of untreated dental caries (0 free of caries; 1–2 moderate; and ≥ 3 high), where the upper cutoff values corresponded to the Significant Caries Index in this population.[22]

Statistical analysis

The SPSS 20.0 statistical package (SPSS Inc., Chicago, USA) was used to analyze the data. Descriptive analysis (including frequency distribution) was performed for overall mean B-ECOHIS scores. Scores for the individual domains were analyzed for differences between oral conditions and socioeconomic and demographic factors. The independent variables also included sociodemographic characteristics (parent's/caregiver's schooling, household income) and characteristics of the children (sex and age). The dependent variable was the impact of dental caries on the quality of life of children with SHCN (total B-ECOHIS score).

The Kolmogorov-Smirnov test verified that the data followed a non-normal distribution. The nonparametric Mann-Whitney test was used. Poisson regression with robust variance was used for the multivariate analysis. The point-biserial correlation (Pearson's correlation) was used to compare age, sex, parent's/caregiver's schooling, household income, and untreated dental caries with the overall B-ECOHIS score. Internal consistency was assessed by Cronbach's alpha for the questionnaire and for the categories.

Ethical aspects

This study complied with Brazilian Resolution No. 466 (2012) and was approved by the Human Research Ethics Committee of *Fluminense Federal University*.

All parents received information regarding the objectives of the study and signed an informed consent form.

Results

A total of 134 children with SHCN were initially enrolled in the study, but 128 (95.5%) eventually participated in the study. Losses occurred due to the absence of a questionnaire filled out by the parents. Most of the questionnaires were answered by mothers (87.5%). The mean (standard deviation) and median age of the children was 5.5 (± 2.22) and 5.0 years, respectively, of whom 69 (53.9%) were < 6 years old, 89 (69.5%) were male, and 51 (38.9%) had autism spectrum disorder. Eighty-four parents (66.1%) had more than eight years of education, and < 2 BMW

was more frequently (64.4%) reported by parents. Untreated caries was prevalent in 57 children (44.5%). Among children with caries, moderate severity (1 to 2 lesions) was observed in 29 (22.7%) and high severity (≥3 lesions) in 28 (21.9%).

Most parents/caregivers reported an impact on OHRQoL (68.75%) (B-ECOHIS score > 0). Parents reported more impacts (B-ECOHIS score > 0) related to the child (69.5%) than to the family (49.6%). Overall, B-ECOHIS scores ranged from 0 to 38 (CIS 0-31 and FIS 0-14). Table 1 displays the distribution of the answers to each B-ECOHIS item in each domain. The B-ECOHIS items with high means corresponding to some type of impact on OHRQoL were 'pain in the teeth, mouth, or jaws' (28.1%) in the CIS and 'been upset' (29.1%) in the FIS. Yet, higher mean values were observed for the function domain in the CIS.

The distribution of the means for each B-ECOHIS domain demonstrates that age, untreated dental caries, and caries severity were significantly associated with an impact on the OHRQoL of the children and

Table 1. Distribution of B-ECOHIS answers given by parents in population-based sample.

Impacts	Never or hardly ever	Occasionally, often or very often	Don't know
	N (%)	N (%)	N (%)
CIS			
Symptoms domain			
Oral/dental pain	91 (71.1)	36 (28.1)	1 (0.8)
Function domain			
Difficulty drinking	92 (71.9)	36 (28.1)	0 (0)
Difficulty eating	95 (74.2)	33 (25.8)	0 (0)
Difficulty pronouncing words	108 (84.4)	20 (15.6)	0 (0)
Missed preschool or school	110 (85.9)	18 (14.1)	0 (0)
Psychological domain			
Trouble sleeping	106 (82.8)	22 (17.2)	0 (0)
Irritable or frustrated	93 (72.6)	34 (26.6)	1 (0.8)
Self-image/ social interaction domain			
Avoided smiling or laughing	116 (90.6)	12 (9.4)	0
Avoided talking	118 (92.2)	10 (7.8)	0
FIS			
Parents distress domain			
Been upset	90 (70.9)	38 (29.1)	0
Felt guilty	96 (75.0)	31 (24.2)	1 (0.8)
Family function domain			
Taken time off from work	114 (89.1)	13 (10.1)	1 (0.8)
Financial impact	111 (86.7)	11 (11.7)	2 (1.6)

of their families. Age showed significant results for the symptoms and function domains of the CIS and for the parent distress domain of the FIS. The highest means were obtained for children aged > 6 years. Untreated dental caries and caries severity showed that the impact was associated with CIS domains (except for the self-image/social interaction domain). Likewise, the highest means were detected in the group with untreated dental caries (≥1) and with high severity of dental caries (Table 2).

Table 2. Mean scores in B-ECOHIS domains according to socioeconomic factors, characteristics of the children, and oral conditions.

Variable	N(%)	SYD	FD	PD	SSD	CIS B-ECOHIS score	PDD	FFD	FIS B-ECOHIS score	Overall B-ECOHIS Score
Age										
< 6 years	69 (53.9)	0.53 (0.86)	2.38 (3.35)	1.21 (1.87)	0.97 (1.86)	4.89 (6.88)	1.41 (2.24)	0.95 (1.54)	2.36 (3.58)	7.28 (9.97)
≥ 6 years	59 (46.1)	1.13 (1.21)	2.82 (2.78)	1.48 (1.70)	0.58 (1.10)	6.01 (5.40)	1.58 (1.80)	0.58 (1.07)	2.17 (2.43)	8.23 (7.16)
p-value		0.010	0.022	0.169	0.307	0.017	0.002	0.203	0.002	0.003
Sex										
Male	89 (69.5)	1.03 (1.19)	2.35 (2.47)	1.13 (1.43)	0.43 (0.94)	4.95 (4.46)	1.33 (1.83)	0.57 (1.17)	1.90 (2.54)	6.90 (6.33)
Female	39 (30.5)	1.32 (1.25)	3.42 (3.16)	2.05 (1.93)	0.79 (1.32)	7.58 (6.30)	1.89 (1.73)	0.58 (0.90)	2.47 (2.25)	10.1 (7.98)
p-value		0.387	0.309	0.170	0.579	0.245	0.682	0.785	0.897	0.343
Parent's/caregiver's schooling*										
≤ 8 years	40 (33.9)	1.33 (1.23)	2.75 (2.96)	1.67 (2.19)	0.67 (1.30)	6.42 (6.56)	2.00 (2.00)	0.33 (0.89)	2.33 (2.54)	8.75 (8.64)
> 8 years	78 (66.1)	1.08 (1.21)	2.77 (2.76)	1.43 (1.52)	0.54 (1.04)	5.82 (4.98)	1.41 (1.72)	0.65 (1.11)	2.05 (2.42)	7.95 (6.67)
p-value		0.664	0.269	0.081	0.415	0.221	0.356	0.225	0.216	0.262
Household income*										
< 2 MW	76 (64.4)	1.13 (1.23)	2.76 (2.57)	1.45 (1.77)	0.74 (1.24)	6.08 (5.56)	1.58 (2.00)	0.45 (1.12)	2.03 (2.72)	8.16 (7.53)
≥ 2 MW	42 (35.6)	1.17 (1.20)	2.78 (3.19)	1.56 (1.58)	0.28 (0.75)	5.78 (5.10)	1.50 (1.43)	0.78 (0.94)	2.28 (1.84)	8.11 (6.53)
p-value		0.894	0.986	0.558	0.208	0.911	0.537	0.054	0.836	0.952
Untreated dental caries										
0	71 (55.5)	0.48 (0.82)	1.89 (2.54)	0.84 (1.63)	0.49 (1.24)	3.70 (5.33)	1.09 (1.98)	0.64 (1.45)	1.72 (3.12)	5.44 (7.63)
≥ 1	57 (44.5)	1.16 (1.22)	3.05 (3.05)	1.73 (1.77)	0.80 (1.56)	6.75 (6.28)	1.82 (2.17)	0.79 (1.28)	2.61 (2.92)	9.45 (8.44)
p-value		0.001	0.008	<0.001	0.103	<0.001	0.017	0.171	0.008	<0.001
Caries Severity										
Caries-free	71 (55.5)	0.48 (0.82)	1.89 (2.54)	0.84 (1.63)	0.50 (1.24)	3.70 (5.39)	1.09 (1.98)	0.64 (1.46)	1.72 (3.12)	5.43 (7.63)
Moderate	29 (22.7)	1.00 (1.22)	2.84 (2.53)	1.36 (1.44)	0.71 (1.21)	5.91 (5.37)	1.68 (2.04)	1.14 (1.56)	2.82 (3.38)	8.82 (8.10)
High	28 (21.9)	1.32 (1.22)	3.27 (3.52)	2.11 (2.01)	0.90 (1.87)	7.60 (7.07)	1.96 (2.32)	0.43 (0.80)	2.40 (2.41)	10.1 (8.87)
p-value		0.001	0.029	0.001	0.262	0.001	0.058	0.137	0.030	0.001
Total mean (SD)	128 (100)	0.77 (1.06)	2.36 (2.82)	1.24 (1.74)	0.62 (1.39)	4.97 (5.91)	1.43 (2.08)	0.69 (1.37)	2.13 (3.02)	7.10 (8.17)

SYD: symptoms domain (score range 0 to 4); FD: function domain (score range 0 to 16); PD: psychological domain (score range 0 to 8); SSD: self-image/social interaction domain (score range 0 to 8); PDD: parents distress domain (score range 0 to 8); FFD: family function domain (score range 0 to 8); MW: minimum wage. Data expressed as mean (SD); Mann-Whitney Y-test. *Missing data =10.

Correlation between variables and the overall B-ECOHIS score was calculated based on 128 subjects, showing a significant relationship between age/untreated dental caries and B-ECOHIS scores (r= 0.218, p= 0.01; r = 0.333, p = <0.001, respectively) (Table 3). In the final multivariate model, a negative impact on OHRQoL was associated with untreated dental caries/caries severity and CIS/overall B-ECOHIS score (Table 4). Cronbach's alpha was 0.86 for the questionnaire as a whole.

Table 3. Correlation values between the B-ECOHIS and variables.

Variable	Overall B-ECOHIS score	
	Correlation coefficient	p-value
Age	0.218	0.01
Sex	0.080	0.37
Parent's/caregiver's schooling	0.109	0.24
Household income	0.108	0.24
Untreated dental caries	0.333	< 0.001

Point-biserial correlation: Pearson's correlation coefficient.

Table 4. Final Poisson regression model for covariates associated with the CIS, FIS, and overall B-ECOHIS score.

Covariates	CIS	FIS	Overall B-ECOHIS score
	Robust PR (95%CI)	Robust PR (95%CI)	Robust PR (95%CI)
Socioeconomic factors			
Parent's/caregiver's schooling			
≤ 8 years	1	1	1
> 8 years	1.40 (0.83 – 2.37)	1.22 (0.67 – 2.22)	1.21 (0.76 – 1.93)
p-value	0.20	0.51	0.64
Household income			
< 2 MW	1	1	1
≥ 2 MW	0.84 (0.52 – 1.34)	0.87 (0.52 – 1.46)	0.81 (0.52 – 1.24)
p-value	0.46	0.61	0.33
Characteristics of the children			
Age			
< 6 years	1	1	1
≥ 6 years	1.54 (0.94 – 2.55)	1.60 (0.90 – 2.83)	1.10 (0.74 – 1.63)
p-value	0.08	0.10	0.64
Sex			
Male	1	1	1
Female	1.13 (0.73 – 1.76)	0.85 (0.51 – 1.43)	1.19 (0.80 – 1.77)
p-value	0.57	0.56	0.38
Oral clinical conditions			
Untreated dental caries			
0	1	1	1
≥ 1	1.89 (1.22 – 2.92)	1.49 (0.90 – 2.46)	1.67 (1.12 – 2.49)
p-value	0.004	0.120	0.011
Severity			
Caries-free	1	1	1
Moderate	1.60 (0.96 – 2.67)	1.60 (0.88 – 2.90)	1.54 (0.97 – 2.46)
High	2.17 (1.31 – 3.60)	1.37 (0.79 – 2.38)	1.81 (1.15 – 2.86)
p-value	0.009	0.277	0.031

PR: prevalence ratio, calculated using Wald's chi-square test; MW: minimum wage.

Discussion

This study evaluates the impact of untreated dental caries, sex, age, and socioeconomic factors on the OHRQoL of children with SHCN. However, few studies have assessed the OHRQoL of children with SHCN.[4, 5] Furthermore, other studies have assessed the impact of dental caries on OHRQoL, as well as the perception of parents about dental caries, but they have not focused on untreated dental caries.[4, 5, 8, 9] B-ECOHIS is widely used in studies with preschool children.[23,24] It was assumed that the subjects involved in the study lacked self-perception and that the application of B-ECOHIS would be pertinent. The instrument was used in a previous study with children with special needs[4] and presented positive results in relation to its respective objectives.

In the general pediatric population, the prevalence of untreated dental caries ranges from 46% to 53% in developing countries.[25] An untreated dental caries prevalence of 44.5% was observed in the present study. Similar results were found in children with cerebral palsy.[26] However, some studies involving individuals with SHCN may report higher[4,5,6,7] or low caries prevalence rates.[27] These studies used the WHO criteria considering decayed (d/D), filled (f/F), and missing (m/M) teeth, but in the present study only the component 'decayed – d/D' was used. This shows that the values of the DMFT index and of the simplified indices used in the current study may present numerical differences. Since the presence of caries has demonstrated an association with the impact on the quality of life of children and caregivers, when only untreated dental caries is considered, the impact may be greater than that indicated by the DMFT index.[14]

The results confirmed the association between the presence of dental caries and worse OHRQoL in children with SHCN, as pointed out by previous surveys.[4,8] In addition, caries severity had higher means for high severity in the overall B-ECOHIS score in accordance with some surveys.[4,8,28]

Age dichotomization allowed evaluating in which phases the impact may be more present in childhood, whether in younger (aged < 6 years) or in older (aged ≥ 6 years) children. In this study, the biggest impact was observed in children aged > 6 years. The finding that older children have a greater chance of experiencing a negative impact on their OHRQoL seemingly stems from the fact that such children have caries in more advanced stages of decay and also have a greater capacity to communicate their parents about the effects of oral health conditions on their quality of life.[11,14]

Parents with a lower socioeconomic status were more likely to rate their children's oral health as 'worse than that of other children.[29] Low-income caregivers tended to report higher scores, as also found in other studies.[4, 8, 30] A study carried out in the highlands of the state of Rio de Janeiro also showed lack of a statistically significant association between family income and OHRQoL,[5] as pointed out in this study (the referenced study did not use the ECOHIS). Most parents reported some impact on the quality of life of their children, indicating that this impact is stronger on the child than on the family. These findings are consistent with the extant literature.[4, 12] The prevalence of impact on children's quality of life (CIS) in the present study (69.5%) was similar to that reported in a previous study involving children and parents who sought treatment at a dental school (69.3%).[8] Our study showed that among the children whose quality of life was negatively affected, the most frequently reported impacts regarded 'pain in the teeth, mouth, or jaws'. In the FIS, the 'been upset' item was the most widely reported one. These results are consistent with other studies on this issue.[4,28]

This study shows a positive yet weak correlation between untreated dental caries and its impact on quality of life. A previous study performed with adolescents with juvenile idiopathic arthritis found no significant correlation between dental caries and OHRQoL.[9] However, in line with the above-mentioned findings, another research paper showed a significant and weak correlation between dental caries and quality of life.[31] Yet, this study is probably the first to correlate demographic and oral condition variables with OHRQoL for this population. Furthermore, there are few epidemiological studies on oral health directed towards children with SHCN.

The present study has limitations inherent to its cross-sectional design for having grouped all children

with disabilities with their various incapacitating conditions into one single group (the systemic conditions of the evaluated children have very different limitations). Therefore, some individuals have very limited verbal ability, while others may be capable of expressing their discomfort or reason for being 'upset'. Furthermore, the diagnosis must have impacted their oral health, their quality of life, and the parents' ability to assess their children's quality of life. Also, the answers to the questionnaires might have been subject to information bias. In addition, although the pre-calculated sample size was reached and a margin of 17.5% was added to make up for possible losses, we considered the size of the non-representative sample, assuming it as a convenience sample. Nonetheless, the use of a larger sample is suggested (categorizing children with SHCN into groups according to their medical condition / degree of intellectual disabilities) to confirm or disprove our results. A number of measures were taken to reduce the information bias, including the use of a validated questionnaire — one of the major strengths of the present study — and the undertaking of a pilot study.

Conclusion

In conclusion, untreated dental caries is associated with a negative impact on the OHRQoL of children with SHCN and of their families. Untreated dental caries and severity of dental caries showed an impact associated with the CIS domains (except for the self-image/social interaction domain). Better OHRQoL was reported in younger children and in families in which the parents had a lower level of schooling and income. An understanding of these influences can help clinicians and researchers assess oral health needs, establish priorities of care, and evaluate various treatment strategies, especially among children with SHCN.

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