Caries and quality of life in an Amazonian slum

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Abstract

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Background: The Community of Claverito is one of many informal urban floating communities located on the Amazon River in Peru.

Aim: To assess the dental health status and evaluate the oral-health related quality of life (OHRQoL) among the pediatric population of the Community of Claverito, a slum in the river floodplain of Iquitos, Peru.

Design: For this cross-sectional study, dental health status information was recorded for 67 children using the World Health Organization Oral Assessment form. OHRQoL information was recorded for 28 children using the validated Parental-Caregivers Perception Questionnaire (P-CPQ).

Results: The prevalence of untreated dental caries was 97%. The median DFT/dft (decayed and filled teeth index) score for the sample population was 7.0, and the Significant Caries (SiC) Index DFT/dft was 11.0. Median DFT was significantly greater among children whose primary

caregiver was not their mother. The average total P-CPQ score was 38.5. Significant associations were observed between OHRQoL and caregiver age.

Conclusions: Children of the Community of Claverito exhibit levels of decay roughly twice that of their domestic peers. Similarly, P-CPQ scores from our study population were more than double those of children from private and public schools in Lima, Peru.

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1. INTRODUCTION

According to estimates from the 2015 Global Burden of Disease (GBD) Study, untreated oral disease, including caries, severe periodontitis, and tooth loss, affects half the global population.[1] In fact, untreated dental caries in permanent teeth was the most prevalent disease among 313 assessed conditions, and from the two-and-a-half billion individuals affected 573 million of them were children. Unfortunately, the prevalence of these conditions continues to increase despite the overwhelming data on the impact of oral diseases on the general health and quality of life of the individuals affected.[2]

Oral health is a determinant factor for quality of life,[3] and dental disease is associated with a negative impact on quality of life.[4] The effects of oral diseases manifest as pain, impairment, and loss of function. Because the burden of disease is unevenly distributed, persons from minorities and low socio-economic backgrounds (as determined by educational background, occupation, income, and ethnicity) are often the most affected by oral diseases. Trends in the inverse association between oral health disparities and socioeconomic status/position are consistent in highly developed,[5-7] developing,[8] and underdeveloped countries,[9] demonstrating that individuals of lower socioeconomic status experience higher levels of oral disease.

At the most extreme end of the socioeconomic spectrum, growing populations of marginalized individuals worldwide reside in slums. Identifying and quantifying slum populations, however, has been complicated by the fact that the term ‘slum’ is a broad descriptor that lacks a universally agreed upon definition. In an effort to better measure slum populations, the United Nations Human Settlements Programme (UN-Habitat) developed an operational definition.[10] Based on this definition, individuals living in slum households lack a combination of the following:

durable housing, sufficient living space, ready access to safe water, access to adequate sanitation, and security of tenure. The UN-Habitat estimates that as of 2014, one in eight people globally lived in slums.[11] In developing countries alone, 881 million people resided in these poor, informal settlements, which represents an increase of 28% since 2000. Residents of these deprived communities, especially children, are susceptible to under-nutrition and mal-nutrition, infectious diseases, and risks of injury. Moreover, these populations often lack or are denied access to basic services, including medical and dental care.[10] Despite the rapid growth of slums, and the myriad of environmental factors predisposing these populations to health risks, these individuals receive relatively limited attention in medical and oral health research.[12]

Iquitos, Peru is the largest city in the Peruvian rainforest and the fifth largest city in Peru, with approximately 500,000 documented residents. In recent years, the city has experienced a rapid increase of immigrants moving from the surrounding jungle seeking jobs, education, and health opportunities. In the already dense city, migrants are forced to find affordable housing, which often results in the development of informal communities. Floating structures are built on the Amazon River, and these have become home for many migrants. Unfortunately, due to such precarious housing and poor environmental conditions, residents of these communities experience chronic illnesses, vector borne and infectious diseases, exposure to severe storms and flooding, and lack of water, sanitary infrastructure, and access to food.[13] Based on these characteristics, and the UN-Habitat Operational Definition, these informal settlements are slums.

In 2017, a collaborative group from the University of Washington (UW) schools and departments of Dentistry, Environmental Engineering, Environmental and Occupational Health, Global Health, Landscape Architecture, Neurology, and Nursing developed a transdisciplinary program, InterACTION Labs, to design and implement research projects aimed at advancing the

health, community strength, and future development of residents of one of these informal river communities - the Community of Claverito.[14,15] As a contributor to InterACTION Labs, dental faculty collected information about the community's oral health status and the impact of oral health on the residents' quality of life.

Few studies specifically report on the oral health status of slum-dwelling children,[16,17] and, to date, no literature exists on oral-health related quality of life (OHRQoL) among this population. In order to develop sustainable and scalable population health interventions, community-level baseline assessments of both disease and the perceptions of health are necessary. The purpose of this study was threefold: 1) to describe the prevalence and distribution of dental caries among the pediatric population of a slum community located on the Amazon River in Iquitos, Peru, 2) to assess the parental/caregiver perceptions of their children's OHRQoL, and 3) to evaluate the relationship between caries and OHRQoL. We hypothesized that the pediatric population of the Community of Claverito would have a high level of untreated dental decay and that the severity of dental decay would be associated with lower OHRQoL.

2. MATERIALS AND METHODS

2.1 ETHICAL CONSIDERATIONS

This cross-sectional study was approved by the UW Ethics Committee (# STUDY00000022). Informed consent/assent forms were signed by the pediatric participants and their parents and caregivers, in accordance with the Declaration of Helsinki.

2.2 POPULATION AND STUDY SAMPLE

This was a population-based cross-sectional study of all children aged 0-18 years and their parents and caregivers from the Community of Claverito in Iquitos, Peru. In 2018, there were 270 documented individuals living in the Community of Claverito, and 51.1% were children aged 0-18 years. The community is comprised of 51 houses, 44 of which have members of the household 18 years or younger. There are on average 2.7 children per household. All members of the community were invited to participate in this transdisciplinary study. A total of 67 children participated in the study (response rate: 48.6%).

2.3 DATA COLLECTION

Data collection was performed over two days in February 2018. Informed consent/assent was obtained and demographic information was collected on the pediatric participants and their parents/caregivers. Data collection was performed in the participants' households. If a member of the family was not present on the first day of data collection, the team returned to reattempt data collection on the second day. Dentition status was recorded for participants 18 years and younger using the WHO Oral Assessment form[18] by a calibrated team of dentists.

Accompanying parents or caregivers were interviewed to assess OHRQoL using the Peruvian version of the Parental-Caregiver Perceptions Questionnaire (P-CPQ).[19] In 18 of the families with two or more children, the parent/caregiver elected to complete only one P-CPQ survey for the household. The reference child was randomly chosen among the children in the family being examined. The P-CPQ consists of two questions which measure global ratings of the child's oral health and the impact of the child's oral/orofacial condition on his or her overall well-being, and thirty-one questions representing four health domains: oral symptoms (6), functional limitations (8), emotional well-being (7), and social well-being (10). The global ratings questions each have a five-point response format. The first question asked the parent/caregiver to rate the health of their child's teeth, lips, jaw, and mouth and includes the following five-point response format: "Excellent"=0, "Very good"=1, "Good"=2, "Fair"=3, "Poor"=4. The second question asked the parent/caregiver to indicate how much their child's overall well-being is affected by the condition of his/her teeth, lips, jaw, or mouth and includes the following five-point response format: "Not at all"=0, "Very little"=1, "Some"=2, "A lot"=3, "Very much"=4. Higher global ratings scores denote a poorer rating of the child's oral health and a greater impact of the child's oral health status on their overall well-being. The health domains questions asked how often in the last three months the child experienced symptoms or discomfort due to the condition of their teeth, lips, mouth, and jaws, and included the following five-point response format: "never"=0, "once or twice"=1, "sometimes"=2, "often"=3, "every day or almost every day"=4. A "don't know" response was also allowed, and these responses were given the value 0.[20] The responses to the health domains questions were reported as separate domain scores and as a total score. The total score was the sum of the thirty-one health domains questions, and could range from 0 to 124. Higher domain scores

and total score indicate a greater degree of the impact of the child's oral health status on their quality of life.

Dentition status and P-CPQ surveys were recorded on paper forms and entered into and managed using REDCap (Research Electronic Data Capture) tools hosted at the University of Washington. REDCap is a secure, web-based application designed to support data capture for research studies.[21] Additional demographic data, including gender, age, and highest educational degree received were collected as part of the InterACTION Labs project.

2.4 STATISTICAL ANALYSIS

Statistical analyses were performed using the statistical software R[22] and RStudio.[23] Percent with untreated decay (%D/%d), and median and inter-quartile range DT/dt, MT, FT/ft, DFT/dft, and DMFT scores were calculated for all participants 18 years and younger with dentition status data. In addition, the median Significant Caries Index (SiC Index),[24] which traditionally calculated as the mean DFT/dft or DMFT for the one third of the population with the highest caries scores, was also calculated.

Fisher's exact test was used to test for statistically significant differences in %D/%d based on child gender, child age, relationship of caregiver to the child, and caregiver age. The Mann-Whitney U test was used to test for statistically significant differences in DFT/dft and SiC Index DFT/dft scores based on child gender, relationship of caregiver to the child, and caregiver age.

For participants with P-CPQ survey data, median and inter-quartile range global health rating scores and P-CPQ domain and total scores were calculated. The Mann-Whitney U test was used to test for statistically significant differences in scores based on child gender, relationship of caregiver to the child, caregiver age, and SiC Index DFT/dft. The Kruskal-Wallis H test was used to test for statistically significant differences in scores based on child age. Because of the large

numbers of ties for many measures in these data, p-values for the Mann-Whitney and Kruskal-Wallis tests were computed using null distributions estimated using 10,000 Monte-Carlo permutation samples. In addition, frequency of scores for the thirty-one oral-health questions, collectively and by domain, were calculated.

Spearman's rank correlation coefficients were calculated to test for relationships between dental health status (DFT/dft scores and SiC Index DFT/dft scores) and global health rating scores and P-CPQ domain and total scores. All analyses were tested at the 95% confidence level.

3. RESULTS

Dentition status was recorded for 67 of the 138 community members 18 years and younger, which represents 48.6% of the pediatric population of the Community of Claverito (Table 1). Thirty-two of these participants were male, and the median age was 9.0 years (Q1-Q3, 6.0-13.5 years). Untreated decay was observed in 97% of all participants and in 100% of females, participants aged 0-5 years, and participants aged 12-18 years. The median DFT/dft score was 7.0 (Q1-Q3, 3.0-10.0), and the median SiC Index DFT/dft score was 11.0 (Q1-Q3, 10.0-13.8), with no statistically significant difference observed between males and females.

The P-CPQ survey was administered to 37 parents and caregivers, representing 84% of the households with children 18 years and younger. Of these, 28 surveys were completed on behalf of children with dentition status data (representing 64% of the families with children). Among this subgroup of 28 participants, twelve were male, and the median age was 9.0 years (Q1-Q3, 6.0-12.0 years) (Table 2). The mother was the primary caregiver for 23 of the participants (82%), and 21 of the caregivers were 30 years and older (75%). For 25 of the 28 caregivers (89%), education data was available, and the median years of education was 6.0 years (Q1-Q3, 3.5-7.5 years).

Untreated decay was observed in 27 out of 28 (96%) of these participants, and there were no statistically significant differences in %D/%d based on child gender, child age, relationship of caregiver to the child, or caregiver age. The median DFT/dft score was 8.0 (Q1-Q3, 3.0-10.0), and the median SiC Index DFT/dft score was 12.0 (Q1-Q3, 10.0-14.0). DFT/dft scores were statistically significantly higher among participants whose primary caregiver was not their mother, and a similar but not statistically significant trend was observed for SiC Index DFT/dft

scores. DFT/dft and SiC Index DFT/dft scores were also higher among males and among participants whose primary caregiver was under 30 years of age, but these differences were not statistically significant.

The median global rating score for oral health was 3.0 (Q1-Q3, 3.0-3.3), and the score did not vary based on child gender, child age, relationship of caregiver to the child, caregiver age, or SiC Index DFT/dft (Table 3). The median global rating score for overall well-being was 3.0 (Q1-Q3, 2.0-3.0), with statistically significantly higher scores observed among participants whose caregiver was 30 years of age or older, and marginally significantly higher scores observed among participants age 12-18 years (Table 3).

The median total P-CPQ score was 38.5 (Q1-Q3, 17.5-49.0) (Table 4). The condition which parents/caregivers reported their children most frequently experienced symptoms or discomfort was ‘food caught between teeth,’ and the condition which parents/caregivers reported their children least frequently experienced symptoms was ‘left out by other children’ (Supplemental Table 1). The oral symptoms domain scores were significantly higher among participants whose caregiver was 30 years of age or older. Although not statistically significant, total P-CPQ and the other three domain scores (functional limitations, emotional well-being, social well-being) were also higher among participants whose caregiver was 30 years of age or older. Additionally, when the oral symptoms domain scores were stratified by child age, a marginally significant difference was observed, with scores increasing with the age of the child. This trend was also observed for total P-CPQ and the other three domain scores.

Weak positive correlations were observed between DFT/dft scores and the global health rating scores and P-CPQ domain and total scores (Table 5). Correlations between SiC Index DFT/dft scores and P-CPQ scores were inconsistent. Positive correlations were observed between

SiC Index DFT/dft scores and the global rating of oral health and the functional limitations domain score, whereas negative correlations were observed between SiC Index DFT/dft scores and the remaining P-CPQ scores.

4. DISCUSSION

The purpose of this study was to describe the prevalence and distribution of dental caries among the pediatric population of a slum community located on the Amazon River floodplain in Iquitos, Peru, to assess the parental/caregiver perceptions of their children's OHRQoL, and to evaluate the relationship between caries and OHRQoL.

Our study population represented children in primary, mixed, and permanent dentition, and we observed that untreated dental caries was nearly universal (97%). Furthermore, only six participants were observed to have filled teeth and eight participants were observed to have missing teeth, suggesting that few children in this community receive restorative or surgical treatment. DFT/dft scores were used to describe the dental health status of the pediatric population because they were highly similar to DT/dt and DMFT scores (Supplemental Table 2).

The median DFT/dft score of 7 indicates the level of dental disease is high in this community, and the median SiC Index DFT/dft score of 11 suggests that the burden of disease is unevenly distributed, with a subset of the children experiencing more profound disease. The OHRQoL results indicate that collectively the parents/caregivers perceive their children's oral health status to be fair-to-poor, and they perceive that their children's oral health status has a significant impact on their quality of life and overall wellbeing.

When DFT/dft scores and P-CPQ domain and total scores were examined according to the relationship of caregiver to the child, significantly lower disease levels and generally lower P-CPQ scores were observed among children whose primary caregiver was their mother. Few studies have reported on the impact of the relationship of the caregiver to the child on OHRQoL, and while two studies found no association, our findings are consistent with a study among children with AIDS which assessed OHRQoL using the CPQ 11-14. This study reported that

children whose primary caregiver was their mother had significantly lower scores for the social well-being subscale and generally lower scores across the other three domains.[25]

Interestingly, when DFT/dft scores and P-CPQ total and domain scores when examined by the age of child's primary caregiver, we observed an inverse relationship between dental health status and OHRQoL. Compared to children with caregivers under 30 years of age, children with caregivers 30 years or older were found to have lower DFT/dft scores and significantly higher scores for the global rating of overall well-being and the oral symptoms domain. Furthermore, the total P-CPQ score and three other domain scores followed a similar trend. Seven studies have previously reported on the association between the mother's or caregiver's age and children's OHRQoL, and the results are mixed.[26] The relationship observed in our study may reflect the fact that older parents/caregivers in this community are more aware of the importance of oral health and better attuned to the well-being of their children.

An inverse relationship between DFT/dft scores and P-CPQ total and domain scores was noted when scores were stratified based on age of the child. Although we did not test for differences in DFT/dft and SiC Index DFT/dft scores between age groups (due to the fact the age groups generally corresponded to primary, mixed, and permanent dentitions, and therefore the number of teeth risk for decay or filling would logically differ by age group), participants 12-18 years of age were observed to have lower DFT/dft scores and generally higher global ratings and P-CQP scores. Previous studies have reported on lower levels of agreement between self- and parental/caregiver-ratings of OHRQoL among older children and have suggested that this may be attributed to older children spending less time with and sharing less personal information with their parents/caregivers.[27]

When the frequency of the P-CPQ domain scores were examined, scores in the oral symptoms domain were generally higher whereas scores in the social well-being domain were generally lower. In the Community of Claverito, the impact of the children's oral health status on quality of life appears to manifest most meaningfully by way of oral symptoms, whereas the effect on their social well-being appears to be less significant. In a study among parents of Syrian refugee children, the short-form Parental-Caregiver Perceptions Questionnaire-8 (P-CPQ-8) was administered, and the oral symptoms domain score also was observed to have the highest average score.[28] In studies comparing P-CPQ scores before and after children underwent dental treatment under general anesthesia, not only were statistically significant decreases in oral symptoms domain scores consistently observed, but compared to other domains, the oral symptoms domain scores exhibited the greatest change.[29-34] These findings suggest that access to treatment for the children of Community of Claverito could not only address dental disease but also significantly improve the symptoms associated with poor dentition status.

This study was not without limitations. Owing to the cross-sectional study design, we are only able to report associations and not causal relationships. The response rate was 48.6% for the dental examination and 20% for the OHRQoL interviews. Nine of the P-CPQ surveys were completed on behalf of participants > 18 years of age or on behalf of participants without dentition status data. Also, due to the length of the P-CPQ form, and in an effort to reduce the burden on the parents, 18 parents/caregivers completed only one P-CPQ survey for the household. These two factors reduced the sample size for the OHRQoL analyses. In addition, at the time of the analyses, participant-specific dietary data and fluoride exposure data was not available. Furthermore, although few children in our study had evidence of dental treatment, data related to interest in, access to, and utilization of dental services were not captured as part of this

study. This information would aid in understanding barriers to care for the children of the Community of Claverito and in the implementation of tailored interventions.

The results of this study confirm the hypothesis that children living in Claverito had an extremely high prevalence of dental caries (97%, %D/%d), a high level of caries (median DFT/dft score 7.0), and that their poor oral health affected their quality of life (38.5, median total P-CPQ score). Additionally, our findings suggest that these children lack access to preventive and rehabilitative dental services. Independently, these results are alarming, and when compared to national averages for Peru, the findings are even more worrisome.

With respect to access to care, in our study population, only 14 (21%) of the 67 children with dentition status data exhibited history of extractions or restorations. Our results are consistent with a recent study evaluating factors that determine access to oral health services among children under twelve years of age in Peru. This study found that wealth index, caregivers' education level, natural region of residence, and age were significant predisposing factors to access to care.[35] Compared to the national average of roughly 30%, only about 20% of children who lived in jungle regions, who came from the poorest families, or whose caregivers' highest level of education was primary school or less had access to dental health services.

The prevalence of dental caries and levels of dental caries among the children of Claverito were extremely high (97%, %D/%d and median DFT/dft score 7.0). A national survey conducted by the Ministry of Health of Peru in 2012-2014 reported the prevalence of dental caries was 59.1% among children age 0-5 years, 85.6% among children age 6-11 years, and 57.6% among children age 12-18 years.[36] A 2002 Pan American Health Organization study reported a DMFT score of 3.7 score of Peruvian children age 12 years.[37] The prevalence of caries

and level of disease among the children of the Community of Claverito were 50%-100% greater than the national averages in Peru.

Although OHRQoL scores are more subjective than DFT/dft scores, a recent survey of 200 children from two public schools and two private schools in Lima, Peru provides a point of reference.[19] They reported an average total P-CPQ score of 15.6, and when stratified by caries experience, children with caries had an average total P-CPQ score of 21.3. The children of the Community of Claverito had P-CPQ scores 80-150% higher than their domestic peers, which likely reflects their sharply higher caries experience. Given such high level of oral disease, further investigation should assess the impact of children's oral health on the quality of life of their families. Lastly, because our results suggest that the compromised oral health status of these children negatively impacts their quality of life, collaborative efforts with the community and with local health system towards policy change to improve availability and access to oral health services should be the next steps for achieving better health for all members of the Community of Claverito.

TABLE 1 Demographics and DHS measures of all participants with caries data (N = 67)

	Participants	Untreated decay (%D/%d)		DFT/dft		SiC Index DFT/dft		
	N (%)	N (%)	*P* value	Median (Q1-Q3)	*P* value	N	Median (Q1-Q3)	*P* value
All	67 (100)	65 (97)		7.0 (3.0-10.0)		23	11.0 (10.0-13.8)	
Child's gender								
Male	32 (48)	30 (94)	.22†	7.0 (2.0-10.0)	.83‡, .88§	11	12.0 (10.0-12.5)	.71‡, .72§
Female	35 (52)	35 (100)		7.0 (3.5-9.5)		12	11.0 (9.8-14.0)	
Child's age								
0 to 5 years	14 (21)	14 (100)	.69†	8.0 (4.3-8.0)		5	9.0 (8.0-10.0)	
6 to 11 years	30 (45)	28 (93)		6.0 (2.3-11.0)		10	12.0 (11.0-13.8)	
12 to 18 years	23 (34)	23 (100)		7.0 (3.0-10.0)		8	10.5 (10.0-12.5)	

† Fisher's exact test ‡ Mann-Whitney U test § Mann-Whitney U permutation test

TABLE 2 Demographics and DHS measures of participants with P-CPQ data (N=28)

	Participants	Untreated decay ((%D/%d)		DFT/dft		SiC Index DFT/dft		
	N (%)	N (%)	*P* value	Median (Q1-Q3)	*P* value	N	Median (Q1-Q3)	*P* value
All	28 (100)	27 (96)		8.0 (3.0-10.0)		9	12.0 (10.0-14.0)	
Child's gender								
Male	12 (43)	11 (92)	.43†	10.0 (2.8-12.3)	.23‡, .22§	4	13.5 (12.8-14.8)	.08‡, .09§
Female	16 (57)	16 (100)		6.5 (3.8-8.0)		5	10.0 (8.0-10.0)	
Child's age								
0 to 5 years	6 (21)	6 (100)	1†	8.0 (5.8-8.0)		2	9.0 (8.5-9.5)	
6 to 11 years	14 (50)	13 (93)		8.0 (3.0-11.8)		5	13.0 (12.0-14.0)	
12 to 18 years	8 (29)	8 (100)		5.5 (2.8-10.0)		3	10.0 (10.0-13.5)	
P-CPQ completed by								
Mother	23 (82)	22 (96)	1†	6.0 (2.5-10.0)	**.03‡, .03§**	8	10.0 (10.0-12.3)	.06‡, .08§
Other caregiver	5 (18)	5 (100)		11.0 (8.0-14.0)		2	15.5 (14.8-16.3)	
Caregiver's age								
Under 30 years	7 (25)	7 (100)	1†	8.0 (6.5-13.5)	.17‡, .18§	2	14.0 (14.0-14.0)	.17‡, .22§
30 years and over	21 (75)	20 (95)		7.0 (2.0-10.0)		7	10.0 (10.0-11.5)	

† Fisher's exact test ‡ Mann-Whitney U test § Mann-Whitney U permutation test

TABLE 3 Demographics and median global rating of oral health and overall well-being (N = 28)

	Oral health (0-4)		Overall well-being (0-4)	
	Median (Q1-Q3)	***P* value**	**Median (Q1-Q3)**	***P* value**
All participants	3.0 (3.0-3.3)		3.0 (2.0-3.0)	
Child's gender				
Male	3.0 (3.0-4.0)	.65†, .65‡	3.0 (2.0-3.0)	.98†, 1‡
Female	3.0 (3.0-3.0)		2.5 (2.0-3.3)	
Child's age				
0 to 5 years	3.0 (2.3-3.8)	.37§, .38¶	2.0 (2.0-2.8)	.05§, .05¶
6 to 11 years	3.0 (3.0-3.0)		2.0 (2.0-3.0)	
12 to 18 years	3.0 (3.0-4.0)		3.5 (3.0-4.0)	
P-CPQ completed by				
Mother	3.0 (3.0-3.0)	.27†, .44‡	3.0 (2.0-3.0)	.51†, .49‡
Other caregiver	3.0 (3.0-4.0)		3.0 (1.0-3.0)	
Caregiver's age				
Under 30 years	3.0 (3.0-3.5)	.88†, .99‡	2.0 (1.0-2.0)	**.003†, .001‡**
30 years and over	3.0 (3.0-3.0)		3.0 (2.0-3.0)	
SiC Index DFT/dft				
Non-SiC	3.0 (3.0-3.5)	1†, 1‡	2.0 (2.0-3.0)	.44†, .47‡
SiC	3.0 (3.0-3.0)		3.0 (2.0-3.0)	

† Mann-Whitney U test ‡ Mann-Whitney U permutation test § Kruskal-Wallis H test ¶ Kruskal-Wallis H test permutation test

TABLE 4 Demographics and median P-CPQ scores (N = 28)

	Oral symptoms (0-24)		Functional limitations (0-32)		Emotional well-being (0-28)		Social well-being (0-40)		Total P-CPQ (0-124)	
	Median (Q1-Q3)	***P* value**	**Median (Q1-Q3)**	***P* value**	**Median (Q1-Q3)**	***P* value**	**Median (Q1-Q3)**	***P* value**	**Median (Q1-Q3)**	***P* value**
All participants	9.0 (6.0-16.0)		10.0 (3.8-13.5)		8.0 (4.0-10.5)		8.0 (1.0-12.3)		38.5 (17.5-49.0)	
Child's gender										
Male	7.5 (5.5-13.5)	.49†, .50‡	11.0 (5.5-16.3)	.15†, .15‡	7.0 (5.5-10.5)	1†, 1‡	7.5 (1.8-12.3)	1†, 1‡	38.0 (20.5-48.0)	.91†, .91‡
Female	9.5 (7.5-16.0)		10.0 (1.5-11.3)		8.0 (3.0-10.5)		8.0 (0.8-10.5)		39.5 (15.0-49.0)	
Child's age										
0 to 5 years	4.0 (4.0-10.0)	.05§, .05¶	5.0 (1.0-9.8)	.13§, .13¶	6.0 (1.5-7.5)	.13§, .14¶	4.0 (0.0-8.0)	.44‡, .46¶	19.0 (7.0-38.5)	.20‡, .20¶
6 to 11 years	8.0 (6.3-12.0)		10.0 (2.3-11.0)		6.5 (4.0-10.0)		7.0 (1.3-12.8)		38.0 (12.8-45.0)	
12 to 18 years	14.5 (9.8-18.0)		12.5 (11.3-15.0)		9.0 (8.0-13.8)		8.0 (7.0-10.8)		45.0 (36.5-52.3)	
P-CPQ completed by										
Mother	9.0 (6.0-14.5)	.32†, .32‡	10.0 (3.5-12.5)	.47†, .47‡	7.0 (4.0-10.5)	.42†, .41‡	7.0 (1.0-8.5)	.29†, .30‡	37.0 (17.0-47.5)	.35†, .35‡
Other caregiver	12.0 (8.0-20.0)		11.0 (10.0-16.0)		10.0 (8.0-10.0)		12.0 (8.0-15.0)		44.0 (40.0-56.0)	
Caregiver's age										
Under 30 years	4.0 (4.0-7.5)	**.02†, .02‡**	6.0 (0.0-10.5)	.14†, .14‡	6.0 (0.0-7.0)	.10†, .10‡	0.0 (0.0-10)	.18†, .17‡	16.0 (4.0-38.0)	.08†, .07‡
30 years and over	10.0 (8.0-17.0)		11.0 (6.0-15.0)		8.0 (6.0-12.0)		8.0 (4.0-12.0)		41.0 (25.0-49.0)	
SiC Index DFT/dft										
Non-SiC	9.0 (6.0-16.5)	.29†, .29‡	11.0 (4.5-14.0)	.86†, .85‡	8.0 (3.5-11.0)	.73†, .72‡	7.0 (0.5-12.0)	.59†, .58‡	41.0 (17.0-52.5)	.77†, .77‡
SiC	8.0 (4.0-10.0)		10.0 (4.0-12.0)		8.0 (6.0-10.0)		8.0 (7.0-12.0)		38.0 (22.0-40.0)	

† Mann-Whitney U test ‡ Mann-Whitney U permutation test § Kruskal-Wallis H test ¶ Kruskal-Wallis H test permutation test

TABLE 5 Spearman's rank correlation between DHS and P-CPQ (N = 28)

	Oral health		Overall well-being		Oral symptoms		Functional limitations		Emotional well-being		Social well-being		Total P-CPQ	
	ρ	***P* value**	***ρ***	***P* value**	***ρ***	***P* value**	***ρ***	***P* value**	***ρ***	***P* value**	***ρ***	***P* value**	***ρ***	***P* value**
DFT/dft	0.17	.39	0.05	.82	0.02	.93	0.12	.53	0.21	.29	0.12	.56	0.13	.51
SiC Index DFT	0.52	.15	-0.01	.98	-0.28	.47	0.15	.70	-0.33	.39	-0.36	.33	-0.28	.47

SUPPLEMENTAL TABLE 1 Individual P-CPQ question scores collectively and by domain, reported as frequency (N = 28)

	"never"=0	"once or twice"=1	"sometimes"=2	"often"=3	"every day or almost every day"=4
All questions	**49.5**	**10.3**	**24.1**	**7.9**	**8.2**
P-CPQ Subscales					
Oral symptoms (n = 6)	**36.3**	**4.8**	**28.6**	**10.7**	**19.6**
Food caught between teeth	10.7	3.6	42.9	10.7	32.1
Pain in teeth/mouth	25.0	3.6	42.9	10.7	17.9
Bad breath	32.1	7.1	17.9	17.9	25.0
Mouth sores	39.3	3.6	35.7	14.3	7.1
Bleeding gums	50.0	3.6	14.3	7.1	25.0
Food stuck to roof of mouth	60.7	7.1	17.9	3.6	10.7
Functional limitations (n = 8)	**47.8**	**10.7**	**23.7**	**8.0**	**9.8**
Difficulty chewing firm foods	28.6	0	28.6	17.9	25.0
Unclear speech	46.4	14.3	28.6	7.1	3.6
Difficulty drinking/eating hot/cold foods	46.4	7.1	17.9	17.9	10.7
Difficulty eating foods would like to eat	42.9	7.1	35.7	3.6	10.7
Slow eating	42.9	21.4	14.3	7.1	14.3
Breathing through mouth	71.4	10.7	10.7	3.6	3.6
Restricted diet	57.1	7.1	21.4	7.1	7.1
Trouble sleeping	57.1	7.1	21.4	7.1	7.1
Emotional well-being (n = 7)	**49.2**	**12.3**	**25.1**	**7.7**	**5.7**
Upset	42.9	10.7	35.7	35.7	7.1
Irritable/frustrated	21.4	14.3	35.7	14.3	14.3
Worried he/she is less attractive than others	71.4	7.1	14.3	3.6	3.6
Shy/embarrassed	51.9	11.1	22.2	14.8	0
Anxious/fearful	32.1	10.7	39.3	10.7	7.1
Worried that is different from other people	53.6	25.0	14.3	3.6	3.6
Worried about having fewer friends	71.4	7.1	14.3	3.6	3.6
Social well-being (n = 10)	**59.1**	**11.8**	**21.2**	**6.1**	**1.8**
Teased/called names by other children	66.7	14.8	11.1	7.4	0
Avoided smiling when around other children	50.0	14.3	28.6	3.6	3.6
Asked by other children about condition	38.6	3.6	14.3	0	3.6
Not wanted to speak/read aloud in class	53.6	10.7	25.0	10.7	0
Not wanted to talk to other children	64.3	7.1	14.3	14.3	0
Left out by other children	75.0	7.1	10.7	0	7.1
Had hard time playing attention in school	35.7	17.9	39.3	3.6	3.6
Not wanted/unable to be with other children	53.7	25.0	7.1	14.3	0
Missed school	53.6	14.3	28.6	3.6	0
Not wanted/unable to take part in activities (sports, drama, clubs)	60.7	3.6	32.1	3.6	0

SUPPLEMENTAL TABLE 2 Demographics and DHS measures of all participants with caries data (N = 67)

	Participants	DT/dt	DFT/dft	DMFT/dmft	SiC Index DFT/dft		SiC Index DMFT/dmft
	N (%)	Median (Q1-Q3)	Median (Q1-Q3)	Median (Q1-Q3)	N	Median (Q1-Q3)	Median (Q1-Q3)
All	67 (100)	6.0 (3.0-10.0)	7.0 (3.0-10.0)		23	11.0 (10.0-13.8)	
Child's gender							
Male	32 (48)	7.0 (2.0-10.0)	7.0 (2.0-10.0)		11	12.0 (10.0-12.5)	
Female	35 (52)	6.0 (3.0-9.5)	7.0 (3.5-9.5)		12	11.0 (9.8-14.0)	
Child's age							
0 to 5 years	14 (21)	8.0 (4.3-8.0)	8.0 (4.3-8.0)		5	9.0 (8.0-10.0)	
6 to 11 years	30 (45)	6.0 (2.3-10.8)	6.0 (2.3-11.0)		10	12.0 (11.0-13.8)	
12 to 18 years	23 (34)	6.0 (3.0-10.0)	7.0 (3.0-10.0)	7.0 (3.0-10.5)	8	10.5 (10.0-12.5)	11.5 (11.0-14.3)

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APPENDIX A

INSTRUCTIONS TO PARENTS

1. This questionnaire is about the effects of oral conditions on children's well-being and everyday life, and the effects on their families. We are interested in any condition that involves teeth, lips, mouth or jaws. **Please answer each question.**

2. To answer the question please put an ☒ **in the box by the response**.

3. Please give the response that **best describes your child's experience**. If the question does not apply to your child, please answer with "Never".

   Example: How often has your child had a hard time paying attention in school?

   If your child has had a hard time paying attention in school because of problems with his/her teeth, lips, mouth or jaws, choose the appropriate response. If it has happened for other reasons, choose "Never".

❑	❑	❑	❑	❑	❑
Never	Once or twice	Sometimes	Often	Everyday or almost everyday	Don't know

4. Please **do not discuss the questions with your child,** as we are interested only in the parents' perspective in this questionnaire.

SECTION 1: Child's oral health and wellbeing

1. **How would you rate the health of your child's teeth, lips, jaws and mouth?**

❑ Excellent ❑ Very good ❑ Good ❑ Fair ❑ Poor

2. **How much is your child's overall wellbeing affected by the condition of his/her teeth, lips, jaws or mouth?**

❑ Not at all ❑ Very little ❑ Some ❑ A lot ❑ Very much

SECTION 2: The following questions ask about symptoms and discomfort that children may experience due to the condition of their teeth, lips, mouth and jaws

During the last 3 months, how often has your child had:

3. **Pain in the teeth, lips, jaws or mouth?**

❑ Never ❑ Once or twice ❑ Sometimes ❑ Often ❑ Everyday or almost everyday ❑ Don't know

4. Bleeding gums?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

5. Sores in the mouth?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

6. Bad breath?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

7. Food stuck in the roof of the mouth?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

8. Food caught in or between the teeth?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

9. Difficulty biting or chewing foods such as fresh apple, corn on the cob or firm meat?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

During the last 3 months, because of his/her teeth, lips, mouth, or jaws, how often has your child:

10. Breathed through the mouth?

❑ Never ❑ Once or twice ❑ Sometimes ❑ Often ❑ Everyday or almost everyday ❑ Don't know

11. Had trouble sleeping?

❑ Never ❑ Once or twice ❑ Sometimes ❑ Often ❑ Everyday or almost everyday ❑ Don't know

12. Had difficulty saying any words?

❑ Never ❑ Once or twice ❑ Sometimes ❑ Often ❑ Everyday or almost everyday ❑ Don't know

13. Taken longer than others to eat a meal?

❑ Never ❑ Once or twice ❑ Sometimes ❑ Often ❑ Everyday or almost everyday ❑ Don't know

14. Had difficulty drinking or eating hot or cold foods?

❑ Never ❑ Once or twice ❑ Sometimes ❑ Often ❑ Everyday or almost everyday ❑ Don't know

15. Had difficulty eating foods he/she would like to eat?

❑ Never ❑ Once or twice ❑ Sometimes ❑ Often ❑ Everyday or almost everyday ❑ Don't know

16. Had diet restricted to certain types of food (e.g. soft food)?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

SECTION 3: The following questions ask about the effects that the condition of children's teeth, lips, mouth and jaws may have on their feelings and everyday activities

During the last 3 months, because of his/her teeth, lips, mouth or jaws, how often has your child been:

17. Upset?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

18. Irritable or frustrated?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

19. Anxious or fearful?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

During the <u>last 3 months</u>, because of his/her <u>teeth, lips, mouth or jaws</u>, how often has your child:

20. Missed school (e.g. pain, appointments, surgery)?

❑	❑	❑	❑	❑	❑
Never	Once or twice	Sometimes	Often	Everyday or almost everyday	Don't know

21. Had a hard time paying attention in school?

❑	❑	❑	❑	❑	❑
Never	Once or twice	Sometimes	Often	Everyday or almost everyday	Don't know

22. Not wanted to speak or read out loud in class?

❑	❑	❑	❑	❑	❑
Never	Once or twice	Sometimes	Often	Everyday or almost everyday	Don't know

23. Not wanted to talk to other children?

❑	❑	❑	❑	❑	❑
Never	Once or twice	Sometimes	Often	Everyday or almost everyday	Don't know

24. Avoided smiling or laughing when around other children?

❑	❑	❑	❑	❑	❑
Never	Once or twice	Sometimes	Often	Everyday or almost everyday	Don't know

During the last 3 months, because of his/her teeth, lips, mouth or jaws, how often has your child:

25. Worried that he/she is not as healthy as other people?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

26. Worried that he/she is different than other people?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

27. Worried that he/she is not as good-looking as other people?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

28. Acted shy or embarrassed?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

29. Been teased or called names by other children?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

30. Been left out by other children?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

31. Not wanted or been unable to spend time with other children?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

32. Not wanted or been unable to participate in activities such as sports, clubs, drama, music, school trips?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

33. Worried that he/she has fewer friends?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

During the <u>last 3 months</u>, how often has your child been:

34. Concerned what other people think about his/her teeth, lips, mouth or jaws?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

35. Asked questions by other children about his/her teeth, lips, mouth or jaws?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

SECTION 4: The following questions ask about effects that a child's oral condition may have on PARENTS AND OTHER FAMILY MEMBERS

During the last 3 months, because of your child's teeth, lips, mouth or jaws, how often have you or another family member:

36. Been upset?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

37. Had sleep disrupted?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

38. Felt guilty?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

39. Taken time off work (e.g. pain, appointments, surgery)?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

40. Had less time for yourself or the family?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

41. Worried that your child will have fewer life opportunities (e.g. for dating, getting married, having children, getting a job he/she will like)?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

42. Felt uncomfortable in public places (e.g. stores, restaurants) with your child?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

During the last 3 months, because of his/her teeth, lips, mouth, or jaws, how often has your child:

43. Been jealous of you or others in the family?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

44. Blamed you or another person in the family?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

45. Argued with you or others in the family?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

46. Required more attention from you or others in the family?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

During the last 3 months, how often has the condition of your child's teeth, lips, mouth or jaws:

47. Interfered with family activities at home or elsewhere?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

48. Caused disagreement or conflict in your family?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

49. Caused financial difficulties for your family?

❑ Never	❑ Once or twice	❑ Sometimes	❑ Often	❑ Everyday or almost everyday	❑ Don't know

SECTION 5: Child's gender and age

a. Your child is:

- ❑ MALE
- ❑ FEMALE

b. Your child's age is: _____YEARS

Questionnaire completed by:

- ❑ MOTHER
- ❑ FATHER
- ❑ OTHER _____

Date completed: _____ / _____ / _____
DAY MONTH YEAR

To test how good this questionnaire is at giving us the information we need, we would like a group of parents to complete it again.

Would you be willing to complete another copy of the questionnaire in the next 2 weeks?

☐ **Yes**

THANK YOU FOR YOUR PARTICIPATION !

APPENDIX B

P-CPQ Domains and Corresponding Survey Questions

Global ratings	
Oral health	pcpq1
Overall well-being	pcpq2
Subscales	
Oral symptoms (n = 6)	
Food caught between teeth	pcpq8
Pain in teeth/mouth	pcpq3
Bad breath	pcpq6
Mouth sores	pcpq5
Bleeding gums	pcpq4
Food stuck to roof of mouth	pcpq7
Functional limitations (n = 8)	
Difficulty chewing firm foods	pcpq9
Unclear speech	pcpq12
Difficulty drinking/eating hot/cold foods	pcpq14
Difficulty eating foods would like to eat	pcpq15
Slow eating	pcpq13
Breathing through mouth	pcpq10
Restricted diet	pcpq16
Trouble sleeping	pcpq11
Emotional well-being (n = 7)	
Upset	pcpq17
Irritable/frustrated	pcpq18
Worried he/she is less attractive than others	pcpq27
Shy/embarrassed	pcpq28
Anxious/fearful	pcpq19
Worried that is different from other people	pcpq26
Worried about having fewer friends	pcpq33
Social well-being (n = 10)	
Teased/called names by other children	pcpq29
Avoided smiling when around other children	pcpq24
Asked by other children about condition	pcpq35
Not wanted to speak/read aloud in class	pcpq22
Not wanted to talk to other children	pcpq23
Left out by other children	pcpq30
Had hard time playing attention in school	pcpq21
Not wanted/unable to be with other children	pcpq31
Missed school	pcpq20
Not wanted/unable to take part in activities (sports, drama, clubs)	pcpq32