# Association Between Child Caries and Child and Family Quality of Life in an Amazonian Slum

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## Abstract

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**Purpose:** To assess child and caregiver dental health status (DHS) and to measure the associations between child DHS and child and family quality of life in the informal Community of Claverito located on the Amazon River in Iquitos, Peru.

**Methods:** DHS, as measured by decayed and filled teeth (DFT/dft), was recorded for 66 children and 35 caregivers using the World Health Organization Oral Assessment form. Oral health-related quality of life (OHRQoL) information for 64 children was measured using the Parental-Caregiver Perceptions Questionnaire (P-CPQ). The family impact of child oral disorders was measured using the Family Impact Scale (FIS). Descriptive statistics, correlations, and regression analyses were used to evaluate the associations between DFT/dft, P-CPQ, and FIS scores with significance level set at 5%.

**Results:** The prevalence of untreated child dental caries was 97%. The child and caregiver's mean DFT/dft scores were 6.8 (SD ± 4.5) and 8.7 (SD ± 13.3), respectively. Mean total P-CPQ and total

FIS scores were 33.4 and 12.5, respectively. A significant positive association was observed between child DFT/dft scores and total FIS scores ($p < 0.01$). Significant associations were also observed between child DFT/dft scores and caregiver age ($p < 0.01$) and child DFT/dft scores and caregiver DFT scores ($p < 0.01$).

**Conclusions:** Children and their caregivers living in the Community of Claverito exhibited high levels of untreated decay. There was a significant association between child DFT/dft scores and family impact scores, which suggests that poor child DHS may have a negative effect on the family quality of life. Because this was a cross-sectional study, further research is required to establish a causal effect.

**Key Words:** Dental Caries, Pediatric Dentistry, Peru, Quality of Life, Slums

This research adds to existing efforts within the University of Washington Department of Pediatric Dentistry. It is part of an overarching study examining oral health and quality of life in an Amazonian slum. Parts are reprinted with written permission and referenced from “Caries and Quality of Life in an Amazonian Slum” by Horton, Marc, et al. University of Washington, 2019.

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# DEDICATION

I dedicate my thesis to:

My family for their encouragement, love, and continuous support. Thank you for always inspiring me and giving me strength to reach for the stars and chase my dreams. I love you!

# CHAPTER 1. INTRODUCTION

Combating poverty, disease, and environmental degradation at a global level are among the United Nation's (UN) top priorities through its Sustainable Development Goals (SDGs).[1] With the pledge to ensure "no one will be left behind," health is a fundamental aspect of the SDGs, with the ultimate aim of promoting "well-being for all at all ages".[2] According to estimates from the 2015 and 2017 Global Burden of Disease (GBD) Study, oral disorders (including caries, periodontal disease, and edentulism) were the most prevalent diseases among 354 assessed conditions, and dental caries of the primary teeth affected more than 570 million children.[3,4] Oral disorders manifest as pain, impairment, and loss of function, and can affect individuals throughout their lifetime. And, like other chronic diseases, oral diseases disproportionally affect the poor and socially disadvantaged.

Trends in the inverse association between oral health disparities and socioeconomic status are consistent in highly developed,[5,6] developing,[7] and underdeveloped countries,[8] demonstrating that individuals of lower socioeconomic status experience higher levels of oral disease.[9] At the most extreme end of the socioeconomic spectrum, growing populations of marginalized individuals worldwide reside in slums. According to the UN Human Settlements Programme (UN-Habitat), as of 2014, one in eight people globally lived in slums and lacked access to safe water, durable housing, sufficient living space, and security of tenure that prevents forced evictions.[9,10] Slum-dwelling residents often lack or are denied access to basic services, including medical and dental care.[9,11] Despite the rapid growth of slums, and the many environmental factors predisposing these populations to health risks, these populations receive relatively limited attention in medical and oral health research.[9,12]

Iquitos, Peru, is the largest city in the Peruvian Amazonian rainforest. 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 or construct 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 immigrants. 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.[9,13] In 2017, a collaborative group from the University of Washington (UW) schools and departments of Dentistry, Civil and Environmental Engineering, Environmental and Occupational Health, Global Health, Landscape Architecture, Neurology, and Nursing teamed up with the Centro de Investigaciones Tecnológicas Biomédicas y Medioambientales (CITBM), the Universidad Nacional de la Amazonía Peruana (UNAP) and the Instituto Nacional de Salud (INS) in Peru and developed a transdisciplinary action research 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.[9]

Few studies specifically report on the oral health status of slum-dwelling children and its impact on their oral-health related quality of life (OHRQoL) or families' quality of life.[16,17] In order to develop sustainable and scalable population health interventions, community-level baseline assessments of both disease and quality of life are necessary.[9] The purpose of this study was twofold: 1) to describe the prevalence and distribution of dental caries among the pediatric and caregiver populations of a slum community located on the Amazon River in Iquitos, Peru; and 2) to evaluate the relationships between the children's dental health status and the OHRQoL of the

children and the impact on their families. We hypothesized that the pediatric and caregiver population of the Community of Claverito would have a high level of untreated dental decay and that the children's poor dental health status would be associated with lower quality of life for both the children and their families.

# CHAPTER 2. MATERIALS AND METHODS

## 2.1 ETHICAL CONSIDERATIONS

This cross-sectional study was approved by Ethics Committees at both UW (# STUDY00000022) and The Instituto de Medicina Tropical "Daniel Alcides Carrión" at the Universidad Nacional Mayor de San Marcos in Peru (#CIEI-2018-004). Informed consent/assent forms were signed by the pediatric participants and their parents and caregivers, in accordance with the Declaration of Helsinki.

## 2.2 STUDY POPULATION

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 138 (51.1%) were children aged 0-18 years. The community is comprised of 50 houses, 44 of which have members of the household 18 years or younger. There were on average 2.7 children per household. All members of the community were invited to participate in this transdisciplinary study. We report on analyses of data from participants for which child and caregiver dental records and caregiver surveys were collected.[9]

## 2.3 DATA COLLECTION

Data collection was performed over two days in February 2018 in the participants' houses. Informed consent/assent was obtained, and demographic information was collected on the pediatric participants and their caregivers. 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.[9] Dentition status was recorded for participants 18 years and younger and for their caregivers using the WHO

Oral Assessment form[18] by a calibrated team of public health dentists. Dental records were collected for 66 children and 35 caregivers. Accompanying parents or caregivers were interviewed to assess quality of life using the Parental-Caregiver Perceptions Questionnaire (P-CPQ) and Family Impact Scale (FIS), previously validated in Spanish.[19,20] One P-CPQ/FIS survey was administered per household.

The P-CPQ[9,21] 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 questions), functional limitations (8 questions), emotional well-being (7 questions), and social well-being (10 questions). The two global ratings questions each have a five-point response format. The first question asks 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 asks 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 ask 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 include 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 is also allowed, and these responses are given the value 0. The responses to the health domains questions are reported as separate domain scores and as a total score. The total score is the sum of the thirty-one health domains questions and can 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.

The FIS[22] consists of 14 questions, which measure the impact of the child's oral/orofacial condition on his or her family's quality of life. The 14 questions are divided into four sub-scales: parental/family activity (5 questions), parental emotions (4 questions), family conflict (4 questions) and financial burden (1 question). The questions ask the parent/caregiver to indicate frequency of events in the previous 3 months and include 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 is also allowed, and these responses are given the value 0. The responses are reported as subscale scores and a total score, which can range from 0 to 56. Higher scores indicate greater impact of a child's oral condition on family quality of life.

Dentition status and P-CPQ and FIS surveys were administered verbally by Spanish speaking Peruvian dental team members, recorded on paper forms and were 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.[23] Additional demographic data, including gender and age, was collected as part of the InterACTION Labs project.

## 2.4 STATISTICAL ANALYSIS

Statistical analyses were performed using the statistical software R, version 3.6.1.[24] Descriptive statistics were calculated for all participants 18 years and younger and their caregivers. Pearson correlation coefficients were calculated to evaluate the relationships between dental health status (DFT/dft scores) and P-CPQ domain and total scores as well as FIS subscales and total scores.

Unadjusted and adjusted linear regression models with generalized estimating equation (GEE) were fit to the data to evaluate the relationships between both demographic variables (child's gender, child's age, caregiver's age, caregiver's dental health status) and OHRQoL variables (which caregiver completed the OHRQoL survey, total P-CPQ score, and total FIS score) with child's dental health status. GEE was utilized to account for clustering of children within households. Hypothesis tests were performed using a 5% significance level.

# CHAPTER 3. RESULTS

Dentition status and demographics were recorded for 66 community members 18 years and younger and for 35 of their caregivers (Table 1). Of the participants 18 years and younger, thirty-two were male (48%), and the mean age was 9.4 years (Standard Deviation (SD) ± 4.4). Untreated decay was observed in 97% of all pediatric participants, and the mean DFT/dft score was 6.8 (SD ± 4.5). The mean age of the caregivers was 37.7 years (SD ± 13.3), and the mother was the primary caregiver for the majority of the children (83%). The caregiver's mean DFT score was 8.7 (SD ± 13.3), and 27% of caregivers had a DFT score greater than 11.

One P-CPQ/FIS survey was administered per household, and data was recorded for 35 households. In 18 of the households, the P-CPQ/FIS survey was completed on behalf of two or more children. P-CPQ/FIS data was available for 64 children with DFT/dft data. The P-CPQ scores ranged from 1 to 84 with a mean score of 33.4 (SD ± 20.0) (Table 2). A weak positive correlation was observed between total P-CPQ and child DFT/dft scores. Weak positive correlations were also observed between DFT/dft scores and global rating of oral health, global rating of overall well-being, and the P-CPQ domains emotional well-being and social well-being. Negative correlations were observed with the P-CPQ domains oral symptoms and functional limitations.

The FIS scores ranged from 0 to 35 with a mean score of 12.5 (SD ± 7.9) (Table 2). A statistically significant positive correlation was observed between total FIS and child DFT/dft scores ($R=0.3$, $p<.05$). The FIS subscale scores were observed to have positive but non-significant correlations with child DFT/dft scores.

In both the unadjusted and adjusted regression analyses, we observed no relationship between the variables child gender, child age, and primary caregiver and child DFT/dft scores (Table 3). Exploring the relationship between caregiver age and child DFT/dft scores, in both the

unadjusted and adjusted models we observed that DFT/dft scores were lower among children with caregivers 31-40 years compared to children with caregivers 18 to 30 years (ß = -3.3 & -3.8, p<.05). However, there was no significant difference in DFT/dft scores among children with caregivers greater than 40 years compared to children with caregivers 18 to 30 years. Evaluating the relationship between caregiver DFT scores and child DFT/dft scores, in the unadjusted model we observed child DFT/dft scores were higher among children with caregivers with DFT scores of 7-11 (ß = 2.8) and >11 (ß = 3.7) compared with children with caregivers with DFT scores < 7 (p<.05). In the adjusted model, the association remained statistically significant only among children with caregivers with DFT scores of 7-11 (ß = 2.6, p < .01). Assessing the relationship between the OHRQoL scores and child DFT/dft scores, in both the unadjusted and adjusted analyses, a one-point increase in FIS total score was associated with an increase in child DFT/dft score (unadjusted: ß = 0.18, p = .04; adjusted: ß = 0.31, p < .01). There was no statistically significant association between the P-CPQ total score and child DFT/dft scores.

# CHAPTER 4. DISCUSSION

The aim of this study was to determine the dental health status of children and their caregivers in the Claverito Community in Iquitos, Peru and to assess the associations between the children's dental health status and their quality of life and the quality of life of their families. We hypothesized that the population of the Claverito Community would have a high level of untreated dental decay and that the severity of children's dental decay would be associated with lower quality of life for the children and their families.

The results of this study reveal poor oral health status for the children and caregivers and an association between child dental health status and family quality of life. Ninety-seven percent of the children in this slum community were observed to have untreated dental decay, and only six children had filled teeth and only eight children had missing teeth. We observed mean child DFT/dft and mean caregiver DFT scores of 6.8 and 8.7, respectively. Collectively, these results indicate a high level of dental disease and limited access to dental care, and these results supported our hypothesis. Our findings also corroborate a significant relationship between child DFT/dft scores and caregiver DFT scores, which is in agreement with existing studies suggesting that caregiver's oral health status is a strong predictor of the oral health status of their children.[25] We additionally hypothesized that child dental health status would correlate with the quality of life of both the child and the family. Although we did not find a significant association between total P-CPQ scores and child DFT/dft scores, the poor oral health status of the children was observed to have a negative association with the quality of life of the family, as reflected in the FIS scores.

The prevalence of dental caries and DFT/dft scores among the children living in the Community of Claverito is extremely high. A national survey conducted by the Ministry of Health

of Peru in 2012-2014 reported the prevalence of dental caries in Peru 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.[9,26] A 2019 study reported on a selection of studies on early childhood caries in Peru published between 2010 and 2019 and found an average dmft between 3.6 and 5.[27] The prevalence of caries and level of disease among the children in our study was 50%-100% greater than the national averages in Peru.

With respect to access to care, only 14 (21%) of the 66 children in our study population 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.[28] Nationally, roughly 30% of children had access to dental health services, whereas 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 these services.

We did not find significant association between the total P-CPQ score and child DFT/dft. Because P-CPQ was through caregiver's perception and because we were limited to one survey per family, our data could have been overly subjective and therefore our correlation appeared to be low. 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.[9,19] The study 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. Although we did not observe an association between total P-CPQ scores and child DFT/dft scores, the children of

the Community of Claverito had P-CPQ scores 80-150% higher than their domestic peers, which may reflect their sharply higher caries experience.[9]

Additionally, we found caregivers' age to be a significant factor associated with child DFT/dft scores. Specifically, children of caregivers 31-40 years had significantly lower levels of dental disease when compared to children with caregivers 18 to 30 years. Our findings are in agreement with previous studies that report that parents younger than thirty years of age have children with a higher prevalence of dental caries and correspondingly poorer OHRQoL.[29] Caregivers in the third decade of their life may be more aware of the importance of oral health and better attuned to the well-being of their children. They may also have more life experience, be more financially stable, or have more time to spend with their children when compared to the younger caregivers.[30] For caregivers greater than 40 years, a negative, but not statistically significant, relationship was also observed. Older caregivers may include grandparents or parents with multiple children, and older caregivers may experience more fatigue, may have poorer health, may also care for their own parents while raising children, or may have limited resources due to the complexity of caring for multiple children.

Instruments to measure burden of oral disease on the family are limited. This study provided a unique insight into the impact of child DHS on the family using the validated FIS survey. As hypothesized, the poor oral health status of the children was observed to have a negative impact on the quality of life of the family. Our results are similar to those of a Brazilan study which found that severity of dental caries was negatively associated with total FIS scores and with three of the four subscales.[31] Our findings suggest that efforts to improve the oral health of slum communities, like the Community of Claverito, could reduce levels of dental disease and improve family quality of life.

Several factors affected the results of this study. Our cross-sectional study only allowed us to provide association, not causation. Additionally, the sample size was limited, which reduced the power of the study. This was due, in part, to the two-day time frame available to complete exams and administer surveys, and it was also due to participant fatigue. Dentistry was among one of eight groups from InterACTION Labs interviewing families in the community, and participants were allowed to consent/assent to individual components of the project, therefore some families declined to participate in the oral health component. Furthermore, due to the length of the OHRQoL questionnaires, and in an effort to reduce the burden on the caregivers, a single P-CPQ and FIS survey was completed per household instead of per child.[9] The Generalized Estimating Equations method was utilized to account for the effect of clustering by household. Finally, at the time of the analyses, participant-specific dietary data and fluoride exposure data was not available, and data related to interest in, access to, and utilization of dental services was 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.[9]

Lastly, we recognize that it is conventional to analyze DHS and OHRQoL data with OHRQoL scores as the outcome variable. Because our study design was cross-sectional, because we were aiming at associations between caries and quality of life, and because our study data set had a multi-level structure with the child as the unit of observation (clustering by household) and quality of life (P-CPQ and FIS) (measured at the household level), the child's DFT/dft score was used as the outcome variable. This analysis approach allowed us to make the most efficient use of the data by assessing independent associations of P-CPQ and FIS scores with caries, thus including both variables as independent variables in the same model. If the P-CPQ and FIS scores were used as outcome variables, the analysis would have needed to be done at the household level, and this

would have resulted in a consequent significant decrease in sample size and a need to summarize the children's DFT/dft measures at the household level.

# CHAPTER 5. CONCLUSION

In summary, results from this study supported our hypotheses that children and their caregivers living in Community of Claverito have a high level of untreated dental decay and that the children's poor oral health is associated with lower quality of life for their families. There are an estimated 90,000 people living in riverine slum communities in Iquitos that could benefit from an increase in oral health services. Policy changes to improve availability and access to oral health services are needed to achieve better health for informal communities like the one of Claverito.

**Table 1: Demographics and dental health status of child and caregiver.**

| **Children** | |
|---|---|
| All children, n (%) | 66 (100%) |
| Gender, n (%) | |
| Male | 32 (48%) |
| Female | 34 (52%) |
| Age, yr, mean ± SD, median (IQR) | 9.4 ± 4.4, 9 (6 – 13) |
| Age categories, n (%) | |
| 0 to 5 years | 14 (21%) |
| 6 to 11 years | 30 (33%) |
| 12 to 18 years | 22 (45%) |
| DFT/dft, mean ± SD, median (IQR) | 6.8 ± 4.5, 6.5 (3 – 10) |
| DFT/dft categories, n (%) | |
| 0 to 4 teeth | 24 (36%) |
| 5 to 9 teeth | 24 (36%) |
| 10 to 20 teeth | 18 (27%) |
| Untreated dental decay, n (%) | 64 (97%) |
| **Caregivers** | |
| All caregivers n (%) | 35 (100%) |
| Age, yr, mean ± SD, median (IQR) | 37.7 ± 13.3, 35 (29, 42) |
| Age categories, n (%) | |
| 18 to 30 years | 11 (31%) |
| 31 to 40 years | 12 (34%) |
| 41 to 76 years | 12 (34%) |
| DFT, mean ± SD, median (IQR) | 8.7 ± 4.7, 9 (5, 11.5) |
| DFT categories, n (%) | |
| 0 to 6 teeth | 12 (36%) |
| 7 to 11 teeth | 12 (36%) |
| > 11 teeth | 9 (27%) |
| Surveys completed by, n (%) | |
| Mother | 29 (83%) |
| Other caregiver | 6 (17%) |

DFT/dft: Decayed filled teeth

**Table 2. P-CPQ and FIS scores and correlation of scores with child DFT/dft.**

| | Mean ± SD, median (IQR) | Correlation (P-Value) |
|---|---|---|
| **Parental/Caregiver Perceptions Questionnaire** | | |
| Global Rating of Oral Health (0-4) | 3.0 ± 0.7, 3 (3, 3) | 0.08 |
| Global Rating of Overall Well-Being (0-4) | 2.5 ± 1.1, 3 (2, 3) | 0.06 |
| Total P-CPQ (0-124) | 33.4 ± 20.0, 33 (17, 45) | 0.03 |
| Oral Symptoms (0 – 24) | 9.9 ± 5.7, 9 (6, 12.5) | -0.13 |
| Functional Limitations (0 – 32) | 9.2 ± 6.8, 10 (3, 12.5) | -0.05 |
| Emotional Well-Being (0 – 28) | 7.2 ± 4.9, 7 (4, 10) | 0.14 |
| Social Well-Being (0 – 40) | 7.1 ± 6.7, 7 (1.5, 9.5) | 0.14 |
| **Family Impact Scale** | | |
| Total FIS (0 – 56) | 12.5 ± 7.9, 11 (8, 18) | 0.30* |
| Parental/Family Activity (0 – 20) | 5.2 ± 4.1, 4 (2, 7.5) | 0.26 |
| Parental Emotions (0 – 16) | 4.4 ± 2.9, 4 (2, 7.5) | 0.09 |
| Family Conflict (0 – 16) | 1.9 ± 2.6, 0 (0, 2) | 0.25 |
| Financial Burden (0 – 4) | 1.0 ± 1.1, 1 (0, 2) | 0.26 |

* Significant at $p < 0.05$.
N= 64 children with DFT/dft scores and oral health related quality of life data
P-CPQ: Parental/Caregiver Perceptions Questionnaire
FIS: Family Impact scale

**Table 3: Regression analysis of child's DFT/dft.**

| | Mean (SD) or Correlation * | Unadjusted Model* | | Adjusted Model† | |
|---|---|---|---|---|---|
| | | Estimate (95% CI) | *P* value | Estimate (95% CI) | *P* value |
| **Children** | | | | | |
| Gender | | | | | |
| Male | 6.8 (4.7) | Reference | | Reference | |
| Female | 6.9 (4.4) | 0.2 (-1.9, 2.3) | 0.86 | 0.1 (-2.0, 2.2) | 0.94 |
| Age | | | | | |
| 0 to 5 years | 7.4 (4.4) | Reference | | Reference | |
| 6 to 11 years | 6.9 (4.8) | -0.4 (-3.6, 2.8) | 0.80 | -0.4 (-3.3, 2.5) | 0.80 |
| 12 to 18 years | 6.4 (4.3) | -0.9 (-4.1, 2.2) | 0.55 | 0.2 (-2.8, 3.1) | 0.91 |
| **Caregivers** | | | | | |
| Age | | | | | |
| 18 to 30 years | 8.5 (4.0) | Reference | | Reference | |
| 31 to 40 years | 5.2 (4.0) | -3.3 (-6.3, -0.3) | 0.03 | -3.8 (-6.5, -1.1) | < 0.01 |
| > 40 years | 7.6 (5.2) | -0.9 (-4.2, 2.4) | 0.60 | 0.2 (-2.6, 3.1) | 0.87 |
| DFT | | | | | |
| 0 to 6 teeth | 5.1 (4.4) | Reference | | Reference | |
| 7 to 11 teeth | 7.9 (3.6) | 2.8 (0.4, 5.1) | 0.02 | 2.6 (0.7, 4.4) | < 0.01 |
| > 11 teeth | 8.8 (5.1) | 3.7 (0.3, 7.1) | 0.03 | 2.8 (-0.2, 5.8) | 0.07 |
| Surveys completed by | | | | | |
| Mother | 6.6 (6.3) | Reference | | Reference | |
| Other caregiver | 7.1 (4.2) | 0.4 (-4.1, 4.9) | 0.85 | -2.0 (-5.3, 1.4) | 0.26 |
| **OHRQoL** | | | | | |
| Total P-CPQ | R = 0.03 | 0.01 (-0.06, 0.07) | 0.86 | -0.06 (-0.13, 0.00) | 0.06 |
| Total FIS | R = 0.30 | 0.18 (0.01, 0.35) | 0.04 | 0.31 (0.10, 0.53) | < 0.01 |

*N=66 for child gender, age; N=64 for caregiver age and gender, P-CPQ and FIS; N=58 for caregiver DFT

†N=58

DFT/dft: Decayed filled teeth

P-CPQ: Parental/Caregiver Perceptions Questionnaire

FIS: Family Impact scale

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# APPENDIX A

## Parental-Caregiver Perceptions Questionnaire (1-35) and Family Impact Scale (36-49)

### 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.

2

**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 <u>symptoms</u> and <u>discomfort</u> that children may experience due to <u>the condition of their teeth, lips, mouth and jaws</u>**

***During the <u>last 3 months</u>, 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 <u>last 3 months</u>, because of his/her <u>teeth, lips, mouth, or jaws</u>, 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 last 3 months, 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 |

# APPENDIX C

**FIS Subscales and Corresponding Survey Questions**

| | |
|---|---|
| **Parental/family Activity (n=5)** | |
| Had sleep disrupted | FIS37 |
| Taken time off work | FIS39 |
| Had less time | FIS40 |
| Required more attention | FIS46 |
| Interfered with family activities | FIS47 |
| **Parental emotions (n = 4)** | |
| Been upset | FIS36 |
| Felt guilty | FIS38 |
| Worried that you child will have fewer life opportunities | FIS41 |
| Felt uncomfortable in public places | FIS42 |
| **Family conflict (n = 4)** | |
| Been jealous | FIS43 |
| Blamed you or another person | FIS44 |
| Argued | FIS45 |
| Caused disagreement or conflict | FIS48 |
| **Financial burden (n=1)** | |
| Caused financial difficulties | FIS49 |