



Parental Perceptions of Oral Health-related Quality of Life for Children with Special Needs: Impact of Oral Rehabilitation Under General Anesthesia

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Abstract

Purpose: The purposes of this study were to: (1) describe the symptoms, daily life problems and parental concerns related to oral health for children with special health care needs; and (2) examine the effectiveness of oral rehabilitation under general anesthesia at improving quality of life (QOL).

Methods: A single-group design measuring change over time was used. Family caregivers of 107 children with special needs, for whom oral rehabilitation under general anesthesia was recommended, completed a QOL survey upon dental examination.

Results: Seventy-three children underwent oral rehabilitation, and 50 completed a follow-up survey. The most frequent survey responses before oral rehabilitation were: (1) spontaneous toothache and pain with hot/cold temperatures (oral symptoms); (2) difficulty eating and sleeping (daily life problems); and (3) worrying about eating and nutrition (parental concerns). Severity ratings for oral symptoms, daily life problems, and parental concerns were significantly lower ($P < .001$), and scores for oral well-being were significantly higher ($P < .001$) following oral rehabilitation.

Conclusions: Family caregivers of special health care needs patients report a variety of oral symptoms, daily life problems, and concerns attributable to their child's oral health that impact QOL. Oral rehabilitation under general anesthesia is effective at improving QOL for special health care needs children and their families. (*Pediatr Dent* 2005;27:137-142)

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Children with special health care needs (SHCN) are at increased risk for dental disease. Neuromuscular, acquired, or genetic disorders often cause alterations or defects in skeletal and facial structures, tooth number and morphology, eruption pattern, and malocclusion. Medications required by children with SHCN are known to cause intrinsic and extrinsic tooth discoloration, gingival enlargement, and xerostomia. Other medications containing sweeteners have been shown to increase the incidence of caries. It is generally agreed that this population of children has higher rates of poor oral hygiene, gingivitis, and periodontitis.¹⁻⁴

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Providing effective and efficient oral health care to children with SHCN is especially challenging for family caregivers and dental providers.^{5,6} There are also disparities among dentists in their ability to provide oral health care for children with SHCN.⁶ Some of the unique challenges for dentists in providing diagnostic, preventive, and restorative procedures for children with SHCN are:

1. the impact of the child's medical condition;
2. behavioral concerns;
3. cognitive limitations;
4. motor deficits limiting seating position for examination and treatment;
5. oral-motor limitations restricting intraoral access.

Limited communicative abilities, involuntary movement, inability to understand the need for dental care, and the inability to cooperate with intraoral procedures are often indications for the use of sedation or general anesthesia, so that optimal dental care may be provided and quality of life (QOL) enhanced.^{7,8}

QOL has been recognized as the most important outcome of medical care for people of all ages and abilities. A complete understanding of oral health-related QOL outcomes is

both a necessary and logical goal to assess and significantly improve the impact of dental care for children with SHCN.^{3,4,9} In recent years, the concept of oral health-related QOL has been introduced, expanding the array of traditional medical factors such as symptom and functional status that have been assessed when measuring QOL outcomes in health care settings. Oral health-related QOL has been described as a multidimensional concept including: (1) survival; (2) absence of symptoms; (3) absence of pain or discomfort; (4) the oral cavity's adequate physical/mechanical functioning; (5) social-emotional functioning; (6) ability to perform self-care; (7) limitation on activities related to role; (8) perceptions of oral health; and (9) satisfaction with oral health.^{10,11}

Recent research has used QOL surveys to measure oral health outcomes for children following oral rehabilitation under general anesthesia.^{8,12-14} In a study by Acs et al,⁸ an improvement in pain was the predominant outcome, while children with SHCN were more likely to have improved eating and sleeping abilities and significantly improved overall health, as reported by parents who responded to a mail survey. White et al¹² reported positive parental evaluations via in-person surveys of both physical and social QOL measures following oral rehabilitation under general anesthesia for children without special needs.

In a study by Filstrup et al,¹³ children with Early Childhood Caries had a significantly improved QOL following oral rehabilitation, as reported by both the children and their parents in a face-to-face survey. Using an initial written survey and follow-up telephone survey of parents, Low et al¹⁴ reported a significant decrease in pain and improvement in eating preferences, quantity of food eaten, and sleep habits after oral rehabilitation under general anesthesia for young children with dental caries. This small but growing body of literature supports the use of QOL surveys as effective tools for measuring the effectiveness of oral rehabilitation. It also supports the hypothesis that oral rehabilitation under general anesthesia can improve QOL for children and their families.

The purposes of this study were to:

1. describe the child's oral symptoms and daily life problems and parents' concerns related to oral health for their children with SHCN;
2. examine the effectiveness of oral rehabilitation under general anesthesia at improving QOL, as reported by parents/family caregivers.

Methods

Program and procedure

Franciscan Hospital for Children (FHC) is a pediatric hospital and rehabilitation center located in Boston, Mass, and is a major teaching affiliate of the Goldman School of Dental Medicine at Boston University. There are approximately 8,000 visits to the dental department at FHC annually. At FHC, oral rehabilitation under general anesthesia is an elective procedure and recommended for individuals whose oral health needs cannot be met in the dental clinic.

Following approval from the FHC's Institutional Review Board, the principal investigators recruited caregivers with children with SHCN presenting to the FHC dental clinic and for whom oral rehabilitation was recommended. Informed consent was obtained from the parents/legal guardians. Patients were eligible for inclusion in this study if they required diagnostic and restorative procedures and/or extractions under general anesthesia. The sample did not include any individual who needed only a dental cleaning.

Family caregivers were asked to complete an oral health-related QOL survey at the time of their child's dental examination. Consent forms and surveys were provided in the participant's primary language (English, Spanish or Vietnamese). Follow-up surveys were conducted by mail. If there was no response after 3 weeks, a reminder letter with an additional survey and self-addressed stamped envelope was sent. Subjects were provided an honorarium upon return of the mail survey.

Dental record reviews to collect demographic (ie, date of birth, primary diagnosis) and clinical variables (ie, procedures performed) were completed by 1 of the study investigators who was oriented to the dental records and trained in data extraction. All survey data were combined with data from the records and entered into a spreadsheet in SPSS 9.0 (Chicago: SPSS, Inc).¹⁵

Subjects

Using consecutive sampling over a 7-month period, the family/caregivers of 107 children with SHCN (mean age=9.6 years±8.5; age range=0.5 to 47.1 years)—for whom oral rehabilitation under general anesthesia was recommended upon dental examination—were recruited for this study. Eighty-eight percent of survey respondents were mothers of the patients, and 8% were fathers. In 2% of the cases, both parents participated. In the final 2%, a legal guardian other than a parent (ie, grandparent) participated. The primary languages of the caregiver participants were as follows: English (87%), Spanish (12%), and Vietnamese (1%).

Of the total group of 107 patients, 59% was male. Based on information collected from the dental record, the patients' primary special health care diagnoses included:

1. cerebral palsy (N=11, 10%);
2. autism/pervasive developmental disorder (N=16, 15%);
3. genetic syndromes (N=10, 9%);
4. behavioral/psychiatric disorders (N=2, 2%);
5. cardiac and/or respiratory conditions (N=4, 4%);
6. severe dental anxiety due to age or trauma (N=47, 44%);
7. other neurological conditions (ie, seizures, traumatic brain injury; N=5, 5%);
8. learning disabilities/attention deficit disorder (N=3, 3%);
9. mental retardation (N=7, 7%);
10. other conditions (ie, hearing loss; N=2, 2%).

The primary dental diagnoses included: (1) dental caries (N=77, 72%); (2) Early Childhood Caries (N=8, 8%); (3) rampant dental caries (N=14, 13%); (4) abscess/infection (N=3, 3%); (5) periodontal disease (N=3, 3%); (6) crowding (N=1, 1%); and (7) trauma (N=1, 1%). Seventy three (68%)

of the 107 patients had oral rehabilitation under general anesthesia. Documented reasons for not undergoing oral rehabilitation under general anesthesia included:

1. parent choice (N=5, 5%);
2. lack of insurance coverage (N=4, 4%);
3. denial by patient's insurance provider (N=5, 5%);
4. procedure cancelled without explanation following scheduling or procedure not scheduled within 4 months of recommendation (N=20, 19%).

All children had complete intraoral and extraoral examinations, radiographs, prophylaxis and fluoride applications. In addition to these procedures, the children underwent other types of preventive, periodontal, restorative, oral surgical and/or pulp therapy treatments. The specific procedures for the group of patients who had oral rehabilitation under general anesthesia included: (1) amalgam (N=44, 60%); (2) composites (N=55, 75%); (3) stainless steel crowns (N=25, 34%); (4) quadrant scaling (N=11, 15%); (5) sealants (N=16, 22%); (6) pulpotomy (N=21, 29%); and (7) simple or surgical extraction with sutures (N=35, 48%).

On average, individuals had 2.86 (± 0.90 ; range=1 to 4) procedures during oral rehabilitation under general anesthesia. Six individuals (8%) had 1 procedure, 17 (23%) had 2 procedures, 31 individuals (43%) had 3 procedures, and 19 (26%) had 4 procedures.

Instrumentation

Based on a comprehensive literature review and the clinical experience at FHC, the authors created the Franciscan Hospital for Children Oral Health-Related Quality of Life (FHC-OHRQOL) for use in this study. Section I of the FHC-OHRQOL, titled "child's oral problems/symptoms" consists of 15 items in which caregivers were asked to rate their child's current oral problems/symptoms (ie, toothaches, painful or bleeding gums). Section II titled, "your child's daily life," consists of 13 items in which caregivers were asked to rate the impact of their child's current oral health on their daily life (ie, "does your child have difficulty getting to sleep because of tooth/mouth pain?"). Section III titled "parental concerns" consists of 9 questions related to parent/caregiver concerns about their child's oral health (ie, "how often do you feel worried about your child's teeth or mouth interfering with their eating and nutrition?").

In these 3 sections, each item was rated on a 6-point scale: never (0); hardly ever (1); once in a while (2); some of the time (3); most of the time (4); or all of the time (5). An additional item titled "other," with the directions to write in any extra problems/symptoms, was included in each section.

In section IV, the authors used a 13-cm visual analog scale (VAS) for each of 4 questions to assess parent's perceptions of their child's oral well-being and QOL. The questions were:

1. What is your opinion of your child's teeth and mouth?
2. How do you think your child's oral health is compared to other individuals of the same age?
3. How do you feel about your child's overall oral well-being?
4. How would you rate your child's overall QOL?

The VAS was constructed with "excellent" and "poor" at the ends of the scale and "good" in the center for questions 1, 3, and 4. For question 2, the VAS was anchored with "better than others his/her age" and "much worse than others his/her age" with "about the same as others his/her age" in the center.

Analysis

Demographic characteristics (ie, age, sex) of the group of individuals who underwent oral rehabilitation (N=73) under general anesthesia were compared with the group of individuals who did not (N=34). In addition, demographic characteristics of the group of individuals who underwent oral rehabilitation and for whom the authors have follow-up information (N=50) were analyzed. These characteristics were compared with the group of individuals who underwent oral rehabilitation, but for whom the authors do not have follow-up information (N=23) using an independent *t* test or chi-square statistic as appropriate.

To describe the severity of oral health conditions prior to oral rehabilitation under general anesthesia, the authors calculated measures of central tendency (mean, median, and mode) for survey sections I (oral symptoms), II (daily life problems), and III (parental concerns). To illustrate severity ratings for individual survey items, the authors combined and recoded the ratings "hardly ever" and "once in a while" and the ratings "some of the time" and "most of the time" from the original 6-point scale to a 4-point scale. The authors also generated frequency counts for each item in survey sections I, II, and III. Since the FHC-OHRQOL consists of a series of adapted and new items for each of these 3 constructs, the authors also calculated a Cronbach's alpha to examine each scale's internal consistency. For survey section IV (oral well-being), the authors converted the original ratings from the 13-cm VAS to a 0-100 metric. The authors then calculated the mean rating for each of this section's 4 questions.

To examine the effectiveness of oral rehabilitation under general anesthesia, the authors calculated summary scores for each child by adding each item's ratings and dividing by the number of items completed within each of the first 3 survey sections. The authors then calculated a mean summary score for each section. The authors used a paired *t* test to compare the mean summary scores for survey sections I, II, and III on the initial FHC-OHRQOL surveys with the summary scores from the follow-up surveys for the group of individuals for whom the authors had available follow-up data. For survey section IV, the authors compared the mean VAS for each of the 4 questions.

Results

Of the 107 patients whose parent/caregivers completed the initial survey, 73 (68%) returned for oral rehabilitation under general anesthesia. The average time from the first survey's completion to oral rehabilitation under general anesthesia was 62.09 (± 44.72) days. The only significant difference in group demographics between the group of patients who received oral rehabilitation (N=73, 68%) and the group that did not (N=34, 32%) was for

gender. A significantly higher percentage of girls (82%) than boys had oral rehabilitation (59%).

Prior to oral rehabilitation, the average (mean) number of symptoms reported was 6.78 (± 4.50) while the median (midpoint) was 6 symptoms, and the most common number of symptoms (mode) was 5. The total number of symptoms reported ranged from 0 to 15. The mean number of daily life problems reported was 4.34 (± 4.17), while the median was 2 problems, and the mode reported was 0 problems. The total number of daily life problems reported ranged from 0 to 13. The mean number of parental concerns reported was 3.99 (± 3.19), while the median was 4 concerns, and the mode was 0 concerns. The total number of concerns reported ranged from 0 to 9.

Frequency counts for the ratings of severity of individual items in survey sections I to III are presented in stacked bar graphs in Figures 1 to 3. The internal consistency of each of these scales was high (symptoms, Cronbach's $\alpha=0.90$; daily life problems, Cronbach's $\alpha=0.89$; and parental concerns, Cronbach's $\alpha=0.90$).

Of those subjects who received oral rehabilitation under general anesthesia ($N=73$), the authors have 50 (69%) follow-up surveys available for analysis. There were no significant differences in group demographics between those individuals the authors have follow-up surveys ($N=50$) and those for whom the authors do not have follow-up surveys ($N=23$). The average time from oral rehabilitation under general anesthesia to the completion of the follow-up survey was 74.06 days (± 42.01).

The results of the paired *t* test to compare the mean summary scores on the initial FHC-OHRQOL surveys with the summary scores from the follow-up surveys are in Table 1. In general, there was a reduction of oral symptoms, daily life problems, and parental concerns following oral rehabilitation under general anesthesia. Table 2 shows an increase in mean VAS ratings of oral well-being scores (section IV) from initial survey to follow-up.

Discussion

This experience at FHC is consistent with the description of individuals for whom oral rehabilitation under general

anesthesia is generally recommended. These individuals included:

1. those under 3 years of age who have significant dental disease and dental care needs;
2. children who are unable to behaviorally, emotionally, and/or physically tolerate the required care in a dental office or clinic;
3. patients whose physical and/or cognitive impairments limit the dental care that can be delivered in the clinical setting.⁷

As is common, adults with SHCN often continue to receive dental care from their pediatric providers.⁶ Thus, the authors chose to include 10 patients over 21 years of age in this sample.

Spontaneous toothache and pain with hot/cold temperatures were the most frequently reported symptoms prior to oral rehabilitation (survey section I). These symptoms are consistent with both the high frequency of dental caries in this sample and with a high prevalence of caries among individuals with SHCN.^{1,4,5,8} The most frequently reported daily life problems were difficulty eating, refusing certain foods because of pain, and difficulty falling to sleep and waking up from sleep due to tooth pain (survey section II). This was consistent with the reported QOL outcomes reported by Acs et al⁸ on perceived outcomes and parental satisfaction following dental rehabilitation under general anesthesia for children with SHCN. Based on the reported symptoms and daily life problems, the authors were not surprised that the most frequent parental concern was worrying about eating and nutrition (survey section III).

On a 6-point rating scale, from "never" (0) to "all of the time" (5), the authors were surprised that the mean summary scores of the ratings were so low for oral symptoms (1.4 ± 0.86), daily life problems (0.74 ± 0.78), and parental concerns (1.07 ± 1.0) prior to oral rehabilitation.

Table 1. Comparison of Mean Summary Scores From Initial FHC-OHRQOL and Follow-up Surveys (N=50)

| | Initial survey mean (\pm) summary score | Follow-up survey mean (\pm) summary score | <i>P</i> |
|--|--|--|----------|
| Survey section I: Oral symptoms | 1.14 \pm 0.86 | 0.41 \pm 0.45 | <.0001 |
| Survey section II: Daily life problems | 0.74 \pm 0.78 | 0.26 \pm 0.36 | <.0001 |
| Survey section III: Parental concerns | 1.07 \pm 1.0 | 0.43 \pm 0.63 | <.0001 |

Table 2. FHC-OHRQOL Survey Section IV: Oral Well-being (N=50)

| | Initial survey* | Follow-up survey* | Mean change score | <i>P</i> |
|---|-----------------|-------------------|-------------------|----------|
| What is your opinion of the appearance of your child's teeth and mouth? | 31.68(23.21) | 63.29(25.04) | 31.61(29.85) | <.001 |
| How do you think your child's oral health compares to other children of the same age? | 27.15(21.34) | 43.94(25.38) | 16.80(27.86) | <.001 |
| How do you feel about your child's overall oral well-being? | 36.83(27.46) | 64.86(23.24) | 28.03(35.66) | <.001 |
| How would you rate your child's overall quality of life? | 72.19(22.31) | 78.19(23.45) | 5.60(21.67) | .056 |

*Mean (\pm) on VAS ratings converted to a 0-100 metric.

The changes in mean summary scores indicate however, that oral rehabilitation under general anesthesia was effective at minimizing or alleviating oral symptoms, daily life problems, and parental concerns.

With the exception of overall QOL, all oral well-being scores were significantly improved on the VAS following oral rehabilitation. This is consistent with the findings by Acs et al,⁸ in which individuals with and without medically or developmentally compromising conditions were significantly more likely to have improved eating and sleeping abilities. This is also consistent with the findings by White et al,¹² who reported improvements in dental outcome (ie, pain relief and improved masticatory efficiency) and improved social functioning following oral rehabilitation for preschool children without SHCN.

For this study, the authors used a single-group design measuring change over time. A randomized, controlled trial is the preferred choice, but recruitment of subjects to match groups in age, gender, description of SHCN, and oral health concerns was not feasible during this 1-year project. Approximately one third of this study's original sample of 107 did not return for oral rehabilitation under general anesthesia. This group could have served as a control group, but the authors did not collect follow-up survey data for this group. Of those who did receive oral rehabilitation under general anesthesia, 31% did not mail back the follow-up survey.

In future work, the authors believe it is important to examine the influence of any previous experience with dental procedures under general anesthesia and its impact on the child's oral symptoms, daily life problems, parental concerns, and overall QOL.

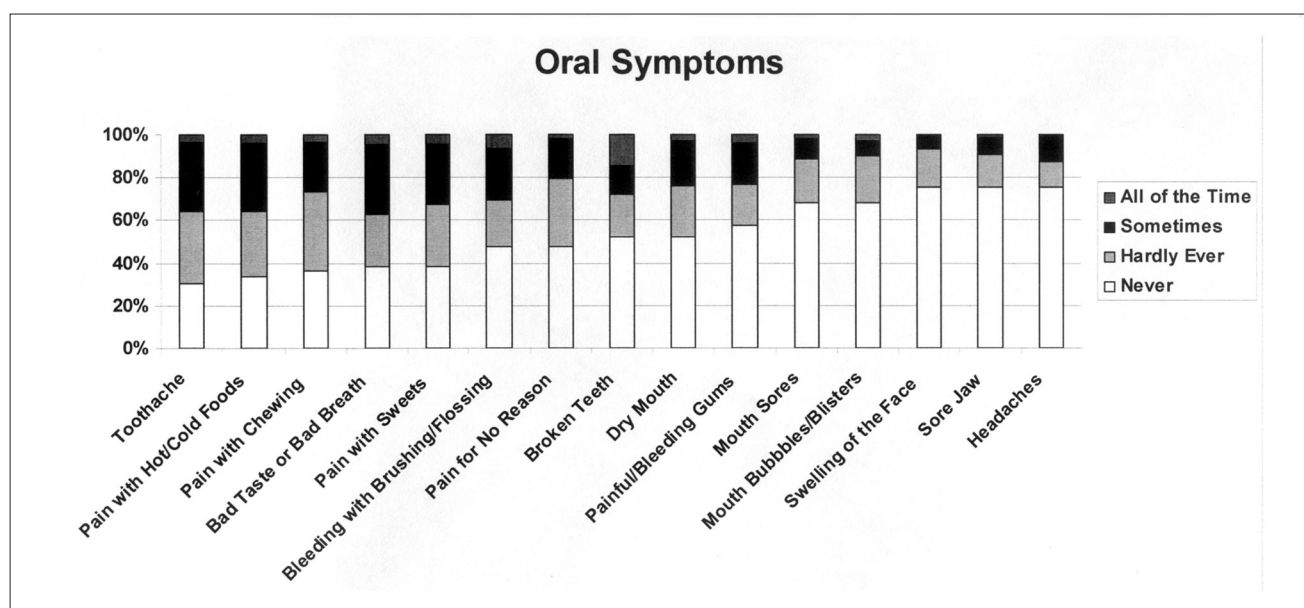


Figure 1. Frequency of item ratings for FHC-OHRQOL section I—oral symptoms before oral rehabilitation.

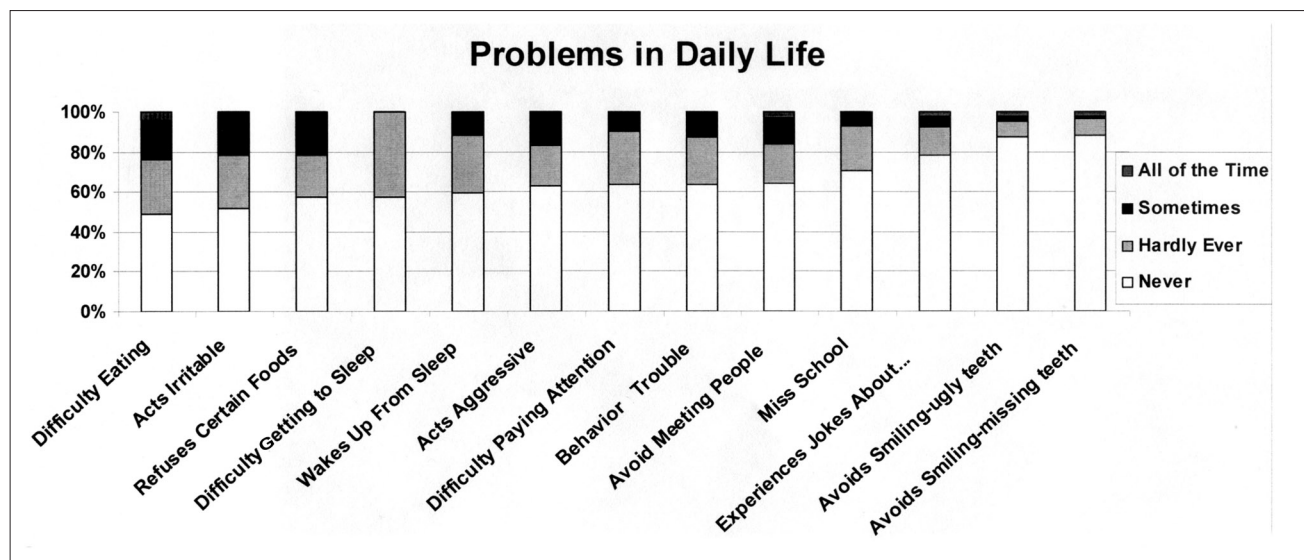


Figure 2. Frequency of item ratings for FHC-OHRQOL section II—problems in daily life before oral rehabilitation.

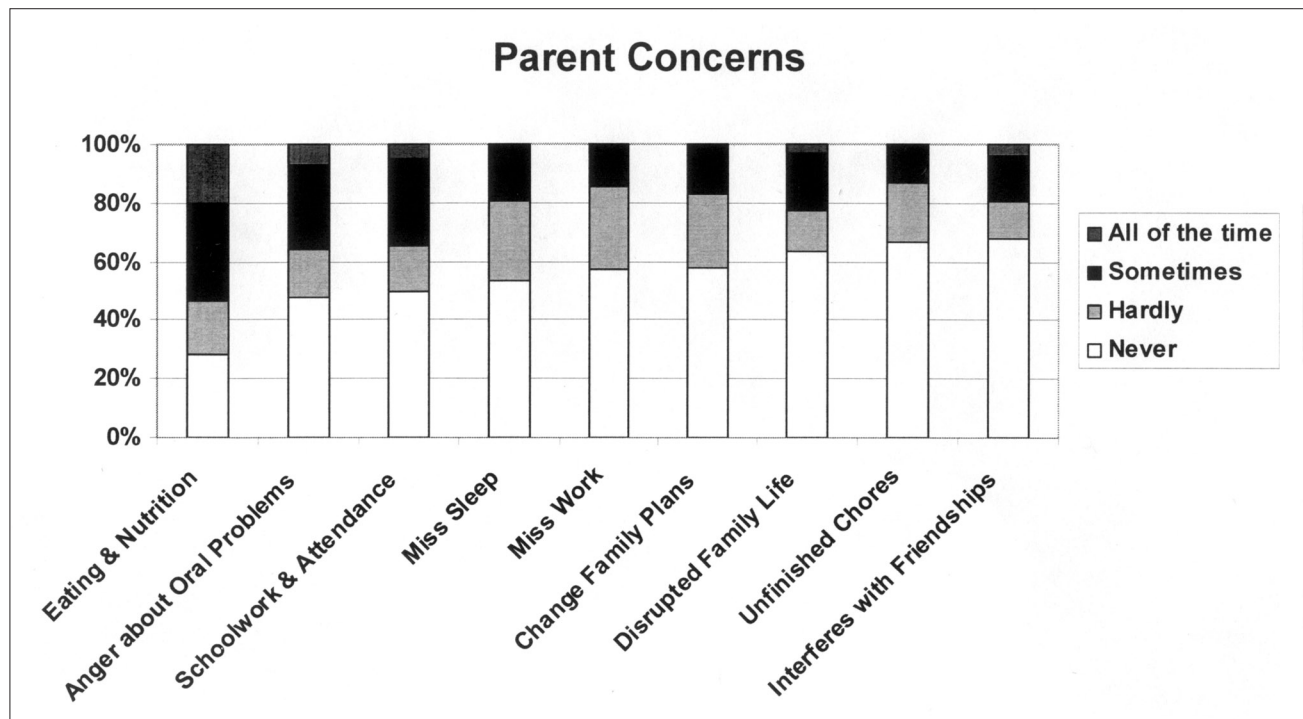


Figure 3. Frequency of item ratings for FHC-OHRQOL section III—parental concerns before oral rehabilitation.

The authors also recognize the need to examine the psychometric properties of the FHC-OHRQOL in future work. Further study is needed to understand the relationship between oral rehabilitation with general anesthesia and improved QOL.

Conclusions

Based on this study's results, the following conclusions can be made:

1. Family caregivers of individuals with SHCN report a variety of oral symptoms, daily life problems, and concerns attributable to their child's oral health that impact the child's and family's QOL.
2. Oral rehabilitation under general anesthesia is effective at minimizing or alleviating symptoms, problems, and concerns and improving QOL for children with SHCN and their families.

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