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CHILDREN WITH SPECIAL NEEDS ORAL HEALTH QUALITY OF LIFE SURVEY

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University.

by

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## Abstract

### CHILDREN WITH SPECIAL NEEDS ORAL HEALTH QUALITY OF LIFE SURVEY

By Kristin Elizabeth Nelson, D.M.D., M.S.D.

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science of Dentistry at Virginia Commonwealth University.

Virginia Commonwealth University, 2007

Major Director: Tegwyn H. Brickhouse, D.D.S., Ph.D.  
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**Purpose:** The purpose of this study was to assess the oral health quality of life of children with special health care needs. This study examined the effects of oral health conditions on general well-being and family life of these children. A secondary aim of the study was to investigate correlations between specific health care conditions, gender, and age of these children and their global ratings of oral health and well-being.

**Methods:** This study was a cross-sectional design with subjects who are members of the Virginia Care Connection for Children program, based at Virginia

Commonwealth University. The oral health quality of life was measured using a shortened version of the Parental – Caregiver Perceptions Questionnaire (P-CPQ). The questionnaire includes measures of global ratings of oral health and well-being as well as effects of oral health on domains of oral symptoms, functional limitations, emotional well-being, and family well-being/parental distress. The parents/caregivers were asked to report on these domains as they related to their child's oral health within the past 3 months. Additional survey items included questions regarding demographic factors of the child (age, sex, special health care conditions) and parent (i.e. mother, father, or other).

**Results:** The survey was sent out to 429 individuals and 137 usable surveys were returned for a response rate of 32%. Special health care conditions of the children were categorized and reported as follows: 1) Neurodevelopmental/Genetic/Neuromuscular disorders, N=69 (59.13%); 2) Respiratory disorders, N=12 (10.43%); 3) Cardiac disorders, N=5 (4.35%); 4) Craniofacial disorders, N=12 (10.43%); 5) Metabolic disorders, N=15 (13.04%); 6) Psychological disorders, N=3 (2.61%). In general, caregivers reported the children to have a fair to good oral health quality of life in each domain. It was determined that two of the domains, functional limitations and emotional well-being, were not correlated with the child's oral health or well-being. However, the oral symptoms and family well-being/parental distress domains did have a positive correlation ( $p = 0.0340$  and  $p = 0.0420$ , respectively).

**Conclusions:** In a population of children with special health care needs it appears that oral symptoms and family well-being outweighed functional limitations and emotional well-being.

## BACKGROUND AND SIGNIFICANCE

### **Oral Health of Children with Special Health Care Needs**

Pediatric dentists have traditionally been viewed by the dental community as the specialty group best prepared to treat children with special health care needs (CSHCN), including children with cerebral palsy, developmental delays, and those who are medically compromised.<sup>1,2</sup> This may be due the fact that graduate pediatric residency programs provide formal training in behavior management techniques and these children often present with various cognitive and physical limitations.<sup>2</sup> It has been well-established that dental care is the leading unmet health care need among CSHCN, with more than three quarters of a million CSHCN nationally being unable to obtain needed dental care.<sup>3</sup> The US Surgeon General has identified access to care as a major issue contributing to the unmet dental care needs of these children.<sup>4</sup> In addition, children with special health care needs are at increased risk for dental disease.<sup>5</sup> Neuromuscular, acquired, or genetic disorders often cause alterations or defects in skeletal and facial structures, tooth number and morphology, eruption pattern, and malocclusion.<sup>5</sup> Children with special health care needs often require medications that are known to cause intrinsic and extrinsic tooth discoloration, gingival enlargement, and xerostomia.<sup>5</sup>

Further, medications containing sweeteners can cause an increased incidence of caries in this population.<sup>5</sup> It is generally agreed among dental health care providers that children with special health care needs have higher rates of poor oral hygiene, gingivitis, and periodontitis.<sup>5</sup>

Little research has been done as to the characteristics and quality of life of CSHCN who have unmet dental care needs.<sup>3</sup> As a specialty group, if we are to provide the needed dental treatment in a meaningful and compassionate manner, it is essential for practitioners to have some appreciation for how the oral health conditions of CSHCN affect their general well-being and quality of life.<sup>6</sup> In addition, we must also recognize how the oral health quality of life affects the family and caregivers of these children. Parental/caregiver perceptions of children's oral health-related quality of life is especially important for CSHCN due to the fact that many of these patients face limitations in their cognitive capacities and communication skills.<sup>7</sup> These families often face great emotional and financial strain in trying to gain access to all the necessary health services for their children.

The medical field has begun to recognize that dental care should be an integral part of coordinated care for CSHCN.<sup>3</sup> **Care Connection for Children (CCC)**, a partner in the Virginia children's special health needs network and sponsored by the Virginia Department of Health, helps to coordinate health care and alleviate issues of access to care for children with special health care needs.<sup>8</sup> The CCC consists of a statewide network of regional programs that provides health care services, community support and resources to children with special health care needs.<sup>8</sup> Professional care

coordinators work closely with the children and their families to coordinate all services offered by the various health care providers for CSHCN.<sup>8</sup> In central Virginia, there are over 400 families of CSHCN that participate in the CCC program.

### **Oral Health-Related Quality of Life**

As mentioned previously, few studies have been conducted to assess oral health-related quality of life of CSHCN. Health-related quality of life perspectives can be very helpful when assessing outcomes of various diseases and disorders because they have the advantage of being multi-dimensional, considering symptoms, physical functioning, and emotional and social well-being.<sup>9</sup> Oral health-related quality of life (OHRQoL) measures document the functional and psychosocial outcomes of oral disorders.<sup>10</sup> It is now generally accepted in the research community that they are essential as clinical indicators when assessing the oral health of individuals and populations, making clinical decisions, and evaluating dental interventions, services, and programs.<sup>10</sup> Jokovic et al developed the only measure currently available to determine OHRQoL for children.<sup>11</sup> It is a measure of the impact of oral and orofacial conditions on the functional, emotional, and social well-being of children of different ages and developmental differences.<sup>10</sup> Further, it was intended to conform to contemporary concepts of child health as "...the physical, emotional, and social functioning of the child and when indicated, his or her family..." as defined by the American Academy of Pediatrics.<sup>9, 10, 12</sup> In order to satisfy all of these intentions, the OHRQoL measure was developed with several components

including a Parental Perceptions Questionnaire (P-CPQ), a Family Impact Scale, and three age-specific Child Perception Questionnaires (CPQ ages 6-7, CPQ ages 8-10, CPQ ages 11-14).<sup>9</sup> In the present study, oral health quality of life of CSHCN participating in the Care Connection for Children program will be assessed using a shortened version of the Child Oral Health Parental-Caregiver Perceptions Questionnaire which includes items from the Family Impact Scale. The questionnaire includes measures of global ratings of oral health as well as effects of oral health on domains of oral symptoms, functional limitations, emotional well-being, and family well-being/parental distress.

#### **Parental – Caregiver Perceptions Questionnaire (P-CPQ)**

According to Locker et al, there are two broad concepts that need to be addressed with respect to outcomes of oral and oro-facial conditions in children: 1) the child's oral health-related quality of life and 2) the impact of the child's condition on the family.<sup>12</sup> In determining OHQoL in children, Filstrup et al stated that it is often necessary to use a "proxy rater" when the child is either unable or unwilling to complete the oral health-related QOL measure.<sup>13</sup> Such is the case with many children with special health care needs. In addition, adults are generally responsible for and make decisions about their child's health.<sup>14</sup> Therefore, assessing parents' perceptions about oral health problems, including oral symptoms, functional limitations, and effects on emotional and social well-being is imperative.<sup>14</sup> Evidence also shows that dental disease in children results in lost workdays for caregivers as well as time and money spent in accessing dental care.<sup>14</sup> Thus,

the impact of dental disease in children on their caregivers and families are also important to measure as part of assessing OHRQoL in children.<sup>14</sup>

Jokovic et al developed the P-CPQ (Parental- Caregiver Perceptions Questionnaire) to measure parental or caregiver perceptions of a child's oral health-related quality of life and the impact of the child's condition on the family.<sup>11</sup> The P-CPQ questionnaire was created for use in clinical trials and evaluation research. As mentioned previously, the four domains assessed in the P-CPQ are: oral symptoms, functional limitations, emotional well-being and social well-being.

The Family Impact Scale was developed by Locker et al as one component of the Child Oral Health-Related Quality of Life Instrument in addition to the Parental-Caregiver Perceptions Questionnaire.<sup>12</sup> Because of the specific aims of the P-CPQ stated above, the Family Impact Scale is included in the parental-caregiver questionnaire. There are several reasons why a Family Impact Scale is an essential component of child health-related quality of life measures.<sup>12</sup> These reasons include: (1) the central role played by the family in child health; (2) the likelihood that chronic illness in a child will impact on the family to some degree; (3) the fact that health care interventions often address parental needs and concerns as well as the child's; and (5) the fact that parental reports of a child's health may be influenced by the degree to which the parent is physically or emotionally affected by the child's condition.<sup>12</sup>

The purpose of this study was to assess the oral health quality of life of children with special health care needs enrolled in the CCC program using the Parental Perceptions Questionnaire (P-CPQ).<sup>11, 12</sup> This study examined the effects of oral health

conditions on general well-being and family life of these children. A secondary aim of the study was to investigate correlations between specific health care conditions, gender, and age of these children and their and global ratings of oral health and well-being.

## MATERIALS AND METHODS

### **Patient Sample and Design**

This study was a cross-sectional survey design with subjects who are members of the Central Care Connection for Children program, based at Virginia Commonwealth University. Incentives for participants in the survey included \$10 Wal-Mart gift certificates given to the parents of CSHCN who completed and returned the Child Oral Health Parent-Caregiver Perceptions Questionnaire.

### **Assessment Protocol and Procedure**

The inclusion criterion was participation in the Virginia Care Connection for Children Program. The subjects were parents/caregivers of children with special health care needs participating in this program. A total of 429 study subjects were mailed the modified P-CPQ questionnaire along with two separate self-addressed stamped envelopes to the Virginia Commonwealth University Department of Pediatric Dentistry. One envelope was included in which to return the survey, and a second envelope included to return a mailing address so that \$10 incentive gift cards could be returned to the participants without violating confidentiality of the participant. A 2-month waiting period was allowed for completion and return of the surveys. Incentive cards were

mailed to participants upon return of the survey. This study was approved for human subjects by the Virginia Commonwealth University Institutional Review Board.

### **P-CPQ Measurements**

The oral health quality of life of CSHCN participating in the Virginia CCC program was measured using the Parent-Caregiver Perceptions Questionnaire, including items from the Family Impact scale. There were four domains tested to ascertain oral health quality of life: oral symptoms, functional limitations, emotional well-being and family well-being/parental distress. Additional survey items included questions regarding global ratings of oral health and well-being as well as demographic factors of the child (age, sex, special health care condition) and parent (i.e. mother, father, or other). Figure 1 illustrates an item reduction of the questionnaire.

The performance of the questionnaires has been tested for validity and reliability.<sup>9, 10</sup> The Cronbach's alpha for internal consistency and intraclass correlation coefficient for test-retest reliability for the P-CPQ were 0.94 and 0.85, respectively.<sup>11</sup> The Cronbach's alpha and intraclass correlation coefficients for the Family Impact Scale were 0.83 and 0.80, respectively.<sup>12</sup> These results suggest that both the P-CPQ and Family Impact Scale are valid and reliable.<sup>11, 12</sup> The modified P-CPQ version used in the current study consists of 26 items, including 7 questions from the Family Impact Scale. A sample of the oral health knowledge and quality of life questionnaire has been included in Appendix A.

The questionnaires ask about the frequency of various tooth-related events “in the past 3 months.” The mean and standard deviation (SD) of the item responses are scored from the following coding of the responses: 1 = never, 2 = once or twice, 3 = sometimes, 4 = often, 5 = everyday or almost everyday. The “don’t know” response is not included in the mean and SD but is included in the percentages for each response.

Overall oral health-related quality of life was also assessed on a 5-point response scale by the following 2 questions:

- “How would you rate the health of your child’s teeth, lips, jaws and mouth?”
  - Excellent (1)
  - Very good (2)
  - Good (3)
  - Fair (4)
  - Poor (5)
  
- “How much is your child’s overall well-being affected by the condition of his/her teeth, lips, jaws or mouth?”
  - Not at all (1)
  - Very little (2)
  - Some (3)
  - A lot (4)
  - Very much (5)

### **Special Health Care Condition**

The special health care condition of the child was asked to be reported on the survey by the parent/caregiver along with gender and age. Following compilation of the survey results, the special health care conditions were grouped into 6 categories of condition for purposes of statistical analysis. The categories of condition were grouped as follows: (1) Neurodevelopmental/Genetic/Neuromuscular Disorders (2) Respiratory

Disorders (3) Cardiac Disease/Disorders (4) Craniofacial Disorders (5) Metabolic Disorders and (6) Psychological Disorders. If more than one health condition was listed by the parent/caregiver, the child was categorized according to the most severe condition.

### **Statistical Analysis**

Descriptive statistics were used to summarize the responses to the survey questions. A multivariate analysis of variance was used to identify the major relationships between the overall oral health and well-being questions and the possible predictor variables: gender, age, condition category (6 levels), and the four domain scores. Multiple regression was then used to describe the significant predictors.

## RESULTS

### **Demographics and Descriptive Analyses**

The survey was sent to 429 individuals and 137 usable surveys were returned for a response rate of 32%. Of the caregivers surveyed, 114 (83.21%) were mothers, 11 were fathers (8.03%), and 12 (8.76%) were reported as “other” (i.e. legal guardian, grandparent, etc.). The reported gender of the CSHCN was 73 male (55.3%) and 59 female (44.7%). Special health care conditions of the children were categorized and reported as follows: 1) Neurodevelopmental/Genetic/Neuromuscular disorders, N=69 (59.13%); 2) Respiratory disorders, N=12 (10.43%); 3) Cardiac disorders, N=5 (4.35%); 4) Craniofacial disorders, N=12 (10.43%); 5) Metabolic disorders, N=15 (13.04%); 6) Psychological disorders, N=3 (2.61%). The mean age reported for the child population was 10 years (SD = 5.8, range = 1 to 21). The description of the survey subjects is shown in Table 1 along with responses to the overall oral health and well-being questions. The overall oral health was moderately correlated with the well-being of the child ( $r = 0.33$ ,  $p < .0001$ ).

### **Oral Health Quality of Life Dimensions**

#### *Oral Symptoms, Functional Limitations, Emotional Well-being, Family Well-Being*

For each dimension, parents reported perceived oral health symptoms experienced by their child within the last 3 months. Frequencies of each response are summarized in Table 2. Each of the four domains is scored by averaging the items in that domain. The summary of each of the four domain scores is shown in Table 3. All of the domain averages were nearly two, (the “once or twice” response) ranging from (1.65-2.06) showing that in general, caregivers were reporting the children to have a fair to good oral health quality of life in each domain. All of the domains were significantly correlated to one another. This indicates that functional deficits in one area are related to those in other domains.

#### *Overall Oral Health and Well-Being*

In order to determine the relationship of overall oral health and well-being (the first two items of the questionnaire) to patient characteristics and symptom domains, a MANOVA was used. The MANOVA used the two overall oral health and well-being items as dependent variables, and the following were included as independent variables: gender, age, condition category (6 levels), and the four domain scores. The results indicated that there was no relationship with gender ( $p = 0.78$ ), age ( $p = 0.62$ ), or condition category ( $p = 0.21$ ). Additionally, two of the domains were not related to the overall scores; functional limitations ( $p = 0.52$ ) and emotional wellbeing ( $p = 0.31$ ).

Two of the domains were related to the overall scores; oral symptoms ( $p = 0.0340$ ) and parental distress and family function ( $p = 0.0420$ ). These two domains were used in follow-up analyses to explain the relationships with the overall scores.

First, the relationship to the rating of “the health of your child’s teeth, lips, jaw and mouth” was considered. A final multiple regression indicated that oral symptoms ( $p = 0.0025$ ) and parental distress ( $p = 0.0218$ ) are both related to the overall health of a child’s mouth (R-square = 19%). Figure 2 shows the relationship between oral symptoms, parental distress and the five levels of overall oral health. It indicates that the worse the health of the child’s mouth, the worse the oral symptoms and parental distress. A stepwise multiple regression indicated that there were three items in these two domains that accounted for all of the correlation to the health of a child’s mouth: Question 4 - “bleeding gums” ( $p = 0.0280$ ), Question 6 – “bad breath” ( $p = 0.0017$ ) and Question 22 – parents “feeling guilty” ( $p = 0.0074$ ). These three items accounted for 25% of all the variability in the overall rating of the “health of your child’s teeth, lips, jaw, and mouth.”

The second question asked, “How much is your child’s overall well-being affected by the condition of his/her teeth, lips, jaws or mouth?” A multiple regression indicated that only oral symptoms ( $p = 0.0043$ ) and parental distress ( $p = 0.0148$ ) were significantly related to overall well-being (R-square = 19%). The relationship between oral symptoms, parental distress and the five levels of well-being is shown in Figure 3. Similar to the relationship between overall oral health, this figure indicates that general well-being decreases as oral symptoms and parental distress increase. A stepwise

multiple regression indicated that there were three items in these two domains that accounted for all of the correlation to the child's general well-being: Question 6 – “bad breath” ( $p = 0.0285$ ), Question 22 – parents “feeling guilty” ( $p = 0.0035$ ) and Question 24 – parents “had less time for yourself or the family” ( $p = 0.0234$ ). These three items accounted for 20.4% of all the variability in the question of overall well-being

## DISCUSSION

### **Oral Health Related Quality of Life**

This study utilized the P-CPQ measure of children's oral health-related quality of life to emphasize the importance of oral health quality of life among a population of children with special health care needs and its impact on their families, daily lives, and general well-being. Overall, 13.97% (n=19) of parents/caregivers rated the health of their child's mouth as *excellent*, 19.12% (n=26) responded *very good*, 34.56% (n=47) responded *good*, 25% (n=34) responded *fair*, and 7.35% (n=10) responded *poor*.

The recent interest in assessing the effects of oral health problems on individuals' physical, mental, and social health and well-being reflects a move within dentistry towards a more holistic model of health.<sup>14</sup> However, very few instruments have been developed to assess OHRQoL in children and adolescents. Jokovic and Locker were among the first to develop such an instrument for children ages 6-14. Most recently, Pahel et al developed the Early Childhood Oral Health Impact Scale (ECOHIS). The ECOHIS was created by Pahel et al in order to have a valid and reliable instrument to measure the impact of oral health problems and related treatment experiences on the quality of life of preschool children (ages 3 to 5) and their families.<sup>14</sup>

Although the ECOHIS is based on the P-CPQ measure, Jokovic and Locker originally developed their instrument to be used for children ages 6-14 and their caregivers. The overall objective of the ECOHIS instrument was to “develop a short instrument to be completed by the child’s parent or primary caregiver for use in epidemiological surveys to discriminate between children with and without dental disease.”<sup>14</sup> Although their study population was not limited to CSHCN, they found that more parents rated their child’s general health as ‘excellent or very good’ compared to their dental health (88.6% vs. 50.9%).<sup>14</sup> Our study differed slightly in that 67.65% of parents rated the health of the child’s mouth *excellent/very good/good*, while 52.94% stated that the oral health affected the child’s well-being *some, a lot, or very much*. Thus, the majority of parents surveyed felt that oral health did have an impact on the child’s well-being, and the ratings of their child’s oral health was fairly high.

Baens-Ferrer et al conducted a study comparing parental perceptions of oral health-related quality of life for CSHCN before and after oral rehabilitation under general anesthesia.<sup>5</sup> This study questioned parents on oral symptoms, daily life problems, and parental concerns. Coincident with the findings of this study, they reported that family caregivers of CSHCN report a variety of oral symptoms, daily life problems, and parental concerns attributable to their child’s oral health that impact that child’s and family’s QOL.<sup>5</sup> The most frequently reported symptoms in their study prior to oral rehabilitation under general anesthesia were spontaneous toothache and pain with hot/cold temperatures (oral symptoms), difficulty eating and sleeping (daily life

problems), and worrying about eating and nutrition (parental concerns).<sup>5</sup> Frequency of symptoms in this study are reported in Table 2.

In the current study, the four domains of oral symptoms, functional limitations, emotional well-being, and family well-being/parental distress were compared to the two questions of overall oral health and well-being. It was determined that two of the domains, functional limitations and emotional well-being, were not correlated with the child's oral health or well-being. However, the oral symptoms and family well-being/parental distress domains did have a positive correlation ( $p = 0.0340$  and  $p = 0.0420$  respectively). Thus, in this population it appears that oral symptoms and family well-being outweighed functional limitations and emotional well-being. These findings are not altogether surprising considering that many children in this population already have other significant functional limitations beyond the oral cavity that parents may be more focused on. Also, because of limited cognitive abilities, many of the children may not be able to sufficiently express emotions to their parent/caregiver. It is more likely that parents/caregivers would notice obvious oral symptoms such as "bleeding gums" and "bad breath." These correlations seem sensible considering the high prevalence of poor oral hygiene, gingivitis, and periodontitis among children with special health care needs. In regards to parental distress, it was found that feelings of "guilt" accounted for the correlation to the child's oral health, while items of "feeling guilty" and "had less time for yourself or the family" accounted for the correlation to effects of oral health on overall well-being. Figures 2 and 3 illustrate the relationship between the two domains and the health of the child's mouth and their well-being. The higher the mean score for

oral symptoms and parental distress, the worse the parents rated the health of the child's mouth. As mean scores for oral symptoms and parental distress increased, so did the effects of oral health on the child's well-being.

Locker et al also found significant associations with parent-caregiver global ratings of their child's oral health and overall well-being.<sup>12</sup> The aim of their study was to develop and evaluate the Family Impact Scale, a measure of the family impact of child oral and oro-facial disorders.<sup>12</sup> This formed one component of the COHRQoL instrument. The Family Impact Scale was found to have good construct validity as well as excellent internal consistency reliability. The study also provided some data concerning the nature and extent of family impact resulting from oral and oro-facial conditions in children.<sup>12</sup> Their findings showed that almost three-quarters of the parents/caregivers reported frequent family impact in the previous 3 months.<sup>12</sup> The most common family impacts were the child requiring more attention, financial difficulties, taking time off work, parents feeling guilty, worried and upset about the child's condition and the child being argumentative.<sup>12</sup> This study population also was not limited to CSHCN and their families, however it does similarly illustrate the pervasive effects that oral and oro-facial conditions can have on the functioning of parents/caregivers as well as the family as a whole.<sup>12</sup>

Finally, the survey items were analyzed to determine if a relationship existed between patient characteristics (gender, age, condition category) and overall oral health and well-being. No relationship was found between any of these characteristics. This was contrary to what was expected for the categories of condition. It was thought that

perhaps categories of condition with more functional and cognitive limitations; for example, neurodevelopmental/ genetic/ neuromuscular disorders as well as craniofacial conditions might have had a significant relationship with the child's OHQoL and well-being.

### **Study Limitations**

One obvious limitation of this study is the fact that the parents/caregivers acted as “proxy raters” for their child. Filstrup et al and Jokovic et al both found that children tended to rate their oral health quality of life as more severe compared to their parents.<sup>13,7</sup> Ideally, the views of both the child and the parent should be obtained in order to fully represent the child's oral health-related quality of life.<sup>7</sup> This was not entirely possible with the population of children being studied due to significant cognitive and functional limitations. Another limitation may have been the sample size (n = 137, 32% survey return rate) as well as the uneven distribution of the children into the categories of condition. A second mailing may have improved the response rate but we were not able to over sample according to certain categories of condition. There also may be some selection bias according to who returned the survey. This study population reports in on average a good overall oral health for children and it is possible that those who suffer from poor oral health or who have lower overall well-being may have not returned the survey.

## CONCLUSIONS

This study examined the effects of oral health conditions on general well-being and family life of these children.

1. The majority of caregivers surveyed felt that oral health did have an impact on the child's well-being, with the ratings of their child's oral health being fairly high.
2. Family caregivers of CSHCN report a variety of oral symptoms, daily life problems, and parental concerns attributable to their child's oral health that impact that child's and family's QOL
3. In this population of children with special health care needs, it appears that oral symptoms and family well-being outweighed functional limitations and emotional well-being in impacting oral health quality of life according to parental perceptions.

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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 "x" 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".

- |  |   |
|--|---|
| <input type="checkbox"/> Never<br><input type="checkbox"/> Once or twice<br><input type="checkbox"/> Sometimes | <input type="checkbox"/> Often<br><input type="checkbox"/> Everyday or almost everyday<br><input type="checkbox"/> 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.

<b>SECTION 1: Child's oral health and wellbeing</b>
---

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

- |   |  |
|---|--|
| <input type="checkbox"/> Excellent<br><input type="checkbox"/> Very good<br><input type="checkbox"/> Good | <input type="checkbox"/> Fair<br><input type="checkbox"/> Poor |
|---|--|

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

- |                                      |                                    |
|--------------------------------------|------------------------------------|
| <input type="checkbox"/> Not at all  | <input type="checkbox"/> A lot     |
| <input type="checkbox"/> Very little | <input type="checkbox"/> Very much |
| <input type="checkbox"/> Some        |                                    |

**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?**

- |                                    |                                     |
|------------------------------------|-------------------------------------|
| <input type="checkbox"/> Excellent | <input type="checkbox"/> Fair       |
| <input type="checkbox"/> Very good | <input type="checkbox"/> Poor       |
| <input type="checkbox"/> Good      | <input type="checkbox"/> Don't know |

**4. Bleeding gums?**

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

**5. Sores in the mouth?**

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

**6. Bad breath?**

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

**7. Food stuck in the roof of the mouth?**

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

**8. Food caught in or between the teeth?**

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

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

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> 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?**

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

**11. Had trouble sleeping?**

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

**12. Had difficulty saying any words?**

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

**13. Taken longer than others to eat a meal?**

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

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

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

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

- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

**16. Had diet restricted to certain types of food (for example: soft food)?**

- |                                |                                |
|--------------------------------|--------------------------------|
| <input type="checkbox"/> Never | <input type="checkbox"/> Often |
|--------------------------------|--------------------------------|

- Once or twice  
 Sometimes

- 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

**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 his/her teeth, lips, mouth, or jaws, how often have you or another family member:*

20. **Been upset?**
- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |
21. **Had sleep disrupted?**
- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |
22. **Felt guilty?**
- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |
23. **Taken time off work (for example: pain, appointments, surgery)?**
- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |
24. **Had less time for yourself or the family?**
- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |
25. **Worried that your child will have fewer life opportunities (for example: for dating, getting married, having children, getting a job he/she will like)?**
- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |
26. **Felt uncomfortable in public places (e.g. stores, restaurants) with your child?**
- |  |  |
|--|--|
| <input type="checkbox"/> Never         | <input type="checkbox"/> Often                       |
| <input type="checkbox"/> Once or twice | <input type="checkbox"/> Everyday or almost everyday |
| <input type="checkbox"/> Sometimes     | <input type="checkbox"/> Don't know                  |

<b>Child's gender and age</b>
-------------------------------

a. **Your child is:**

- Male  
 Female

b. **Your child's age is: \_\_\_\_\_ YEARS**

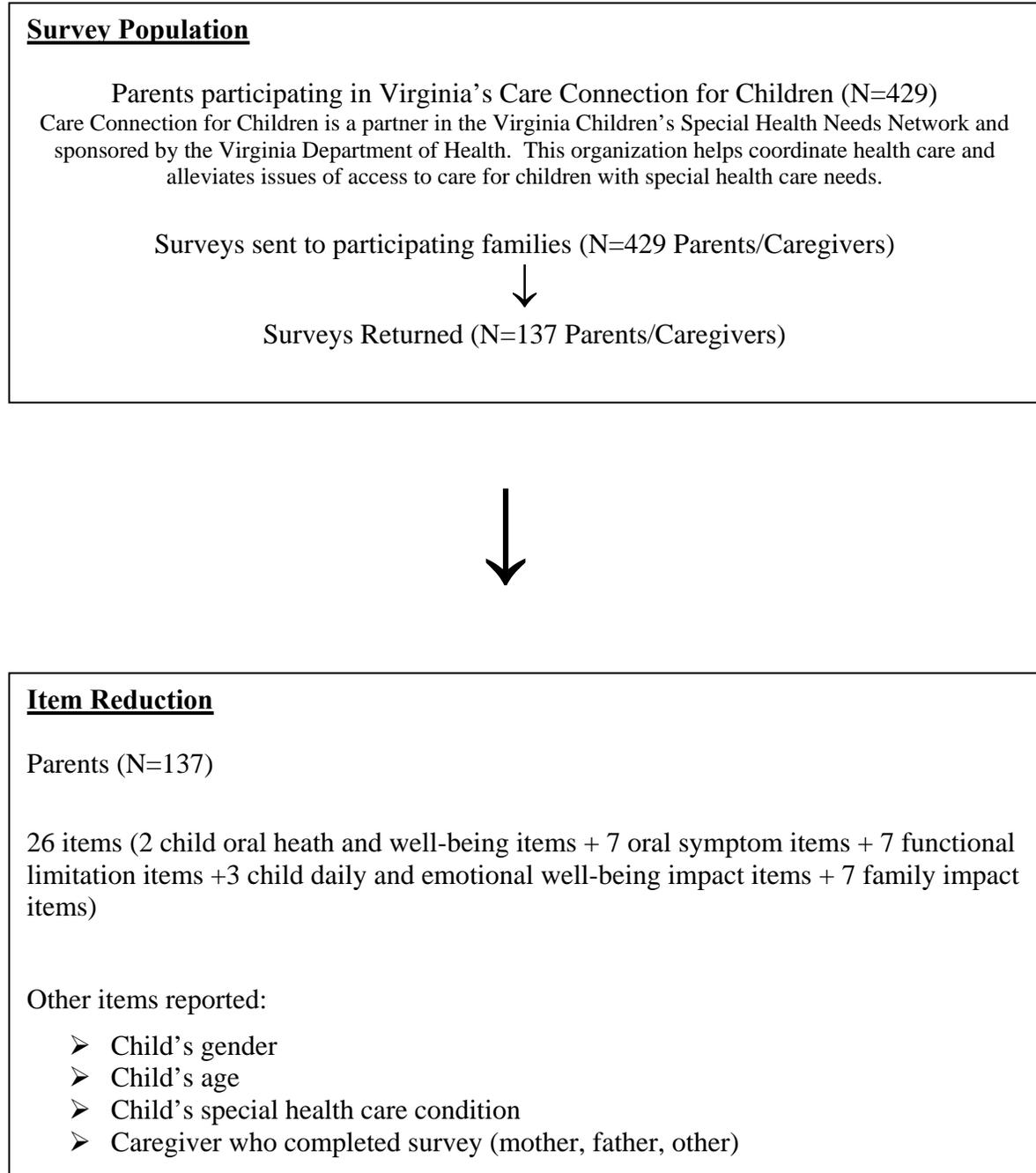
c. **Your child's special health care condition: \_\_\_\_\_.**

**Questionnaire completed by:**

- Mother  
 Father  
 Other \_\_\_\_\_

**Date completed:** \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Day            Month        Year

**THANK- YOU FOR YOUR PARTICIPATION!**

**Figure 1. Survey Item Reduction**

**Table 1: Description of Subjects**

<b>Characteristic</b>	<b>N</b>	<b>Percent</b>
<b>Gender</b>		
F	60	44
M	77	56
<b>Condition</b>		
Neurodevelopmental/Genetic disorders/Neuromuscular	69	58
Respiratory	13	11
Cardiac Disease	5	4
Craniofacial	14	12
Metabolic	16	13
Psychological	3	3
<b>How would you rate the health of your child's teeth, lips, jaws and mouth?</b>		
Excellent	19	14
Very good	26	19
Good	47	35
Fair	34	25
Poor	10	7
<b>How much is your child's overall wellbeing affected by the condition of his/her teeth, lips, jaws or mouth?</b>		
Not at all	42	31
Very little	22	16
Some	37	27
A lot	21	15
Very much	14	10

**Table 2: Item Summary**

Question	Number (Percent)					Mean	SD	
	Never	Once or twice	Some-times	Often	Every-day			Don't Know
<b>Oral Symptoms</b>								
Pain in the teeth, lips, jaws or mouth?	58 (44)	23 (17)	30 (23)	4 (3)	3 (2)	15 (11)	1.91	1.05
Bleeding gums?	86 (63)	19 (14)	21 (15)	2 (1)	6 (4)	2 (1)	1.68	1.08
Sores in the mouth?	103 (75)	15 (11)	14 (10)	1 (1)	0 (0)	4 (3)	1.35	0.70
Bad breath?	36 (26)	24 (18)	41 (30)	21 (15)	15 (11)	0 (0)	2.67	1.31
Food stuck in the roof of the mouth?	89 (66)	14 (10)	18 (13)	3 (2)	3 (2)	8 (6)	1.56	0.98
Food caught in or between the teeth?	44 (32)	27 (20)	51 (38)	9 (7)	3 (2)	2 (1)	2.25	1.06
Difficulty biting or chewing foods such as fresh apple, corn on the cob or firm meat?	70 (53)	12 (9)	20 (15)	10 (8)	16 (12)	4 (3)	2.14	1.46
<b>Functional Limitations</b>								
Breathed through the mouth?	53 (39)	4 (3)	29 (21)	22 (16)	18 (13)	10 (7)	2.59	1.52
Had trouble sleeping?	91 (66)	13 (9)	22 (16)	3 (2)	7 (5)	1 (1)	1.69	1.14
Had difficulty saying any words?	67 (52)	7 (5)	17 (13)	7 (5)	23 (18)	9 (7)	2.27	1.61
Taken longer than others to eat a meal?	64 (49)	12 (9)	21 (16)	10 (8)	20 (15)	3 (2)	2.29	1.53
Had difficulty drinking or eating hot or cold foods?	82 (63)	14 (11)	17 (13)	4 (3)	13 (10)	1 (1)	1.86	1.33
Had difficulty eating foods he/she would like to eat?	86 (65)	9 (7)	17 (13)	8 (6)	9 (7)	3 (2)	1.80	1.28
Had diet restricted to certain types of food (for example: soft food)?	93 (73)	4 (3)	5 (4)	3 (2)	20 (16)	3 (2)	1.82	1.52
<b>Emotional Wellbeing</b>								
Upset?	73 (54)	17 (13)	31 (23)	6 (4)	3 (2)	6 (4)	1.84	1.08
Irritable or frustrated?	72 (53)	23 (17)	24 (18)	7 (5)	2 (1)	7 (5)	1.78	1.03
Anxious or fearful?	98 (73)	9 (7)	13 (10)	3 (2)	0 (0)	11 (8)	1.36	0.77
<b>Parental Distress and Family Function</b>								
Been upset?	73 (54)	20 (15)	34 (25)	3 (2)	1 (1)	5 (4)	1.77	0.97
Had sleep disrupted?	101 (74)	9 (7)	16 (12)	1 (1)	5 (4)	4 (3)	1.48	1.00
Felt guilty?	89 (66)	6 (4)	25 (19)	7 (5)	4 (3)	4 (3)	1.71	1.13
Taken time off work (for example: pain, appointments, surgery)?	87 (64)	19 (14)	20 (15)	6 (4)	2 (1)	1 (1)	1.63	0.99
Had less time for yourself or the family?	100 (74)	3 (2)	14 (10)	9 (7)	8 (6)	1 (1)	1.67	1.25
Worried that your child will have fewer life opportunities?	83 (62)	5 (4)	15 (11)	10 (7)	16 (12)	5 (4)	2.00	1.48
Felt uncomfortable in public places (e.g. stores, restaurants) with your child?	110 (81)	10 (7)	9 (7)	5 (4)	1 (1)	1 (1)	1.35	0.82

**Table 3: Summary of Domain Scores**

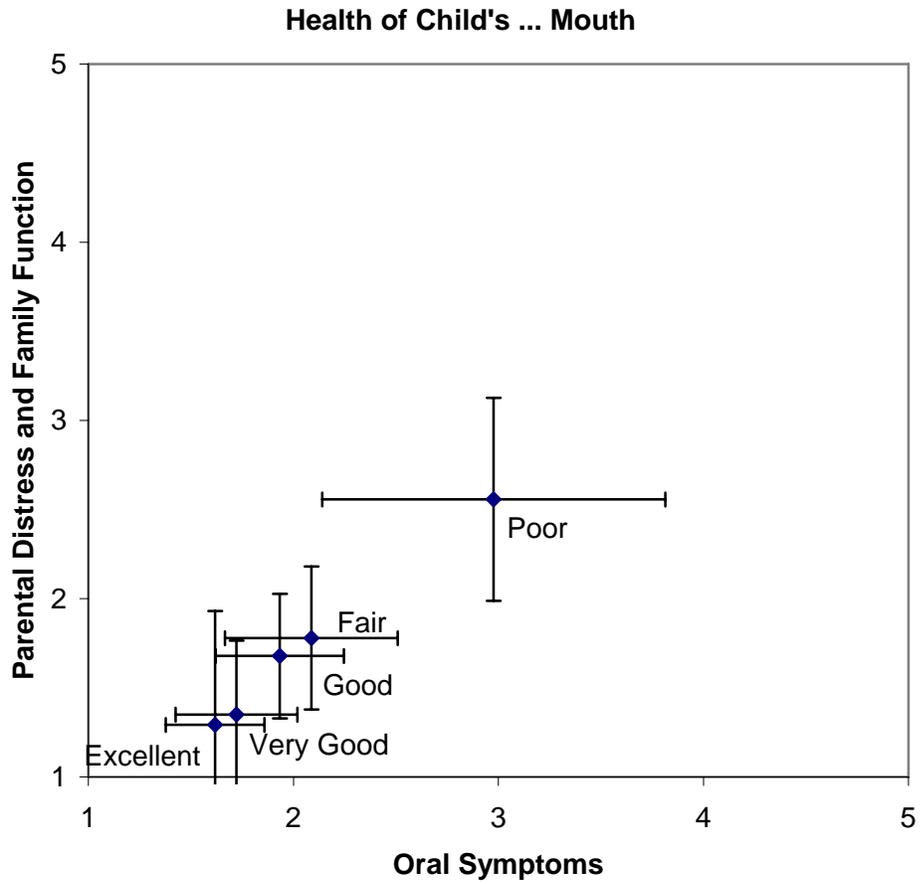
Domain	N	Mean	SD
Oral Symptoms	137	1.96	0.71
Functional Limitations	137	2.06	1.06
Emotional Wellbeing	133	1.71	0.93
Parental Distress and Family Function	137	1.65	0.78

Correlations Domain	Domain		
	Symptoms	Limitations	Wellbeing
Functional Limitations	0.54		
Emotional Wellbeing	0.52	0.52	
Parental Distress & Family Function	0.53	0.73	0.68

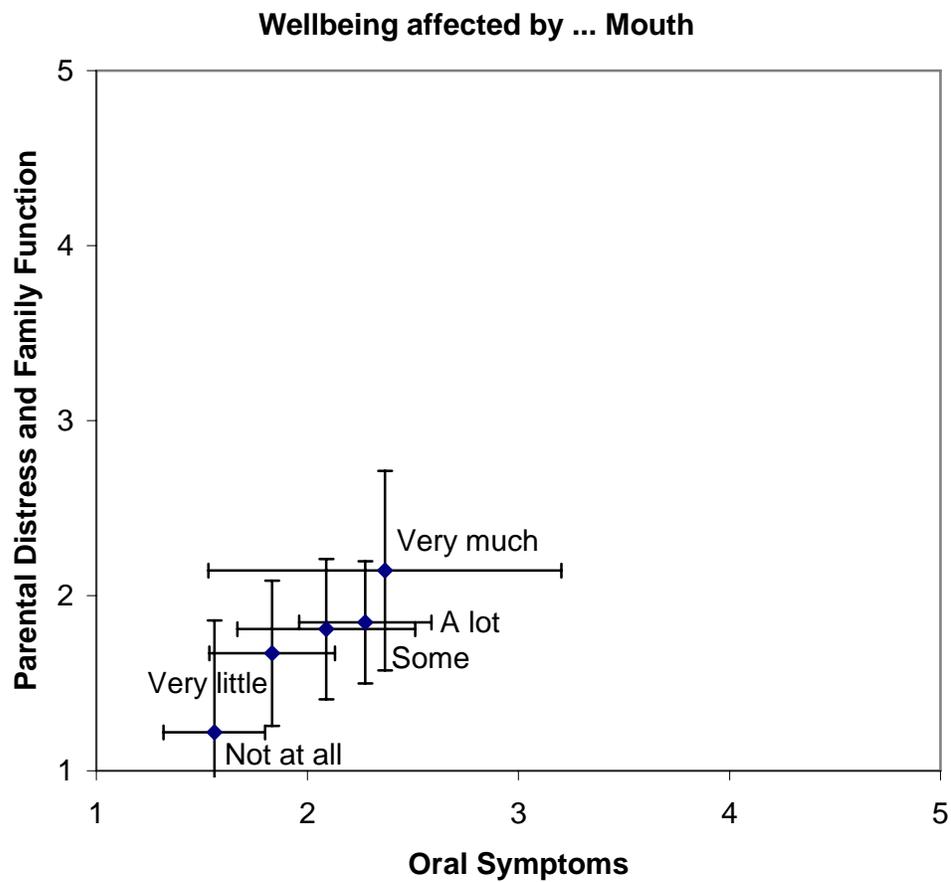
**Figure 2: Relationship between Overall Health of Child’s Mouth and Two Domains**

Health of child's ... mouth	n	Mean	
		Oral Symptoms	Parental Distress and Family Function
Excellent	19	1.62	1.29
Very Good	26	1.72	1.35
Good	47	1.93	1.68
Fair	34	2.09	1.78
Poor	10	2.98	2.56



**Figure 3: Relationship between Well-being and Two Domains**

Wellbeing affected by ... mouth	n	Mean	
		Oral Symptoms	Parental Distress and Family Function
Not at all	42	1.56	1.22
Very little	22	1.83	1.67
Some	37	2.27	1.85
A lot	21	2.09	1.81
Very much	14	2.37	2.14



VITA

Kristin Elizabeth Nelson was born on April 7, 1979 in Indiana, Pennsylvania. She graduated from Sayre School, Lexington, Kentucky, 1997. She attended Denison University in Granville, Ohio. She received her Bachelor of Science in Biology and French, 2001. Dr. Nelson received her Doctor of Dental Medicine from University of Kentucky, Lexington, Kentucky, in 2005.