Assessing the relationship between caregivers' pediatric oral health literacy and children's caries status David M. Avenetti, DDS

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Abstract

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Purpose: The primary aims of this study were to 1) determine if caregivers' oral health literacy is associated with children's caries status using two different oral health literacy instruments, 2) explore if caregivers' scores on these instruments are correlated, and 3) compare caregivers' reading recognition and vocabulary knowledge.

Methods: This was a cross-sectional study of primary caregivers and their 3-to-6 year old children conducted at a combined university-hospital dental clinic. Consenting caregivers completed an 18-item demographic and dental utilization survey, the Rapid Estimate of Adult Literacy in Dentistry (REALD-30), the Oral Health Literacy Inventory for Parents (OH-LIP) Parts I and II. The REALD-30 and OH-LIP I and II interviews were audio-recorded for scoring and reliability testing. All dmft scores were determined during the course of a full dental examination completed by a pediatric dental resident or faculty member.

Results: Fifty-seven caregiver-patient pairs participated in this study. There were strong statistically significant correlations between the REALD-30, OH-LIP I, and OH-LIP II scores (r>0.7, p<0.001). Neither the OH-LIP I, OH-LIP II, or REALD-30 scores were significantly associated with dmft scores in unadjusted or adjusted Poisson regression models. REALD-30 and the OH-LIP I scores were generally high, indicating most caregivers were able to recognize

and pronounce dental terms. OH-LIP II scores revealed wide variation in caregivers' ability to define pediatric dental terms, even though most could pronounce the terms correctly.

Conclusions: These results indicate that the REALD-30 and the OH-LIP II may have wider internal and external validity than the OH-LIP I, given their strong correlation and association with numerous demographic/dental characteristics known to be associated with low oral health literacy. The OH-LIP II offers a deeper understanding of caregivers' oral health literacy than word recognition instruments, as demonstrated by caregivers who frequently had an incorrect or incomplete understanding of common dental terms, despite their ability to pronounce them correctly. Additional research is needed to explore the possible association between caregiver oral health literacy, caries in children, and factors which may influence this relationship. Since caregivers are primarily responsible for the oral health practices of young children, their oral health literacy levels can affect their children's oral health and caries experience. Pediatric dentists should be aware of oral health literacy levels and appropriately tailor oral health messages.

TABLE OF CONTENTS

List of Tables	Page ii
List of Figures	Page iii
List of Appendices	Page iv
Background	Page 1
Methods	Page 5
Results	Page 10
Discussion	Page 14
Conclusions	Page 25
Tables	Page 26
Figures	Page 36
References	Page 47
Appendices	Page 49

LIST OF TABLES

Table 1. Child and Caregiver Demographics and Household Characteristics	Page 26
Table 2. Child and Caregiver Past Dental Utilization and Self-Reported Oral Health Characteristics	Page 28
Table 3a. Caregiver Oral Health Literacy Scores and Child dmft Scores' Associations with Selected Characteristics	Page 29
Table 3b. Pearson Correlations between Continuous Demographic Variables and Outcome Measures	Page 31
Table 4. Pearson Correlations between Oral Health Literacy Instruments	Page 32
Table 5. Association between Child dmft and Caregiver Oral Health Literacy Scores	Page 33
Table 6. Percentage of Correct Responses on the OH-LIP I and the OH-LIP II	Page 34
Table 7. Percentage of Correct Responses on the REALD-30	Page 35

LIST OF FIGURES

Figure 1. Histogram of dmft Scores and Summary of dmft Distribution	Page 36
Figure 2. Histogram of REALD-30 Scores	Page 37
Figure 3. Histogram of OH-LIP I Scores	Page 38
Figure 4. Histogram of OH-LIP II Scores	Page 39
Figure 5. Scatterplot of dmft and REALD-30 Scores	Page 40
Figure 6. Scatterplot of dmft and OH-LIP I Scores	Page 41
Figure 7. Scatterplot of dmft and OH-LIP II Scores	Page 42
Figure 8. Scatterplot of REALD-30 and OH-LIP I Scores	Page 43
Figure 9. Scatterplot of REALD-30 and OH-LIP II Scores	Page 44
Figure 10. Scatterplot of OH-LIP I and OH-LIP II Scores	Page 45
Figure 11. Caregiver Vocabulary Knowledge on the OH-LIP II	Page 46

LIST OF APPENDICES

Appendix 1. Study Procedures Flow sheet	Page 49
Appendix 2. Subject Recruitment Script	Page 50
Appendix 3. Data Collection Survey	Page 53
Appendix 4. REALD-30 Terms	Page 56
Appendix 5. OH-LIP I and II Terms	Page 57
Appendix 6. Informed Consent	Page 58
Appendix 7 HIPAA Authorization Form	Page 61

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BACKGROUND

Defining Literacy, Health Literacy, and Oral Health Literacy

More than 22 percent of U.S. citizens are considered to be illiterate or lack functional literacy. Functional literacy is defined as the ability "to manage daily living and employment tasks that require reading skills beyond a basic level," while illiteracy is the inability to read or write in any language. Both illiteracy and a low functional literacy have been associated with behaviors that lead to poorer health such as lower prescription adherence, decreased preventive visits, and increased emergency room utilization for non-emergent conditions. The Institute of Medicine described the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health care decisions as health literacy. This definition recognizes that a person's ability to understand and utilize health-related information requires additional skills beyond being able to simply read information. It also acknowledges that a person having general literacy or functional literacy may not necessarily have adequate health literacy.

Although general health and oral health are related, dentistry encompasses more specific vocabulary and concepts than those described by the broader construct of health literacy.⁵ Consequently, the American Dental Association recognized oral health literacy as a subcategory of health literacy and defined it as "the degree to which individuals have the capacity to obtain, process, and understand oral health information and services needed to make appropriate health decisions." ⁶

Many measurement tools, including the Test of Functional Health Literacy in Adults (TOFHLA), The Newest Vital Sign, and The Rapid Estimate of Adult Literacy in Medicine (REALM), were developed as a means of assessing functional literacy and health literacy.⁷⁻⁹ The tools were designed to be used as a method of rapid health literacy assessment— using reading recognition or basic question and answering. Results can theoretically be used for research, to identify those with low health literacy, and programmatic planning. Methods of assessing oral health literacy have been adapted from these instruments. Some examples are the Test of Functional Health Literacy in Dentistry (TOFHLiD), the Rapid Estimate of Adult Literacy in Dentistry-99 (REALD-99), and REALD-30.¹⁰⁻¹² Similar to medicine, many of these instruments rely on word recognition. Richman et al found that this approach may overestimate health literacy and oral health literacy.¹³

Pediatric dentistry is a specialty area devoted to the diagnosis, treatment, and prevention of oral disease in children. This discipline utilizes terminology and concepts which may not be used widely in general dentistry. Consequently, a person with high oral health literacy may not have high pediatric-specific oral health literacy. Pediatric dentistry is unique in that practitioners must provide pediatric specific oral health information to both patients and their caregivers. Additionally, caregivers of young children assume the primary responsibility of helping their young children maintain good oral health practices. 14

The relationship between caries status in children and their caregivers' scores on the REALD-30 was explored by Miller et al.¹⁵ A limitation of this study was that it utilized a caries severity index to indicate children's caries status and a word-recognition tool to assess oral health literacy. The caries severity index describes a child as either caries free with no treatment needs, low to moderate treatment needs (defined as visible occlusal and posterior interproximal carious lesions), or advanced treatment needs (defined as visible anterior carious lesions). They found that children with mild to moderate treatment needs were more likely to have caregivers with higher oral health literacy scores on the REALD-30.¹⁵ Next steps are to evaluate the relationship between caries and oral health literacy using a more specific measure of caries assessment and a measure of oral health literacy that includes vocabulary knowledge in the context of pediatric dentistry. Including vocabulary knowledge in the assessment of oral health literacy, but the definition also includes a person's ability to understand and act on health recommendations.⁴

Recognizing that the REALD-30 and other tools utilize terminology that is not pediatric-specific, Richman et al sought to develop the Oral Health Literacy Inventory for Parents (OH-LIP), which is designed to measure parental oral health literacy in pediatric dentistry. The OH-LIP has three components; Part I evaluates word recognition, Part II evaluates vocabulary knowledge, and Part III evaluates comprehension and contextual knowledge. They found that reading recognition was not significantly associated with vocabulary knowledge or comprehension, but that vocabulary knowledge was strongly associated with comprehension. They also found that caregivers' report of children's oral health status was not significantly associated with any of the three measures. The authors concluded that vocabulary knowledge may be a better indicator of pediatric oral health literacy than caregivers' ability to read terms correctly. The authors concluded that vocabulary knowledge may be a better indicator of pediatric oral health literacy than caregivers' ability to read terms correctly.

A well-established method to quantify caries in dentistry is the number of decayed, missing, and filled teeth (dmft). The primary dentition consists of twenty teeth; therefore, the maximum number of decayed, missing, or filled teeth in a primary dentition is twenty. Previous studies have recognized the need for more specific caries measurement tools to examine the association between oral health literacy and caries status. ¹⁵ Reporting caries through dmft scores is more specific than methods used in previous oral health literacy studies such as the caries severity index or caregiver report of oral health. ¹⁶ In addition, it has not yet been determined if vocabulary knowledge is associated with oral health outcomes such as caries status. To build on previous research, the primary aims of this study were to determine if caregivers' oral health literacy is associated with children's caries status using the REALD-30 and OH-LIP I and II, to explore if caregivers' scores on these instruments are correlated, and to compare caregivers' reading recognition and vocabulary knowledge. A secondary aim was to explore demographic and dental utilization characteristics associated with low oral health literacy scores.

The Epidemiology of Caries in Young Children

Results of the National Health and Nutritional Examination Survey (NHANES) indicate that more than 28% of children are affected by early childhood caries. Early childhood caries describes a severe pattern of dental caries involving primary teeth in young children.¹⁷ The number of children affected by early childhood caries continues to increase, especially among families with low socioeconomic status and certain minority groups, such as Hispanics, African-Americans, and Native Americans. 18 Children who have high levels of dental caries are more likely to have caries in their permanent teeth and poorer oral health as adults, which can lead to a high cumulative cost of treatment over one's lifetime. 19 This pattern occurs not only within individuals but also between generations since parents who have a high caries experience are likely to have children with a high caries experience.²⁰ If pediatric oral health literacy is found to be associated with caries status, then increasing parental oral health literacy may be an effective point of intervention to reduce caries rates in children, especially among members of our most vulnerable populations.²¹ Vann et al examined the oral health literacy among female caregivers and its impact on oral health outcomes in early childhood. They found that that lower caregiver literacy was associated with deleterious oral health behaviors and that this association was more profound in low-income individuals.²² These findings suggest a point of intervention for a population at increased risk or poor oral health.

Oral health and oral health literacy have been prioritized by the Maternal and Child Health Bureau, the American Academy of Pediatrics, the American Dental Association, and the American Academy of Pediatric Dentistry in their policy and intervention strategies as an important method to reduce disparities and improve oral health outcomes. The implications of improving oral health literacy extend beyond children and their caregivers. Appropriately-tailored health communication as a means of preventing caries is important for all members of an interdisciplinary or community-based healthcare team to facilitate promotion of oral health in conjunction with overall health promotion efforts.²³

METHODS

Study Setting and Design

This was a cross-sectional study of caregiver-child pairs recruited from the Center for Pediatric Dentistry (CPD) in Seattle, WA. The CPD was formed as a partnership between the University of Washington Department of Pediatric Dentistry and Seattle Children's Hospital. The patient pool includes both healthy children and children with special health care needs from birth through adolescence.²⁴ This study received minimal-risk approval from the Institutional Review Board of the University of Washington. Fifty-seven caregiver-child pairs were recruited before the enrollment window ended.

Inclusion and Exclusion Criteria

Caregivers of subjects meeting inclusion criteria were recruited from a convenience sample of new patients and recall patients over a five-month study period. To meet inclusion criteria, children needed to be between 36 and 72 months of age and escorted to their dental appointment by a primary caregiver. Limiting the inclusion criteria to this age range increased the likelihood that all primary teeth were fully erupted, the teeth had adequate time at risk to develop caries, and the patient was willing and able to take radiographs if deemed necessary. Since this study proposes that children's caries status is a reflection of caregivers' pediatric oral health literacy, it was imperative that the person participating in the interview be a primary caregiver with influence on the child's oral health regimen. Exclusion criteria were having a sibling already enrolled in the study, caregivers who were not proficient in written and spoken English, patients who had received dental treatment under sedation or general anesthesia, and caregivers with vision or hearing impairments. Only one child per household was eligible for participation to maximize the number of independent observations of caregiver-child pairs. If more than one child was scheduled at the same time and both met age criteria, then one child was randomly selected for participation.

Recruitment and Enrollment

A computerized scheduling system (axiUm®) was used to screen for patients meeting the age criteria. At least one day prior to the child's scheduled appointment, caregivers were contacted via telephone and invited to participate in the study. They were read a brief script regarding the purpose of the study and a determination was made about whether they met the remaining study criteria. Caregiver-patient pairs who met all criteria were asked to arrive

approximately 25 minutes prior to their scheduled appointment on the following day. Upon their arrival, we reviewed consent and verified study eligibility. If consent was given, participants were transferred to a private or semi-private room to complete a demographic survey and the oral health literacy interview.

Demographic Survey

Caregivers completed a demographic survey to obtain information about the following items: age of the caregiver accompanying the child; gender of the caregiver and child; birth date of the child; caregiver's race/ethnicity; primary language(s) spoken in the home; highest level of education of the caregiver; insurance status; marital status; number of people and number of children living in the household; annual household income; caregiver report of the child's oral health status and own oral status; periodicity of dental treatment and history of dental treatment for both the caregiver and the patient. Caregivers were reminded that they could skip items if they did not feel comfortable responding to the question(s). Private vs. public insurance was used as a proxy for low versus higher socioeconomic status since an established income threshold is used to determine Medicaid eligibility.

Oral Health Literacy Interview

After obtaining consent and demographic information, caregivers were audio-recorded while completing the REALD-30 and the OH-LIP Parts I and II. The digitally recorded responses were reviewed and scored at a later time, and randomly selected interviews were re-scored to establish inter and intra rater reliability. All interviews began with the administration of REALD-30. Caregivers were asked to read aloud thirty dental terms printed on individual note cards. The words were arranged from least difficult to most difficult in a standard order dictated by REALD-30 protocol. Caregivers were encouraged to "pass" rather than guess if they did not know a word or did not feel comfortable guessing the pronunciation. Following this, the OH-LIP Part I was administered using a similar set of instructions to read a series of 35 printed terms and say "pass" for terms they could not pronounce. The final component of the oral health literacy assessment was the administration of the OH-LIP Part II which asks caregivers to briefly explain the definition, function and/or importance of each of the 35 words that presented in OH-LIP Part I. They were encouraged to "pass" rather than guess if they did not know the definition.

Clinical Examination

Upon completion of the interview, caregivers and patients were escorted to the clinical examination area for the child's scheduled appointment. All efforts were made to conduct/administer the oral health literacy assessments prior to the clinical examination since oral health instruction provided during the exam had the potential to artificially elevate a caregiver's performance on the pediatric oral health literacy assessments. In certain unavoidable circumstances, interviews were conducted after the child's clinical examination due to clinical constraints, such as the patient and caregiver arriving with insufficient time to complete the research protocol prior to the appointment.

The clinical examination was conducted according to established clinic guidelines and not altered for study participants. For example, patients only completed radiographs if they were otherwise indicated as part of the examination. The resident or faculty member completing the clinical exam was blinded to the caregiver's performance on the oral health literacy assessments to avoid biasing the diagnosis of caries. Prior to initiating the research study, residents were provided information about the research protocol, methods, and purpose. This orientation aimed to ensure that decayed, missing, and filled teeth were diagnosed and recorded in a standardized fashion according to clinical and radiographic presentation to avoid inaccurate dmft counts.

dmft scoring and Oral Health Literacy Assessment

Following the patient's dental examination, the dmft, exam type, whether radiographs were taken, and and number of primary teeth present were abstracted from the patient's chart. In cases where primary teeth had begun to exfoliate, the count of primary teeth was less than 20. Since mandibular primary incisors are generally the first teeth to exfoliate and are the least likely teeth to have caries in the primary and permanent dentition, it was not likely that dmft data resulting from caries on primary incisors was missed. Permanent teeth were not included in the dmft score since there was minimum time-at-risk for these teeth to develop caries.

Operational definitions for each dental term were determined using the standard definitions set forth by the American Dental Association and the American Academy of Pediatric Dentistry. Pronunciation guidelines were determined in advance using literature about the REALD-30 protocol, the OH-LIP protocol, the American Heritage Dictionary or consensus among research team members when terms were not available. Dr. Julia Richman (developer of

the OH-LIP) was consulted to obtain scoring criteria for the OH-LIP II which was developed from a subset of interviews in her study sample.

Fourteen audio recordings were reviewed and scored with a second member of the research team (PL, research committee chair) using the developed scoring criteria as a guide. The purpose of this collaboration was to achieve consistency in scoring. After reasonable levels of consistency (concordance of 90% or greater) and standardization were achieved, the remaining audio recordings were reviewed and scored by one individual (DA). Correct responses to the REALD-30 were assigned a score of 1 and incorrect responses were assigned a score of 0, so total scores could range from 0 to a maximum of 30. Caregiver responses to the OH-LIP Part I were scored so that correct responses were assigned a score of 1, and incorrect responses were assigned a score of 0 so total scores could range from 0 to a maximum of 35. Caregiver responses to the OH-LIP Part II were scored so that correct responses were assigned a score of 2, partially correct responses were assigned a score of 1, and incorrect responses were assigned a score of 0. Total scores could range from 0 to a maximum of 70. For all parts of the interview, "passes" were scored as incorrect.

Data Management

Demographic information, interviews, and caries data were linked via a confidential patient identification number and were stored in a Microsoft Excel® file on a password-protected computer. Once all data collection, entry, and analysis were complete, the audio recordings were deleted. Caregivers' responses to several demographic and dental questions were combined to simplify reporting when response categories had a low number of respondents; these include caregiver's relationship to child, caregiver's ethnicity, primary language spoken in the home, caregiver's marital status, and history of child's last dental visit. Other variables were recoded for statistical analysis to minimize the probability of failing to detect a truly significant difference due to response categories with a low number of respondents; these include dmft scores, caregiver's education, primary language spoken in the home, caregiver's assessment of child's oral health, caregiver's assessment of own oral health, caregiver's last dental visit, and race. To achieve consistency with Miller et al, information about race and socioeconomic status were collected to control for confounding in the regression model. For the regression analysis, race information was collapsed to white vs. non-white, and insurance type was collapsed to public vs. private as a proxy for socioeconomic status.

Statistical Analysis

We determined a priori that a sample of 82 participants was needed to detect a moderate correlation (r=0.3 or greater) between any two of the three oral health literacy assessments with 80% power at an alpha level of 0.05. The primary predictor variable was oral health literacy as measured by the REALD-30 and OH-LIP Parts I and II. The primary outcome measure was dmft scores. The following statistical tests were performed using STATA 11.2®:

- Descriptive statistics (i.e., means, standard deviations, counts, and percentages) were calculated for all variables.
- Mean dmft, REALD-30, OH-LIP, I and OH-LIP II scores were reported for selected demographic variables. Two-sample t-tests with unequal variance were performed to test for differences in mean dmft, REALD-30, OH-LIP, I and OH-LIP II scores for variables containing two categories. Non-parametric methods were used for categorical variables with more than three categories since assumptions for parametric methods were not satisfied. Consequently, Kruskal-Wallis tests were performed to test for differences between dmft, REALD-30, OH-LIP, I and OH-LIP II scores for variables containing three or more categories.
- Pearson correlations with Bonferroni adjustment were calculated to test the pairwise associations between OH-LIP I, OH-LIP II, and REALD-30 scores.
- Unadjusted Poisson regression was performed to test the association between OH-LIP Part I, OH-LIP Part II, and REALD-30 scores with dmft data.
- Adjusted Poisson regression was performed to examine if the relationship between oral health literacy scores (OH-LIP I, OH-LIP II, and REALD-30) and dmft differed when controlling for insurance type and White race.
- We calculated the percentage of respondents that correctly pronounced each term on the REALD-30 and OH-LIP I. We also reported the percentage of respondents that were correct, partially correct, or incorrect on each item of the OH-LIP II.

RESULTS

Fifty-seven parent-caregiver pairs participated in this study. Five caregivers chose not to participate in the study after reviewing consent, and no consenting participants dropped out after enrolling. The mean caregiver age was 35.23 years (SD=7.92), and the mean child age was 4.57 years (SD=1.02). Twenty-three children were three years of age, 11 were four years of age, 18 were five years of age, and five were six years of age. Patients who were already six years of age were included in this study because they had recently turned six. Twenty-five (43.9%) children were male, and 17 (29.8%) caregivers were male. All but three children were accompanied to their visit by their mother or father. The average household size was 4.03 individuals (SD=1.27) with an average of 2.22 (SD=1.09) children living in the home. Only five households had four or more children living in the home. (Table 1)

Twenty-six (45.5%) caregivers identified themselves as White/Caucasian; Asian (17.6%) and Black/African-American (12.3%) were the second and third most prevalent ethnicities. Seven (12.3%) caregivers identified themselves as of "Mixed" ethnicity. Forty-two (73.6%) households spoke English as the primary language in the home. Five (8.8%) households spoke both English and a second language, while six (10.5%) primarily spoke a language other than English. All but two caregivers completed a high school or a high school equivalent level of education. Forty-five (79%) caregivers completed beyond a high school level of education. The predominant insurance type was Public (Medicaid) with 31 (54.4%) of children enrolled. Forty-seven (82.4%) caregivers were married or living with a partner, three were divorced/widowed/separated, and seven were never married. Twenty-two households (38.6%) earned less than \$40,000 annually, and 15 (26.4%) earned \$80,000 or more annually. Seven caregivers preferred not to provide household income information. The mean time to complete the REALD-30, OH-LIP I, and OH-LIP II was 9 minutes and 17 seconds. (Table 1)

Fifty-four children (94.7%) had received an oral exam or cleaning in the past. Eighteen (31.6%) had previously received dental treatment, five (8.8%) sought previous care for an infection or toothache, and two (3.5%) previously sought dental care for trauma. The majority 47 (82.4%) had seen a dentist at least once in the prior 12 months. Fourteen caregivers described their child's oral health as "poor or fair," 22 described it as "good," and 21 described it as "very good or excellent." Forty-seven (82.4%) children had seen a dentist at least once in the prior 12 months. On the day of the study, 41 (71.9%) children received a recall exam and 16 (28.1%) received a new patient examination. Thirty-nine (68.4%) patients received radiographs

in addition to their clinical exam. Fifty-five children had 20 primary teeth present, and two had only 18 primary teeth present. (Table 2)

Sixteen caregivers described their own oral health as "poor or fair," 27 described it as "good," and 14 described it as "very good or excellent." Thirty-four (60.7%) caregivers had seen a dentist within the prior 12 months, and 11 (19.6%) had seen a dentist between one and two years prior. Fifty-six (98.3%) caregivers had previously received an oral exam or cleaning, 44 (77.2%) had received previous dental treatment, 10 (17.5%) sought previous care for an infection or toothache, and five (8.8%) previously sought dental care for trauma. (Table 2)

Statistically significant differences in dmft scores were found between Hispanic vs. non-Hispanic ethnicity (p=0.02), with Hispanic ethnicity having lower dmft scores indicating better oral health status. The dmft scores were significantly associated with caregiver's assessment of child's oral health (<0.001). Caregivers who assessed their child as having "poor or fair" oral health were more likely to have children with higher dmft scores, and caregivers who assessed their child as having "very good or excellent" oral health were more likely to have children with lower dmft scores. Household income and dmft scores were inversely related, but not statistically significant (p=0.09). (Table 3a)

Higher REALD-30 scores were associated with ethnic group (p=0.02), English being the primary language spoken in the home (p=0.01), private insurance (p=0.008), higher household income (p=0.004), a caregiver's assessment of child's oral health as "good, very good, or excellent" (p=0.02), and a caregiver's assessment of their own oral health as "good, very good, or excellent" (p=0.03). Higher OH-LIP I scores were significantly associated with English being the primary language spoken in the home (p=0.01). OH-LIP II scores were significantly associated with English being the primary language spoken in the home (p=0.006), a higher level of caregiver's education (p=0.001), private insurance (p=0.005), higher household income (p=0.006), and a more favorable assessment of the caregiver's own oral health (p=0.002). (Table 3a)

Neither child's age, caregiver's age, number of children in the household, or number of people in the household had a statistically significant correlation with dmft, REALD-30, OH-LIP I, or OH-LIP II. However, there were moderate correlations between child's age and dmft (r=0.25, p=0.051), number of children in the household with OH-LIP I scores (r=-0.24, p=0.08), and number of people in the household with OH-LIP I scores (r=-0.25, p=0.055). (Table 3b)

Each pair-wise correlation among oral health literacy instruments was statistically significant. OH-LIP I scores and REALD-30 scores were very strongly correlated with an r-value of 0.71 (p<0.001). OH-LIP II scores and REALD-30 scores were very strongly correlated with an r-value of 0.77 (p<0.001). OH-LIP I scores and OH-LIP II scores were also very strongly correlated with an r-value of 0.70 (p<0.001). Scatterplots between each pair of instruments were created to evaluate the linearity of the associations. In this dataset, there was one outlier that had very low scores on all three instruments and an additional outlier that had comparatively lower scores on all three instruments. The correlation coefficients were calculated both with and without these outliers, and the values remained relatively unchanged with the outliers' inclusion. In addition, the linear curves ("smoother") with the data point(s) removed generally followed the same shape as the linear curves with the very low data point removed, showing the linear relationship remained relatively unchanged. Consequently, it was not necessary to remove them from the data set for statistical analysis. (Table 4)

Neither the unadjusted or adjusted Poisson regression models (adjusted for insurance type and race) revealed a statistically significant association between dmft and REALD-30 scores, OH-LIP I scores, or OH-LIP II scores. Among the three oral health literacy measurements, the REALD-30 was most strongly associated with dmft: the unadjusted model had a rate ratio of 0.96 (CI=0.93,1.01) with a p-value of 0.15, and the adjusted model had a rate ratio of 0.96 (CI=0.91,1.01) with a p-value of 0.11 (Table 5)

OH-LIP I scores ranged from 13 to 35 (out of a total possible 35) with a median of 35 and mean score of 33.37 (SD=3.51). The six most commonly mispronounced items (terms) on the OH-LIP I were plaque (19% incorrect), enamel (19% incorrect), tartar (13% incorrect), regularly (11% incorrect), pediatric dentist (10% incorrect), and gingivitis (10% incorrect). More than 90% of the sample pronounced the remaining 29 items correctly. Ten items were pronounced correctly by all participants. Cronbach's alpha of OH-LIP I was 0.92 with inter-item covariance of 0.018, showing good internal reliability with the instrument. Cronbach's alpha is used to determine the level of internal consistency and reliability within an instrument. (Table 6)

OH-LIP II scores ranged from 4 to 66 (out of a total possible 70) with a median of 45 and a mean of 42.32 (SD=12.42). The OH-LIP II data showed much wider score distribution compared to OH-LIP I. The OH-LIP II terms most frequently scored as fully correct were: brush (84%), permanent teeth (74%), regularly (70%), bottle (67%), and snacks (65%). The OH-LIP II terms which were least frequently scored as fully correct were tartar (9%), sealant (12%),

plaque (14%), extraction (18%), pediatric dentist (21%), and check-up (21%). Failure to provide a fully correct definition and providing an incorrect definition are not the same, so it is also important to report the words that most frequently received incorrect definitions. The terms most frequently scored as incorrect were tartar (52% incorrect), erupt (52% incorrect), sealant (48% incorrect), primary teeth (44%), and hidden sugars (35% incorrect). (Table 6)

REALD-30 scores ranged from 7 to 30 (out of a total possible 30) with a median of 24 and mean of 22.68 (SD=4.73). The 9 most commonly mispronounced items (terms) on the REALD-30 were: apicoectomy (91% incorrect), bruxism (61% incorrect), temporomandibular (60% incorrect), gingiva (56% incorrect), analgesia (54% incorrect), maloccusion (54% incorrect), hyperemia (53% incorrect), fistula (44% incorrect), and hypoplasia (42% incorrect). The remaining 21 terms were pronounced correctly by more than 70% of caregivers. Three items were pronounced correctly by all participants; these items were smoking, floss, and brush. Cronbach's alpha of REALD-30 was 0.86 with inter-item covariance of 0.026. This shows a high level of internal consistency and reliability within the instrument. (Table 7)

DISCUSSION

The aims of this study were explore if caregivers' scores on two different oral health literacy instruments are correlated, to determine if caregivers' oral health literacy is associated with children's caries, determine demographic factors associated with low oral health literacy, and compare caregivers' reading recognition and vocabulary knowledge. Results pertaining to each of these aims are discussed below.

Comparison of Oral Health Literacy Instruments

A primary aim of this study was to investigate the correlation among these three oral health literacy instruments. This study found that the REALD-30, OH-LIP I and OH-LIP II were each very strongly correlated with one another; however, the strongest correlation was between the REALD-30 and OH-LIP II with an r-value of 0.77 (Table 5). The scatterplot also shows the relationship between the two oral health literacy instruments two be linear. The OH-LIP II and REALD-30 scores were equally correlated with OH-LIP I scores, but the OH-LIP I data was too homogenous to draw meaningful conclusions from this statistic and suggests that the OH-LIP I may not be a necessary component of the OH-LIP instrument. This finding is consistent with the results found by Richman et al.¹³

Each of these three instruments has strengths and limitations for both clinical and research purposes. The REALD-30 uses terminology which is less specific to pediatric dentistry, so the external validity may be limited in a pediatric population. Furthermore, it may not be pragmatic to ask caregivers to read 30 words aloud in a clinical setting to evaluate their oral health literacy. A favorable aspect of the REALD-30 is that it can be administered in two minutes or less in a research setting. The OH-LIP I on the other hand uses terminology which is more specific to pediatric dentistry and offers the benefit of rapid administration. Both the REALD-30 and the OH-LIP I can be administered in two to three minutes. But, this study showed that caregivers are generally able to pronounce words on the OH-LIP I correctly, regardless of their child's dmft score. This produces homogenous results that fail to indicate caregivers who may have low oral health literacy or whose children may have a higher caries risk.

The OH-LIP II uses the same items as the OH-LIP I and thus has the similar advantage of using terminology that is more specific to pediatric dentistry. It also tests an additional dimension of oral health literacy—vocabulary knowledge instead of word recognition alone. The OH-LIP II has limited clinical utility since it is not likely that a pediatric dentist would ask a parent

to read a list of words and then define the words in a clinical setting. The OH-LIP II takes approximately five to seven minutes to administer and an equal amount of time to score. As a research tool, the OH-LIP II can take significantly more time to administer but does elicit a wider distribution of results with more depth of information about the caregiver's oral health literacy.

Since word recognition may overestimate oral health literacy—as indicated by the finding that OH-LIP I scores are generally high regardless of vocabulary knowledge— the OH-LIP II may provide more depth of information about a parent's level of understanding. It is important to recognize that the ability to recognize and/or define a word does not mean that the knowledge will result in positive health behaviors. Nevertheless, it is important for pediatric dentists to consider caregivers' vocabulary knowledge during parent-practitioner interactions by providing information and verifying their understanding of the concepts or terms. Some recommendations for clinicians are to explain concepts in simple terms without the use of dental jargon and to seek feedback through questions to ensure caregivers' understanding of concepts.²⁵

Although there are more psychometrics known about the REALD-30, pediatric dental terms are unique in their focus on concepts and terms which may not be routinely used in an adult dental setting. While the correlation between the REALD-30 and the OH-LIP II is strong, the REALD-30 does not reflect the depth of caregiver understanding. Regardless of a caregivers' ability to score well on the REALD-30, limited pediatric vocabulary knowledge is of concern to practitioners since it can pose a barrier to behavior change.

Instruments' Association with dmft Scores

A second primary aim of this study was to explore the association between the REALD-30, OH-LIP I and OH-LIP with dmft scores. The dmft scores reflect the count of the number of decayes, missing or filled teeth. Count data typically follow a Poisson distribution and this was true in this study as depicted in Figure 1, most children had a dmft count of 0 or 1 with a decreasing number of children having higher dmft counts. Neither the OH-LIP I, OH-LIP II, or REALD-30 had statistically significant associations with dmft scores in either the adjusted and unadjusted Poisson regression models.

Although this study did not detect a significant association between oral health literacy scores and dmft scores, it is likely that oral health literacy still contributes to oral health behaviors and sequelae of such behaviors. A larger sample size would be necessary to draw conclusions about the association between oral health literacy scores and dmft scores. Future

studies could also consider other oral health outcomes and quality of life measures, since dmft is only one measure that reflects oral health.²⁶ For example, a person with low oral health literacy may seek dental care for preventable conditions in an emergency room setting rather than through a dental home.²⁷ This behavior carries both a cost and time burden in a setting which is not intended to deliver primary care. Future studies should explore the relationship between oral health literacy and other outcome measures while also exploring their relationship with intermediate variables such as oral health behavior. It should also seek to not only to include a larger sample, but a sample that is more heterogeneous with regard to socioeconomic status and caries status.

Word Recognition and Vocabulary Knowledge

A secondary aim of this study was to re-examine the proportion of the sample which pronounced terms OH-LIP I correctly and to explore the proportion of the population that was fully correct, partially correct, and incorrect when defining each term on the OH-LIP II. Similar to findings by Richman et al, caregivers had limited understanding of many dental terms commonly used in pediatric dentistry despite their ability to pronounce most pediatric dental terms correctly. Many of the words on the OH-LIP II have definitions which are multidimensional, so a complete definition would describe one or more of the following components: function, context, significance, or purpose of a particular vocabulary term. Caregivers frequently provided definitions which were not incorrect, but due to the lack of depth in the information provided, were scored as partially correct.

During the course of scoring the OH-LIP II, it was difficult to ascertain whether the caregivers had a limited understanding of the concept or whether they felt a brief definition was sufficient for the purpose of the study. Tooth is an example of a word which many people are likely to understand; however, they may not be able to describe the composition or function of a tooth well enough to receive a fully correct score. The distribution of fully correct, partially correct, and incorrect responses are shown quantitatively in Figure 11. Although this was not intended to be a qualitative study, there were some common themes that emerged when reviewing the OH-LIP II recordings. These are described in the Clinical Relevance section and are likely to be the most translational aspect of this study for individual practitioners. Future research could explore common incorrect definitions to quantify specific misconceptions among caregivers for specific terms. It is important for pediatric dentists to be aware of these common

misconceptions since a caregiver's misunderstanding can have serious medico-legal consequences or prevent translation of knowledge into healthy behaviors.

In regards to the OH-LIP I, all eight of the most frequently mispronounced terms in the Richman et al sample were among the most commonly mispronounced terms in this study's sample. These include teething, gingivitis, enamel, abscess, erupt, general anesthesia, and regularly. Furthermore, Richman et al found that only seven of the 35 words were scored as fully correct by more than half of the sample while eight terms were scored as fully correct by more than half of this study's sample. This shows reasonable consistency between the two studies. The only difference in concordance was that our sample did not define extraction correctly a majority of the time, while Richman's study did not define brush or snacks correctly a majority of the time.

A majority of the variance in participants' total scores on both the REALD-30 and the OH-LIP I resulted from mispronunciation in a relatively small number of dental terms. It is likely that shortening the instruments or evaluating a caregiver's ability to pronounce certain words would have the same utility as asking caregivers to pronounce the full list of words. Specifically, it may be possible to select a few key words in each instrument that have a high positive predictive value for having a child with decayed, missing, or filled teeth.

Although it is important to educate caregivers about these commonly used terms in pediatric dentistry, it is more important for providers to modify word choice and avoid dental jargon, simplify explanations, and tailor messages to parents. ²⁵ Caregivers that seek or require more technical information may ask for an alternative explanation at which point the provider can alter the message to meet the expanded needs of the caregiver. The use of visual aids and pictograms can also be helpful in communicating key messages to caregivers. Many caregivers are unable to carry out simple tasks, such as placing the proper amount of toothpaste on a toothbrush, even though they can describe the proper amount using terms recommended by a dentist. ²⁶ Visual aids and pictograms may help caregivers understand difficult concepts.

Associations between Caregivers' Demographics, Oral Health Literacy and Children's Caries Status

Information collected in the demographic and dental utilization survey aimed to describe the study sample and compare factors which are thought to influence caries status and oral health literacy. The study sample, though small, was diverse in many factors. The Seattle population is 70% Caucasian, 14% Asian, 8% Black or African American, 5% biracial. This study sample was 46% Caucasian, 18% Asian, 12% Black or African American, and 12% biracial. Forty-seven percent of this sample had a bachelor's degree compared to 56% of the Seattle population. Seventeen percent of this sample did not speak English in the home compared to 20% of the Seattle population. This shows similar demographic characteristics between the study sample and the Seattle population based on these characteristics.

dmft as a continuous variable was not strongly associated with many demographic or utilization characteristics. This lack of association as likely attributed to the wide variance of dmft scores or attributed to the small sample size. Primary language spoken in the home was strongly associated with REALD-30, OH-LIP I, and OH-LIP II scores. Households where English was the primary language spoken in the home had significantly higher oral health literacy scores. This suggests that non-English speaking, bilingual, or English as second language families may have a more difficult time reading and understanding dental terminology in an English-speaking clinical setting. Although the instruments are intended to be used with English-proficient individuals, these findings still suggest pragmatic challenges in communication when there is a difference between patient and provider languages.

Factors associated with higher socioeconomic status were generally related to having higher oral health literacy scores. The characteristics associated with increased word recognition (REALD-30) and vocabulary knowledge (OH-LIP II) include caregivers who are English-speaking, have higher education levels, earn higher incomes, have private insurance, and perceive a higher oral health status for themselves and their children; however, these associations were not significant with the OH-LIP I. The only demographic factors associated with dmft scores were Hispanic ethnicity and caregiver's report of the child's oral health. Specifically, caregivers of Hispanic or Latin descent or who report their child as having "very good or excellent" oral health are more likely to have children with low dmft scores. Because the majority of our sample was recall/recare patients rather than new patients, this association may be subject to recall bias from knowledge obtained during previous visits.

Limitations

Although the power analysis indicated that 82 pairs were needed to detect a moderate correlation (r=0.3) between any two of the three oral health literacy assessments, only 57 caregiver-child pairs were enrolled during the time available for enrollment. Despite the smaller sample, the associations among the oral health literacy instruments were strong and statistically

significant (r \geq 0.7; p<0.001). It is unlikely that a larger sample size would have affected the Pearson statistics. The primary limitation of the small sample size is the higher probability of failing to detect a statistically significant difference or association in when there may be one. This limitation may have constrained the Kruskal-Wallis and regression analyses.

A primary limitation of this study is that participants were drawn from a relatively small convenience sample in one clinical setting. In order for the findings to be representative of a broader population, this study would need a larger sample and broader demographics. Selection bias was not likely to be a contributing factor in this study since only five caregivers chose not to participate in the study after reviewing consent, and no consenting participants dropped out after enrolling. Additionally, studies carried out in clinical settings do not capture information about people that do not seek dental care. This study describes only children aged 3 to 6. While some may see this as having limited generalizability, it is the primary age range of interest since the primary caregiver oversees the oral health practices of these children.

In certain unavoidable circumstances, interviews were conducted during or after the child's clinical examination due to clinical constraints, such as the patient and caregiver arriving with insufficient time to complete the research protocol prior to the appointment. In some cases, two caregivers escorted the patient to the appointment, so the person primarily responsible for home care was asked to participate while the other caregiver remained with the patient during the course of the clinical exam. Although this occurrence was not tracked, it is estimated that it occurred in fewer than ten cases.

There are some limitations to the methodology for dmft documentation data. Although there are efforts to diagnose and record dmft in a standardized fashion, there is some variability in the providers' diagnoses. That is, there may be some disagreement between whether a tooth is carious. Ideally, dmft scoring would be completed by one or two practitioners, but this was not a plausible option in this clinic setting. Efforts to overcome this challenge were undertaken by introducing the purpose and methods of this study to all pediatric dental residents prior to beginning the study. Initially, this study aimed to record dmfs and dmft; however, there is much wider variability and opportunity for misclassification with dmfs than there is for dmft. For example, a large two-surface carious lesion on a primary first molar may receive a stainless steel crown rather than a two-surface intracoronal restoration. A stainless steel crown would yield a dmfs of 5 for that tooth when only 2 surfaces were carious. If dmft were used, the data would be unaffected by the difference in treatment approaches. Furthermore, dmft is more

conventionally referenced and easily interpreted in the literature. It is likely unnecessary to exclude patients who have dental treatment under general anesthesia or sedation if using dmft (rather than dmfs) since this is a population of particular interest given their high caries risk. For this reason, the exclusion of children with a history of general anesthesia or moderate sedation was not a concern. Despite its limitations, dmft still offers the benefit of being a more specific outcome measure than the caries severity scale.

At this time, there are no published user's manuals for the REALD-30 or OH-LIP so information about scoring these instruments was obtained directly from the developers of the instruments. This introduces the possibility for variability in the scoring of the REALD-30, OH-LIP I, and OH-LIP II between studies. Nevertheless, the purpose of this study is not to compare the REALD-30, OH-LIP I, or OH-LIP II scores with previous studies' findings. The most important factor was establishing inter and intra-rater reliability, which was established at greater than 90% concordance. Deviations from agreement generally resulted when the person has a foreign accent, hesitated in pronouncing the word, or pronounced the word correctly after mispronouncing the word the first time.

The primary limitations in the data analysis are the possibility for residual confounding or confounders that were not included in the adjusted Poisson model. Given the number of statistical tests performed in this study, there is the possibility that we found a statistically significant association in five percent of analyses due to random chance. While the assumption is that caregivers respond truthfully and accurately when responding to guestions on the demographic and dental utilization survey, there is the possibility for incorrect or incomplete information which would affect the quality of the information and statistics. The opportunity for misinformation with self-reported information is a shortcoming of survey methodology. This study was also subject to the constraint of only one caregiver providing all survey information and participating the oral health literacy assessment. Although one can hypothesize that the caregiver primarily responsible for home care is the person escorting the child to their appointment, this is not always the case. When more than one caregiver escorted the child to the appointment, the person who primarily oversees brushing at home was asked to participate in the study. This is also important to consider in the case of custodial/adoptive parents since the oral health of child may be reflective of past home behavior and may not be reflective of the current caregiver's oral health literacy.

Given the cross-sectional nature of this study, we cannot infer temporality or a causal relationship between oral health literacy and caries status. Caregivers of children with previous dental encounters (preventive, restorative, or emergency) will likely have elevated oral health literacy scores as a result of increased interaction with dental professionals. Therefore high oral health literacy among caregivers may be found in children with low levels of decay as well as children with a high number of restored or missing teeth.

Future Directions and Contribution to the Literature

Previous research on oral health literacy primarily addressed instrument development, the readability of patient education materials, and the association between oral health literacy scores and self-reported characteristics using tools such as the Oral Health Impact Profile (OHIP-14). This study is the first to compare the REALD-30 and the OH-LIP I and II. Since the OH-LIP is a pediatric specific instrument, it is important to see how the results compare to the REALD-30 since it was validated with oral health severity scale in a sample of pediatric patients. Future directions called for an evaluation of REALD-30 with a more specific measurement of oral health, such as the dmft, which was the underlying motivation for this study. Furthermore, this study is the second to use the OH-LIP and one of the first to use the REALD-30 outside of the team of researchers that developed the instrument. To expand the utility of the instrument, we recommend that developers of the OH-LIP and REALD-30 create a user's manual to improve the usability and consistency of these instruments for research purposes.

There are some key issues which emerged over the course of this study and should be addressed by future research. First, qualitative studies which measure the frequency of themes provided in caregivers' definitions can expound common misperceptions or misunderstandings. Second, it is important to provide caregivers with correct pronunciations and definitions for the dental terms used in the REALD-30 and OH-LIP I and II at the completion of the interview. There are strong ethical implications if caregivers' misperceptions are not corrected. Clarification can be provided both verbally and in writing. Third, the OH-LIP II should include follow-up questions about each dental term to probe for breadth and depth of vocabulary knowledge. Simply asking what a term means can underestimate a caregiver's true oral health literacy.

To establish temporality between oral health literacy and caries experience, one would need to conduct a longitudinal study which compares the caries experience of children of firsttime parents with high oral health literacy against those with low baseline oral health literacy. If groups were formed prior to the children's first dental visit, this would control for dental experience since frequent pediatric dental experiences can be both the cause and the result of high oral health literacy. This is based on the premise that high oral health literacy can be a preventive factor that leads children to have good oral health, or high oral health literacy can be the result of frequent dental encounters.

Clinical Implications

While the results of this study have implications for future research, there are also significant implications for clinicians in practice. First, the finding that word recognition tends to overestimate oral health literacy suggests that clinicians must be aware of the potential for low oral health literacy, even if a person is able to pronounce words correctly. Using evidence-based techniques such as focusing on only a few simple messages, seeking confirmation of caregiver understanding through basic questions, avoiding dental jargon not widely understood by the public, and using visual aids to support information, clinicians may be able to tailor messages to an appropriate level. ^{25,26} If caregivers do not understand the information provided by a dentist, then it is unlikely that they will be able to apply that knowledge into behavior.

Although the purpose of this study was not to analyze errors in caregivers' understanding, a few terms were missed frequently and these deserve additional attention, especially by dental providers who communicate with caregivers on a daily basis. These terms and common misunderstanding are enumerated below:

- 1. Many caregivers confused plaque and tartar (calculus).
- 2. Few caregivers fully understood that sealants are placed on the occlusal surfaces of posterior teeth (or other pits/fissures) to reduce the risk of caries in these teeth.
- Many caregivers confused sealants with fluoride varnish. They did not fully understand
 that fluoride varnish is professionally applied high-strength fluoride used to prevent
 dental caries.
- 4. Few caregivers described why a tooth may need to be extracted; that is they did not recognize it as an intervention for teeth that are carious, malpositioned, etc.
- 5. Few caregivers described the scheduled and preventive nature of a check-up. Many referred to a check-up as merely a visit to the dentist.
- 6. Few caregivers recognized a pediatric dentist as a dentist who receives specialized training beyond dental school for the care of children and adolescents. Consequently, they only received partial credit.

- 7. Caregivers commonly thought primary teeth were "front teeth" or thought primary teeth and permanent teeth were the same.
- 8. Many caregivers attributed erupt to "being like a volcano"— something abnormal or pathologic without recognizing it as a normal stage of tooth emergence from the gingiva.
- 9. Many caregivers failed to attribute abscess to an infectious process.
- 10. Many caregivers described floss as something used to remove food from between the teeth without understanding the purpose of preventing caries and periodontal disease and without understanding the need for regular flossing.
- 11. Although most caregivers attributed a filling to "fixing cavities," they did not describe the process of removing infected tooth structure and restoring the tooth with a filling material.
- 12. Few caregivers understood the reasons why a stainless steel crown (silver cap) would be necessary for a tooth, i.e., extensive caries or tooth breakdown.
- 13. Many caregivers described fruits as having hidden sugars and having a high sugar content, which suggests that they believe fruits have highly cariogenic properties.
- 14. Many caregivers were confused about the multiple factors that lead to tooth decay—such as diet, hygiene, bacteria, saliva, etc.
- 15. Many caregivers thought that general anesthesia was a locally acting agent.

Although it is important for caregivers to understand these terms based on the premise that knowledge influences behavior, it is also important for caregivers to understand these terms when giving informed consent for treatment. If a caregiver has a limited understanding of certain terms, then informed consent is incomplete and can carry significant medico-legal implications for the dental team.

Implications for the Relationship between Oral Health Literacy and Children's Oral Health

The Institute of Medicine's conceptual model illustrates that culture/society, the healthcare system, and education system each affect oral health literacy. The results of this study support the idea that oral health literacy is multifactorial and influenced by each of these domains. The IOM model posits that oral health literacy affects knowledge, attitudes, and behaviors which ultimately determine oral health. It is important to recognize that oral health literacy is only one contributing factor to oral status. There are many other individual, cultural, and societal factors that affect children's oral health. Although this study did not identify a significant association between oral health literacy and dmft scores, caries status is only one

outcome of interest. We did not explore other outcome variables, such as the oral health related quality of life or health behavior which may be equally meaningful as dmft. Additional research is needed to explore factors that affect the association between oral health literacy and children's oral health. If oral health literacy if found to be an additional correlated of socioeconomic status, then efforts to reduce disparities in oral health and to increase oral health literacy offer potential options for intervention.

Our current ability to measure oral health literacy is constrained by the limitations of instruments available. It is likely that further investigation, modification, and development of novel oral health literacy instruments will increase their validity. Measuring multiple elements of oral health literacy can be time intensive, so using tools that are valid but still brief is important. Additional research can explore correlates of oral health literacy which may be used as a proxy to screen for individuals with low oral health literacy. If these correlates have a strong relationship with oral health literacy, then demographic information which is routinely collected in dental clinics may alert dental providers of the need to spend additional time providing oral health information.

CONCLUSIONS

- 1. The REALD-30 and the OH-LIP II may have wider internal and external validity than the OH-LIP I given their strong correlation and association with numerous demographic/dental characteristics known to be associated with oral health literacy.
- 2. A larger sample size is needed to explore the association between oral health literacy and children's caries status.
- 3. Characteristics generally associated with increased word recognition and vocabulary knowledge include caregivers who are English-speaking, have higher education levels, earn higher incomes, have private insurance, and perceive a higher oral health status for themselves and their children.
- 4. The OH-LIP II offers a deeper understanding of caregivers' oral health literacy than word recognition instruments, as demonstrated by caregivers who frequently had an incorrect or incomplete understanding of common dental terms, despite their ability to pronounce them correctly.
- 5. Pediatric dentists should be aware of oral health literacy levels and appropriately tailor oral health messages, avoid dental jargon, seek feedback, and use visual aids.
- Oral health literacy is a key component of informed consent. Failure to ensure caregivers' understanding of dental procedures can have serious severe medico-legal implications.
- 7. Caregiver oral health literacy is related to behavior which can affect children's oral health and caries experience, but additional research is needed to explore other factors which may influence this relationship, such as caregiver education and socioeconomic factors.

TABLES

Table 1. Child and Caregiver Demographics and Household Chara	
	<u>N (%)</u>
Child's gender	
Male	25 (43.9%)
Female	32 (56.1%)
Caregiver's gender	
Male	17 (29.8%)
Female	40 (70.2%)
Caregiver's relationship to child	
Father	16 (28.1%)
Mother	38 (66.6%)
Other	3 (5.3%)
Caregiver's ethnicity	
White/Caucasian	26 (45.5%)
Black or African American	7 (12.3%)
Asian	10 (17.6%)
Other	7 (12.3%)
Mixed	7 (12.3%)
Hispanic or Latin descent	
Yes	12 (21.1%)
No	45 (78.9%)
Primary language(s) spoken in the home	
English	42 (73.6%)
Spanish	4 (7.0%)
English and Other	5 (8.8%)
Only other	6 (10.5%)
Caregiver's education	
Less than high school	2 (3.5%)
High school/GED	10 (17.5%)
Some college or vocational training	18 (31.6%)
4-year college degree	16 (28.1%)
Graduate or professional schooling	11 (19.3%)
Child's primary insurance type	
Public	31 (54.4%)
Private	26 (45.6%)
Caregiver's marital status	
Married	37 (64.9%)
Living with a partner	10 (17.5%)
Widowed, divorced, or separated	3 (5.3%)
Never married	7 (12.3%)

Household income	
\$19,999 or less	11 (19.3%)
\$20,000 - \$39,999	11 (19.3%)
\$40,000 - \$59,999	10 (17.5%)
\$60,000 - \$79,999	6 (10.5%)
\$80,000 - \$99,999	3 (5.3%)
\$100,000 or more	12 (21.1%)
Prefer not to answer	4 (7.0%)
	Mean (SD)
Caregiver's age (years)	35.23 (7.92)
Child's age (years)	4.57 (1.02)
Household size	4.03 (1.27)
Number of children living in the home	2.22 (1.09)
Interview time	9 min,17 sec (47 sec)

Table 2. Child and Caregiver Past Dental Utilization and Self-Reported Oral Health Characteristics (N=57)

	<u>N (%)</u>
Caregiver's assessment of child's oral health	
Poor	2 (3.5%)
Fair	12 (21.1%)
Good	22 (38.5%)
Very Good	16 (28.1%)
Excellent	5 (8.8%)
History of child's last dental visit	
Never	5 (8.8%)
More than 1 year	5 (8.8%)
1 year or less	47 (82.4%)
Reason for child's previous dental visit(s)*	
Exam or cleaning (including sealants)	54 (94.7%)
Treatment	18 (31.6%)
Infection/toothache	5 (8.8%)
Trauma	2 (3.5%)
Caregiver's assessment of own oral health	
Poor	6 (10.5%)
Fair	10 (17.5%)
Good	27 (47.4%)
Very Good	11 (19.3%)
Excellent	3 (5.3%)
History of caregiver's last dental visit	
Never	1 (1.8%)
More than 3 years	8 (14.3%)
More than 2 but ≤ 3 years	2 (3.6%)
More than 1 but ≤ 2 years	11 (19.6%)
≤ 1 year	34 (60.7%)
Reason for caregiver's previous dental visit(s)*	
Exam or cleaning (including sealants)	56 (98.3%)
Treatment	44 (77.2%)
Infection/toothache	10 (17.5%)
Trauma	5 (8.8%)
Examination type	
New patient exam	16 (28.1%)
Recall exam	41 (71.9%)
Source of dmft data	
Clinical exam only	18 (31.6%)
Clinical and radiographic exams	39 (68.4%)
*More than one option may be selected	

	dmft	REALD-30 Scores	OH-LIP I Scores	OH-LIP II Scores
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Overall	3.98 (4.94)	22.68 (4.73)	33.37 (3.51)	42.32 (12.42
Child's dmft score†				
0	-	23.76 (4.35)	33.92 (1.96)	43.76 (12.17
1 to 5	-	22.08 (4.66)	32.83 (3.24)	39.00 (13.64
6 to 10	-	20.92 (6.42)	32.00 (6.28)	41.17 (15.46
11 to 20	-	22.88 (2.30)	33.37 (3.51)	44.50 (4.92)
p-value	-	0.44	0.65	0.88
Child's gender**				
Male	4.56 (5.80)	22.20 (5.18)	32.72 (4.74)	41.48 (14.47
Female	3.53 (4.20)	23.01 (4.40)	33.88 (2.08)	42.97 (10.75
p-value	0.46	0.51	0.26	0.67
Caregiver's gender**				
Male	5.58 (6.31)	22.94 (5.88)	32.06 (5.56)	39.18 (14.10
Female	3.3 (4.13)	22.58 (4.24)	33.93 (1.99)	43.68 (11.56
p-value	0.18	0.82	0.19	0.25
Caregiver's ethnicity†	_			
White/Caucasian	4.23 (4.97)	24.54 (2.90)	34.46 (1.14)	46.69 (8.06)
Black or African American	3.57 (4.69)	20.71 (7.63)	30.43 (7.96)	34.71 (16.39
Asian	6.00 (6.67)	23.40 (4.67)	32.70 (3.50)	43.70 (14.98
Other	2.43 (3.64)	20.71 (4.99)	32.71 (2.87)	37.29 (13.94
Mixed	2.14 (2.97)	18.71 (3.86)	33.86 (1.77)	36.71 (12.24
p-value	0.72	0.02*	0.16	0.13
Hispanic or Latin descent**				
Yes	1.83 (2.59)	22.25 (4.45)	33.42 (2.35)	43.38 (12.33
No	4.56 (5.27)	22.80 (4.85)	33.36 (3.78)	38.33 (12.43
p-value	0.02*	0.71	0.94	0.22
Primary language(s) spoken in the home**				
English only	3.81 (4.54)	23.88 (3.69)	34.45 (1.04)	45.67 (9.59)
Bilingual or non-English	4.47 (6.07)	19.33 (5.78)	30.33 (5.73)	32.93 (14.82
p-value	0.71	0.01*	0.01*	0.006*
Caregiver's education+				
High school/GED or less	3.83 (3.74)	19.42 (5.63)	31.58 (6.21)	31.58 (12.69
Some college or vocational training	4.56 (5.02)	22.89 (4.46)	33.83 (1.95)	43.00 (10.47
1 year callege degree	2.94 (4.55)	23.38 (24.91)	33.56 (2.90)	42.69 (10.36
4-year college degree	2.01 (1.00)		,	,

Child's primary insurance type**				
Medicaid	4.29 (4.38)	21.23 (5.20)	32.81 (4.46)	38.26 (13.11)
Private	3.62 (5.61)	24.42 (3.54)	34.04 (1.71)	47.15 (9.72)
p-value	0.62	0.008*	0.16	0.005*
Caregiver's marital status†				
Married	3.89 (5.09)	22.11 (5.29)	32.81 (4.18)	42.51 (14.22)
Living with a partner	3.70 (4.16)	24.50 (3.44)	34.10 (1.60)	41.80 (7.45)
Widowed, divorced, or separated	5.33 (6.11)	23.33 (4.16)	34.67 (0.58)	40.33 (12.58)
Never married	4.29 (5.64)	22.86 (3.13)	34.71 (0.76)	42.86 (9.39)
p-value	0.94	0.60	0.32	0.87
Household income†				
\$39,999 or less	4.77 (4.51)	20.36 (5.21)	32.55 (4.92)	36.18 (12.70)
\$40,000 - \$79,999	3.19 (4.59)	23.63 (3.91)	33.25 (2.98)	41.75 (11.45)
\$80,000 or more	2.20 (4.06)	25.20 (3.55)	34.40 (0.91)	49.6 (9.23)
p-value	0.09	0.004*	0.67	0.006*
Caregiver's assessment of child's oral health†				
Poor/Fair	7.43 (5.50)	21.57 (3.80)	33.79 (1.80)	41.57 (8.94)
Good	5.14 (4.85)	21.50 (5.34)	32.55 (5.20)	39.41 (14.94)
Very Good/Excellent	0.48 (1.12)	24.67 (4.10)	33.95 (1.69)	45.86 (11.07)
p-value	<0.001*	0.02*	0.99	0.30
Child's last dental visit†				
Never	4.60 (5.55)	23.40 (2.70)	34.80 (0.45)	37.20 (9.01)
More than 1 year	1.60 (3.58)	18.00 (5.48)	32.2 (3.03)	37.00 (11.81)
1 year or less	4.17 (5.02)	23.11 (4.63)	33.34 (3.72)	43.43 (12.70)
p-value	0.34	0.10	0.14	0.20
Caregiver's assessment of own oral health+				
Poor/Fair	4.63 (4.94)	23.19 (4.52)	33.63 (1.93)	39.94 (10.87)
Good	3.96 (5.30)	21.19 (5.05)	32.70 (4.72)	38.70 (12.99)
Very Good/Excellent	3.29 (4.46)	25.00 (3.33)	34.36 (1.50)	52.00 (7.45)
p-value	0.90	0.03*	0.23	0.002*
Caregiver's last dental visit**				
More than 1 year	3.59 (4.54)	22.14 (4.81)	33.32 (2.73)	39.45 (12.12)
1 year or less	3.97 (5.07)	23.09 (4.78)	33.35 (4.01)	44.06 (12.62)
p-value	0.77	0.47	0.96	0.18
Examination type**				
New patient exam	4.63 (5.74)	22.50 (3.28)	34.31 (1.35)	40.50 (10.7)
Recall exam	3.73 (4.65)	22.76 (5.22)	33.00 (4.01)	43.02 (13.08)
p-value	0.58	0.83	0.07	0.46

^{*} Statistically significant at the alpha = 0.05 level
** Two-sample t-test with unequal variance
†Kruskal-Wallis non-parametric one-way analysis of variance

Table 3b. Pearson Correlations between Continuous Demographic Variables and Outcome Measures

	dmft		REALD-30 Scores		OH-LIP I Scores		OH-LIP II Scores	
	Correlation	<u>p-value</u>	Correlation	<u>p-value</u>	Correlation	p-value	Correlation	<u>p-value</u>
Child's age	0.25	0.051	0.06	0.65	-0.10	0.46	0.09	0.52
Caregiver's age	0.03	0.80	0.18	0.19	0.03	0.79	0.18	0.19
# of children in household	0.13	0.32	-0.12	0.37	-0.24	0.08	-0.18	0.18
# of people in household	0.01	0.57	-0.13	0.35	-0.25	0.055	-0.16	0.23

Table 4. Pearson Correlations between Oral Health Literacy Instruments

	REALD-3	0 Score	OH-LIP	I Score
	Correlation p-value		<u>Correlation</u>	<u>p-value</u>
OH-LIP I Score	0.71	<0.001*		
OH-LIP II Score	0.77	<0.001*	0.70	<0.001*

^{*}Statistically significant at the alpha = 0.05 level with Bonferroni adjustment

Table 5. Association between Child dmft and Caregiver Oral Health Literacy Scores*

	dmft (Crue	de)	dmft (Adjus	sted**)
	RR (95% CI)	<u>p-value</u>	RR (95% CI)	<u>p-value</u>
REALD-30 Score	0.96 (0.93,1.01)	0.15	0.96 (0.91,1.01)	0.11
OH-LIP I Score	0.99 (0.93,1.05)	0.76	0.99 (0.93,1.05)	0.72
OH-LIP II Score	1.00 (0.98,1.02)	0.76	1.01 (0.98,1.03)	0.63

^{*} Poisson regression with robust standard errors
**Adjusted for insurance type (private vs. public) and race (White vs. non-white)

Table 6. Percentage of Correct Responses on OH-LIP I and OH-LIP II

	OH-LIP I:* Word Recognition	OH-LIP II:** Vocabulary Knowledge			
Dental Term	Correct (%)	Fully Correct (%)	Partially Correct (%)	Incorrect (%)	
Brush	100	84	14	2	
Bottle	100	67	24	9	
Snacks	100	65	28	7	
Germs	100	50	39	11	
Floss	100	49	47	4	
Cavities	100	40	48	12	
Bacteria	100	39	52	9	
Infection	100	35	35	30	
Silver cap	100	30	40	30	
Check-up	100	21	77	2	
Permanent teeth	98	74	12	14	
Filling	98	46	42	12	
Acid	98	44	30	26	
Primary teeth	98	40	16	44	
Tooth	98	25	54	21	
Extraction	98	18	73	9	
Decay	97	37	38	25	
Numb	97	37	59	4	
Fluoride varnish	97	35	40	25	
Erupt	97	32	16	52	
Inflammation	97	28	58	14	
Pea-sized amount	95	61	25	14	
Discoloration	95	55	33	12	
Abscess	95	48	26	26	
General anesthesia	95	40	32	28	
Sealant	95	12	40	48	
Teething	93	61	28	11	
Saliva	91	49	44	7	
Hidden sugars	91	42	23	35	
Gingivitis	90	32	40	28	
Pediatric dentist	90	21	75	4	
Regularly	89	70	26	4	
Tartar	87	9	39	52	
Enamel	81	26	48	26	
Plaque	81	14	58	28	

^{*}Cronbach's alpha for OH-LIP I: inter item covariance = 0.018, scale reliability coefficient = 0.92

^{**}Cronbach's alpha for OH-LIP II: inter item covariance = 0.12, scale reliability coefficient = 0.92

Table 7. Percentage of Correct Respons	es on REALD-30
<u>Dental Term</u>	Word Recognition <u>Correct (%)</u>
Smoking	100
Floss	100
Brush	100
Sugar	98
Fluoride	98
Extraction	98
Pulp	96
Braces	96
Restoration	96
Denture	95
Genetics	93
Abscess	93
Sealant	91
Plaque	86
Caries	83
Enamel	79
Dentition	79
Halitosis	79
Incipient	77
Periodontal	74
Cellulitis	72
Hypoplasia	58
Fistula	56
Hyperemia	47
Malocclusion	46
Analgesia	46
Gingiva	44
Temporomandibular	40
Bruxism	39
Apicoectomy	9

^{*}Cronbach's alpha for REALD-30: inter item covariance = 0.026, scale reliability coefficient = 0.86 $\,$

FIGURES

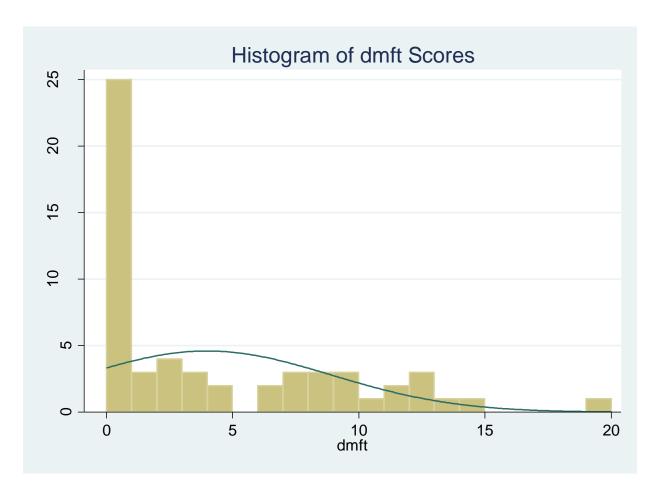


Figure 1. Histogram of dmft Scores

Summary of dmft Histogram Distribution (N=57)	
Decayed, missing, and filled teeth (dmft)	<u>N (%)</u>
0	25 (43.8%)
1 to 5	12 (21.1%)
6 to10	12 (21.1%)
11 to 20	8 (14.0%)

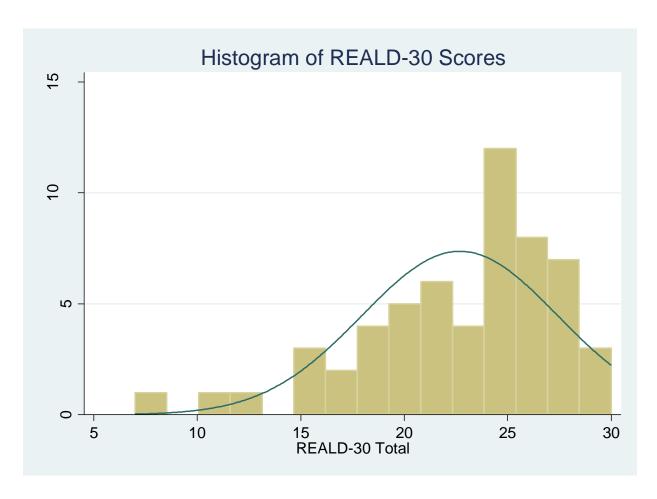


Figure 2. Histogram of REALD-30 Scores

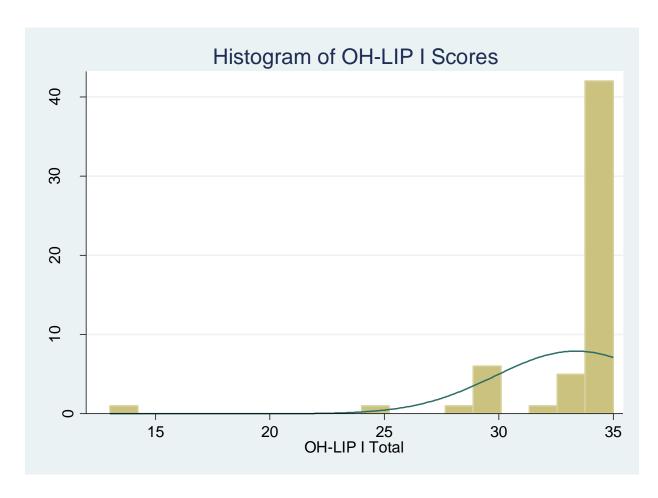


Figure 3. Histogram of OH-LIP I Scores

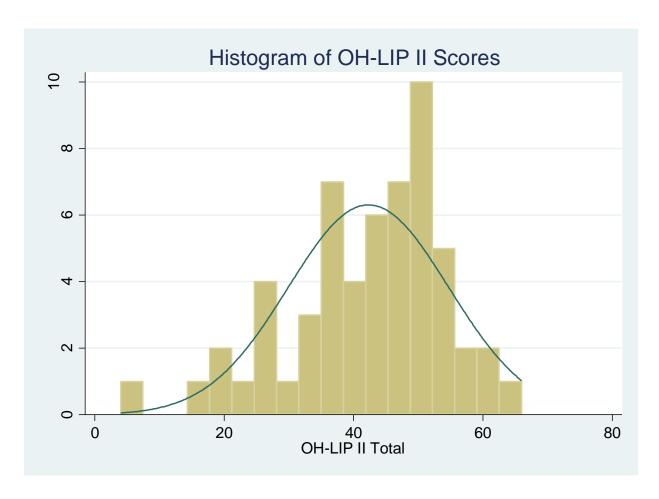


Figure 4. Histogram of OH-LIP II Scores

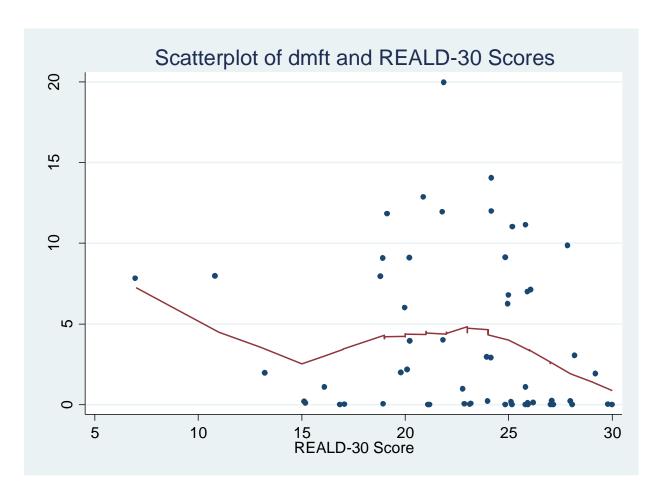


Figure 5. Scatter plot of dmft and REALD-30 Scores, with Lowess smoother

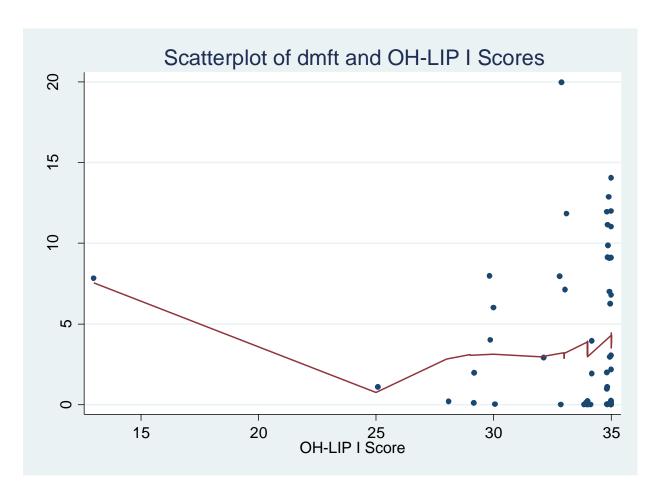


Figure 6. Scatter plot of dmft and OH-LIP I Scores, with Lowess smoother

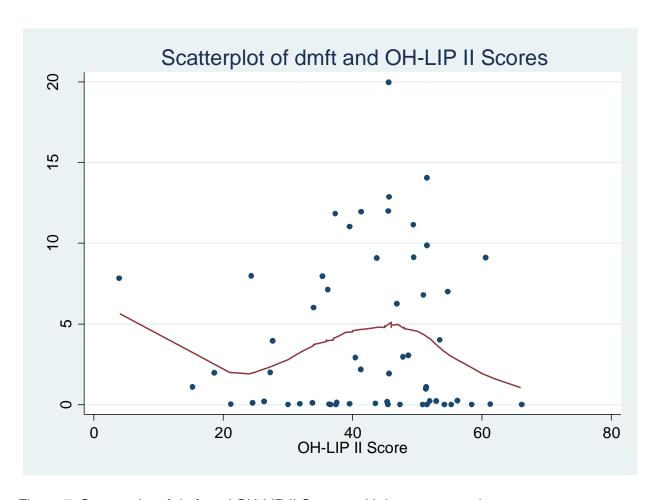


Figure 7. Scatter plot of dmft and OH-LIP II Scores, with Lowess smoother

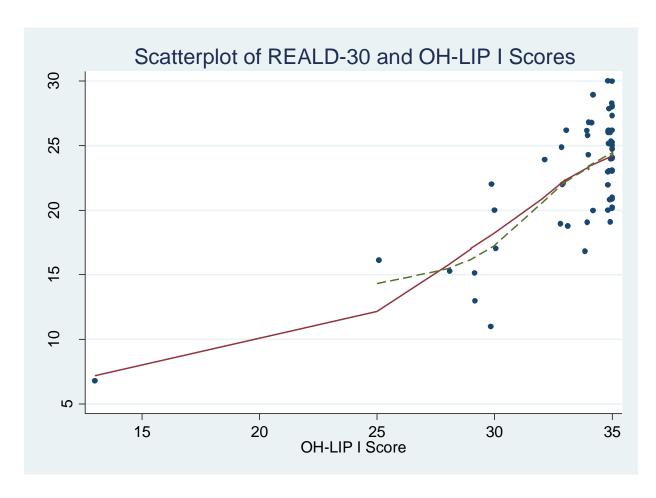


Figure 8. Scatterplot of REALD-30 and OH-LIP I Scores

Dashed line represents Lowess smoother with outlier removed

Solid line represents Lowess smoother with outlier included

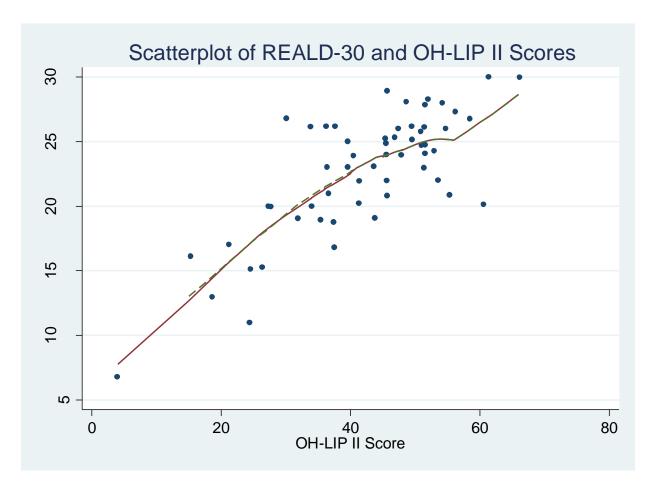


Figure 9. Scatterplot of REALD-30 and OH-LIP II Scores

Dashed line represents Lowess smoother with outlier removed

Solid line represents Lowess smoother with outlier included

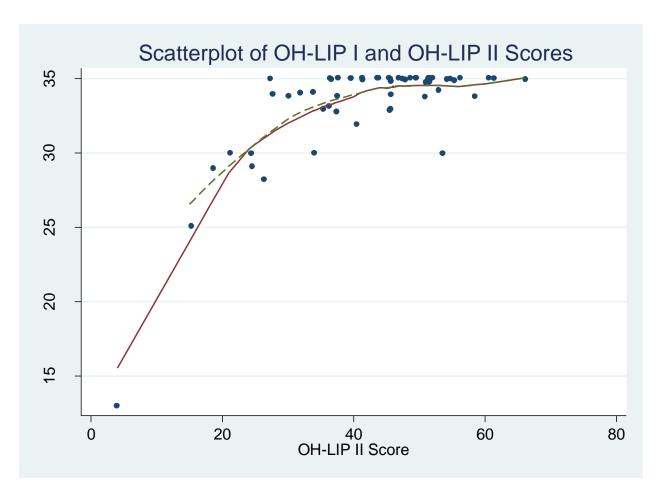


Figure 10. Scatterplot of OH-LIP I and OH-LIP II Scores

Dashed line represents Lowess smoother with outlier removed

Solid line represents Lowess smoother with outlier included

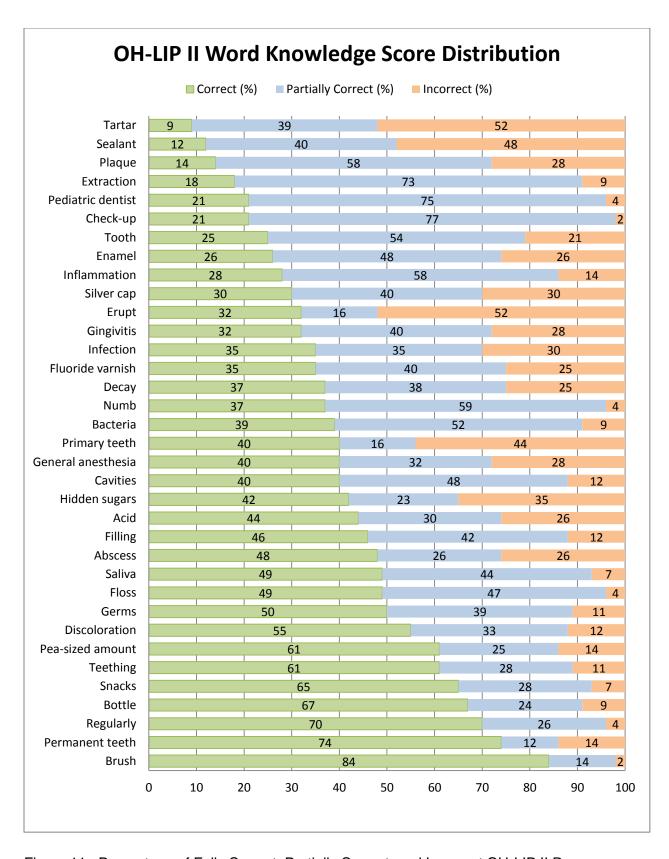


Figure 11. Percentage of Fully Correct, Partially Correct, and Incorrect OH-LIP II Responses

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Appendix I Study Procedure Flow Sheet

Prior to Appointment

- ✓ Review Axium on a weekly basis for study subjects who meet the primary inclusion criteria.
- ✓ Two days prior to scheduled appointments, call caregivers of patients who meet the primary inclusion criteria, and read the telephone script.
- ✓ If no one answers, do not leave a message; attempt to call again one day prior to their appointment.
- ✓ If the family is willing to participate, ask the family to arrive to the dental clinic 25-30 minutes prior to their scheduled appointment.
- ✓ Enter the patient's electronic record number in the "Patient Identifier" excel spreadsheet and assign a Study ID number.

Day of Appointment

- ✓ Meet patient and caregiver in the clinic lobby 25-30 minutes prior to their appointment.
- ✓ Notify the front desk that the patient is a study participant.
- ✓ Escort caregiver and patient to the consultation room and review the secondary inclusion criteria.
- ✓ If secondary inclusion criteria are met, obtain informed consent.
- ✓ If family consents, proceed with demographic survey followed by the recorded interview.
- ✓ Begin and end the recorded interview by verbally identifying the study ID number.
- ✓ After the interview is complete, inform the front desk that the patient is ready for his or her examination.
- ✓ Escort the caregiver and patient to the clinic area for the clinical exam.
- ✓ Ask provider to enter all decayed, missing, and filled surfaces/teeth in the odontogram within 24 hours.

After appointment

- ✓ Access the "Patient Identifier" spreadsheet to identify the electronic chart number corresponding to the patient.
- ✓ Review the electronic record to determine dmft data.
- ✓ Transfer the digital recording of the interview to the secured folder and rename the file based on the study ID number.
- ✓ Listen to the recording and score the OH-LIP I, OH-LIP II, and REALD-30 utilizing predetermined scoring criteria.
- ✓ Transfer all demographic and interview responses/scores to the dataset spreadsheet (which only contains study ID number and no electronic chart numbers).
- ✓ Store all patient documentation in secured file drawers.
- ✓ Select a random subset of patient to determine inter-rater and intra-rater reliability.

Appendix II Telephone Recruitment Script

"Hello, my name is [Study Staff Name], and I am a [Title] at the University of Washington's Center for Pediatric Dentistry. May I speak to [Prospective Subject's Caregiver's Name]?"

If caregiver is available, continue:

"Hi [Caregiver's Name], this is [Study Staff Name], I am contacting you because your child has an appointment at the University of Washington Center for Pediatric Dentistry on [Date]. You and your child may be eligible to participate in a research about parents' dental knowledge and children's cavities. Would you be willing to learn more about the study?"

If no, thank the caregiver for their time. If yes, continue.

"Is this a convenient time for you to hear more about the study?"

If no, ask for a better time to call back. If yes, continue.

"First, let me start by providing some information about the study.

The purpose of this study is to determine if cavities and caregivers' dental knowledge are related. We also hope to test new ways of assessing a caregiver's dental knowledge since this has not been studied well in pediatric dentistry.

This study will include three parts:

- 1. The first part will to complete a brief survey about you and your family.
- 2. The second part will be to complete an audio-recorded interview. During the interview, you will be asked to read and define some words used in dentistry.
- 3. The third part will be for your child to complete his or her dental exam. The steps in the exam will be the same whether or not you choose to participate. No steps will be added or removed. Information about whether your child has cavities will be used in the study.

If you are interested in participating, we will ask you to arrive to your appointment approximately 25-30 minutes early to review consent, complete a survey, and participate in the recorded interview. Your child will receive their exam whether or not you choose to participate. Do you have any questions?

Does this sound like something you would be willing to do?"

If no, thank them for their consideration, and remind them to arrive to their appointment at the time previously arranged. If yes, continue.

Great, I would like to review a few additional questions to ensure that you and your child are eligible to participate.

- 1. Are you this child's primary caregiver?
- 2. Is this the first time you have been asked to participate in this study?
- 3. Are you able to read and speak the English language?
- 4. Do you have any seeing or hearing difficulties (impairments)?

5. Has your child ever received dental treatment while asleep (under sedation or general anesthesia)?

If not eligible, thank them for their willingness to participate. If eligible, continue.

"Based on your responses, you and your child are eligible to participate. We will review the procedures in more detail on the day of the appointment.

Please arrive 25-30 minutes early and check in at the front desk. You will be met in the lobby by a member of the research team. Do you have any additional questions?

If you change your mind or have questions, please contact David Avenetti at 206-543-5800."

Day of Appointment Consent Script

Meet family in the lobby and provide introduction.

"Hello [Name], thank you for agreeing to participate in our study. We have an area where we can review the information that we discussed over the phone."

Escort patient and caregiver to the consultation room.

We will begin by reviewing some information about the study. This is called informed consent and is a part of most research studies. Please read through the following information and let me know if you have any questions. If after reading this, you no longer want to participate, please let me know. If you are still interested in participating, there is a page for you to sign on the back. I will keep one copy of the consent, and you can keep a copy for yourself.

Review informed consent. If consent is obtained, continue.

Survey and Interview Script

"We are ready to begin the survey. Please answer the following questions about you and your family."

Allow time for caregiver to complete survey and ask questions. When survey is complete, proceed.

"We will now move on to the second part. I will hand you a stack of 30 cards and ask you to read aloud the words written on the cards one-by-one. If you do not know a word, you can say "pass" and move onto the next card. When you have completed the first set of cards, we will move on to a second set of cards.

I will hand you the second stack of 35 cards and ask you to read the words written on the cards aloud one-by-one. Again, if you do not know a word, you may say "pass" and move onto the next card."

After you have read the words aloud, we will go through these 35 words again. But, this time you will be asked to say the definition or provide a sentence that describes the meaning of each word. Again, you can feel free to "pass."

This portion will be audi- recorded. Do you have any questions? Are you ready to begin?

We will now begin the recording.

Interviewer should press record and state "beginning interview for study ID number [number]." <u>The OH-LIP and REALD-30 should be administered as described above. When the interview is complete, press stop and state</u> "end of interview for study ID number [number]."

"Thank you for participating in our study. I will let the clinic staff know that [Patient's Name] is ready for his/her exam."

Appendix III Data Collection Materials

	Study	IDN	lumber	_	_	_	_
--	-------	-----	--------	---	---	---	---

Part I. Study Eligibility

Primary Inclusion Criteria

1.	How old is your chil	ld?
	(Inclusion is betwee	en 36 and 72 months of age. Is the child eligible?)
	□ Yes	□ No
		Secondary Inclusion Criteria
2.	Are you their prima	ry caregiver <u>and</u> 18 years of age or older?
	□ Yes	□ No
	What is your relation	uship to the child
3.	Is this the first time	you have been asked to participate in this study?
	□ Yes	□ No
4.	Are you able to read	d and speak in English?
	☐ Yes	□ No
5.	Do you have any see	eing or hearing difficulties (impairments)?
	□ Yes	□ No
б.	Has your child ever	received dental treatment while asleep (under sedation or general anesthesia)?
	□ Yes	□ No
	7. Do the	child and caregiver meet the criteria for the study: Yes No
8.	Survey Start Time:	
9.	Survey Date/_	<u>/</u>

Study	ID	Numb	er.	_	_	_	_

Part II: Demographic Information

10.	What is	your ag	ge?	years								
	What i s Male											
12.	What is	your ch	<u>uld's</u> birth da	te?	mouth		day		year			
	What i s Male		<u>uld's</u> gender? nale									
		n Indian	llowing best d /Alaska Nativo 1	_	ive Hawa				r [or African An	nerican
15. Are you of Hispanic or Latino(a) background? ☐ Yes ☐ No												
16. What is the primary language spoken in your home?												
17. What is the highest level of schooling you have completed? □ Less than high school □ High school/GED □ Some college or vocational training □ 4-year college degree □ Graduate or professional schooling												
	What ty SHS/Co		ental insuranc fedicaid	e does your Priv			□ Self-	pay	□ Other			
		•	arital status? □ Living wit		□ Wide	owed	□ Divor	ced	□ Separa	ted	□ Never man	ied
			ple (adults an □5 □6		currently		n your ho	ousehold?	?			
			dren under ti			ly reside i	-	ousehold □ 10+	?			
□ \$	19,999 o	r less	total family in	39,999	\$ 40,	,000- 59,9		□ \$ 6 0,0	00- 79,99	9		
	How wo	uld you	rate <u>your chi</u> □ Fair	ld's oral he □ Goo		□ Very	Good		□ Excelle	ent		
			when was the Within 4 y									
			for what reaso								□ Never been	to a dentist
	How wo	uld you	rate <u>your</u> ora □ Fair		d	□ Very	Good		□ Excell	ent		
	Prior to Vever		when was the Within 4 y									
			n(s) have <u>you</u>							а	□ Never been	to a dentist

						Study ID Number				
_										
Part	III: Oral Health Liter	racy Inte	rview							
29. Interview start time:				30. Interview end time:						
Dort	IV: Clinical Examina	tion								
				_						
31. New patient exam at CPD Recall exam at CPD										
32. # of primary teeth present: 33. dmft Score: 34. dmft Score:										
	 # of primary teeth p 	present:_	_	33. amfs Sco	re:	34. αmπ Score:				
3	35. □ Clinical exam			☐ Radiographic Exam			☐ Clinical and Radiographic Exam			
						_				
Part	V: Review of Oral He	alth Lite	racy A	ssessment						
	REALD-30		OH-LIP Part 1			OH-LIP Part II				
		Score			Score			Score		
1	Sugar		1	General anesthesia		1	General anesthesia			
2	Smoking		2	Tooth		2	Tooth			
3	Floss		3	Fluoride varnish		3	Fluoride varnish			
4	Brush		4	Silver Cap		4	Silver Cap			
5	Pulp			Tartar		5	Tartar			
6	Fluoride		6	Plaque		6	Plaque			
7	Braces		7	Permanent teeth		7	Permanent teeth			
8	Genetics		8	Decay		8	Decay			
9	Restoration			Numb			Numb			
10	Bruxism		10	Saliva		10	Saliva	\sqcup		
	Abscess			Extraction			Extraction	\perp		
	Extraction		_	Pediatric Dentist		-	Pediatric Dentist	\perp		
-	Denture	\sqcup		Floss	\perp	_	Floss	\vdash		
-	Enamel	\vdash		Hidden sugars	\vdash		Hidden sugars	\vdash		
	Dentition	\square		Bacteria		_	Bacteria	\vdash		
	Plaque	\vdash		Brush	\vdash		Brush	\vdash		
-	Gingiva	\vdash	_	Abscess		-	Abscess	\vdash		
	Malocclusion	\vdash	_	Filling		_	Filling	\vdash		
	Incipient	\vdash		Enamel		-	Enamel Inflammation	\vdash		
	Caries Periodontal	\vdash		Inflammation Gingivitis	\vdash		Gingivitis	\vdash		
	Sealant	\vdash		Snacks	\vdash	_	Snacks	\vdash		
	Hypoplasia	\vdash	_	Infection	\vdash	_	Infection	\vdash		
-	Halitosis	\vdash	_	Check-up		-	Check-up	\vdash		
-	Analgesia		_	Germs		-	Germs	\vdash		
-	Cellulitis		_	Acid		-	Acid	\vdash		
	Fistula	\Box		Discoloration		_	Discoloration	\vdash		
	Temporomandibular	\Box	_	Primary teeth			Primary teeth	\Box		
-	Hyperemia	\Box		Regularly		-	Regularly			
-	Apicoectomy		_	Erupt			Erupt			
	Total			Teething			Teething			
			32	Cavities		32	Cavities			
			33	Pea-sized amount		33	Pea-sized amount			
			_	Bottle		_	Bottle			
			35	Sealant		35	Sealant	igsquare		
				Total			Total			

Date entered into the dataset:

Appendix IV Terms used in the OH-LIP I and II

- 1. General anesthesia
- 2. Tooth
- 3. Fluoride varnish
- 4. Silver Cap
- 5. Tartar
- 6. Plaque
- 7. Permanent teeth
- 8. Decay
- 9. Numb
- 10. Saliva
- 11. Extraction
- 12. Pediatric Dentist
- 13. Floss
- 14. Hidden sugars
- 15. Bacteria
- 16. Brush
- 17. Abscess
- 18. Filling
- 19. Enamel
- 20. Inflammation
- 21. Gingivitis
- 22. Snacks
- 23. Infection
- 24. Check-up
- 25. Germs
- 26. Acid
- 27. Discoloration
- 28. Primary teeth
- 29. Regularly
- 30. Erupt
- 31. Teething
- 32. Cavities
- 33. Pea-sized amount
- 34. Bottle
- 35. Sealant

Appendix V Terms used in the REALD-30

- 1. Sugar
- 2. Smoking
- 3. Floss
- 4. Brush
- 5. Pulp
- 6. Fluoride
- 7. Braces
- 8. Genetics
- 9. Restoration
- 10. Bruxism
- 11. Abscess
- 12. Extraction
- 13. Denture
- 14. Enamel
- 15. Dentition
- 16. Plaque
- 17. Gingiva
- 18. Malocclusion
- 19. Incipient
- 20. Caries
- 21. Periodontal
- 22. Sealant
- 23. Hypoplasia
- 24. Halitosis
- 25. Analgesia
- 26. Cellulitis
- 27. Fistula
- 28. Temporomandibular
- 29. Hyperemia
- 30. Apicoectomy

Appendix VI Study Consent Form

PROJECT TITLE

Assessing the relationship between caregivers' pediatric oral health literacy and children's caries status

RESEARCHERS

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JoAnna Scott, PhD, (206) 543-5800 Acting Assistant Professor of Pediatric Dentistry, University of Washington School of Dentistry

RESEARCHERS STATEMENT

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions, you can decide if you want to be in the study or not. This process is called "informed consent." We will give you a copy of this form for your records.

PURPOSE

The purpose of this study is to determine if cavities in children and the parent or caregiver's dental knowledge are related. We also hope to measure different ways of rating caregiver's dental knowledge since this has not been studied well in pediatric dentistry.

STUDY PROCEDURES

This study will include three parts:

- 1. The first part will to complete a brief survey which asks about age, race, gender, education, number of people living in your home, income, marital status, and dental information.
- 2. The second part will be to complete an audio-recorded interview. During the interview, you will be asked to read and define some words used in dentistry. Recordings will be kept for an anticipated one to two weeks.
- 3. The third part will be for your child to have his or her dental exam ("check-up"). The steps in the exam will be the same whether or not you choose to participate. No steps will be added or removed. Information about whether your child has cavities will be used in the study.

We estimate that the survey and interview will take approximately 20-25 minutes to complete (beyond the time taken for informed consent). You may skip any survey or interview questions that you do not feel comfortable answering. If you have any questions about the research study, you may contact any members of the research team at the phone number listed above. Your child's dental record will be accessed following the exam, and data from the dental record will be linked to information provided during the interview.

RISKS, STRESS, or DISCOMFORT

During the interview, you will be asked to read and define words. You may not know what some of the words mean, and this is okay. The anticipated stress from this is likely to be low. We do not anticipate any physical risks or discomfort.

BENEFITS OF THE STUDY

Your contribution to our research will help researchers better understand the link between cavities in children and parents' dental knowledge. There is no monetary compensation for participating in the study. You may not benefit directly from study participation.

CONFIDENTIALITY OF RESEARCH INFORMATION

All data will be confidential, and all personal information will be removed/deleted after the study is completed. The results of our study will be summarized, but these results will not contain any personal information.

Audio recordings will be stored securely using password-protected computers. Files will be deleted after the study is complete, as late as 2014. All papers will be stored in a locked file cabinet and will be shredded after the study is complete. The risk of someone else being able to access this information is very low, and we will make all efforts to keep your information private.

Government or university staff sometimes reviews studies such as this one to make sure they are being done safely and legally. If a review of this study takes place, your records may be examined. The reviewers will protect your privacy. The study records will not be used to put you at legal risk of harm.

OTHER INFORMATION

Your participation in this study is completely voluntary. You may refuse to participate or choose to withdraw at any time.

Subject's statement:

Are you willing and able to participate in this survey: [] Yes	[]	No							
This study has been explained to me. I consent for my child and I to take part in this research. I have had a chance to ask questions. If I have questions later about the research, I can ask one of the researchers listed above. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098. I will receive a copy of this consent form.									
Printed name of caregiver/subjectSignature of caregiver/subject	С	Date							
Relationship of caregiver to minor subject									
Researcher's statement:									
Printed name of study staff obtaining consentSignature	Г)ate							

Appendix VII HIPAA Authorization Form

For the Use of Patient Health Information for Research

Research Title: Assessing the Relationship Between Caregivers' Pediatric

Oral Health Literacy and Children's Caries Status

Lead researcher: David Avenetti, DDS

Institution of lead researcher: University of Washington

A. Purpose of this form

The purpose of this form is to give your permission to the research team to obtain and use your patient health information. Your patient information will be used to do the research named above.

This document is also used for <u>parents</u> to provide permission to obtain the patient information of their minor children, and for <u>legally-authorized representatives</u> of subjects (such as an appropriate family member) to provide permission to obtain patient information of individuals who are not capable themselves of providing permission. In such cases, the terms "you" and "your patient information" refer to the subject rather than the person providing permission.

State and federal privacy laws protect your patient information. These laws say that, in most cases, your health care provider can release your identifiable patient information to the research team only if you give permission by signing this form.

You do not have to sign this permission form. If you do not, you will not be allowed to join the research study. Your decision to not sign this permission will not affect any other treatment, health care, enrollment in health plans or eligibility for benefits.

B. The patient information that will be obtained and used

"Patient information" means the health information in your medical or other healthcare records. It also includes information in your records that can identify you. For example, it can include your name, address, phone number, birthdate, and medical record number.

1. Location of patient information

By signing this form you are giving permission to the following organization(s) to disclose your patient information for this research:

University of Washington Center for Pediatric Dentistry

2. Patient information that will be released for research use

This permission is for the health care provided to you during the following time period: the time of your first dental exam at the University of Washington Center for Pediatric Dentistry until the end of this research study.

The specific information that will be released and used for this research is described below: Dental records, including radiographs.

C. How your patient information will be used

The researcher will use your patient information only in the ways that are described in the research consent form that you sign and as described here.

The research consent form describes who will have access to your information. It also describes how your information will be protected. You can ask questions about what the research team will do with your information and how they will protect it.

The privacy laws do not always require the receiver of your information to keep your information confidential. After your information has been given to others, there is a risk that it could be shared without your permission.

D. Expiration

This permission for the researchers to obtain your patient information: ends on June 30, 2013.

E. Canceling your permission

You may change your mind at any time. To take back your permission, you must send your written request to:

David Avenetti, 6222 Northeast 74th Street Seattle, WA 98115

If you take back your permission, the research team may still keep and use any patient information about you that they already have. But they can't obtain more health information about you for this research unless it is required by a federal agency that is monitoring the research.

If you take back your permission, you will need to leave the research study. Changing your mind will not affect any other treatment, payment, health care, enrollment in health plans or eligibility for benefits.

F. Giving permission

You give your permission to release your information by signing this form.								
Printed Name of Research Subject	Birthdate							

Printed Name of Person Authorized to Give Permission

Date of signature

Relationship to Subject and Description of Authority

(Examples: parent of a young child; sister of an individual who is in a coma; researcher who signs for a subject who is unable to physically sign the authorization but was observed by the researcher to read and otherwise agree to the authorization.)

You will receive a copy of this signed form. Please keep it with your personal records.