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Neurodevelopmental Disorders & Oral Health-Related Quality of Life for Children and Their Caregivers

by
Helen Mo

THESIS

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in

Oral and Craniofacial Sciences

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GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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Neurodevelopmental Disorders & Oral Health-Related Quality of Life for Children and Their Caregivers

Helen Mo

ABSTRACT

Purpose: To assess age-related differences in oral health related quality of life for a population of children with neurodevelopmental disorders (NDDs) and their caregivers.

Methods: Participants included children referred to at the Service Training Advocacy Research (STAR) Center for Autism Spectrum Disorders (ASDs) and NDDs at the University of California, San Francisco (UCSF). An oral health survey consisting of two previously validated surveys 1) the World Health Organization (WHO) oral questionnaire and 2) the Early Childhood Oral Health Impact Scale (ECOHIS) was given to their primary caregivers. The survey was used to assess the child's oral health, parental perception of the child's health, parental comfort level in providing dental care, and overall oral health-related quality of life (OHRQL). Data was collected, and subjects were categorized into two groups by age: 1) those under 6 years of age, and 2) those 6 years and older. Appropriate statistical analyses were conducted with $p\text{-value} < 0.05$ to be statistically significant. Linear regressions were completed to compare age to ECOHIS scores.

Results: Statistically significant differences in OHRQL were present between age groups for ECOHIS-total and ECOHIS-family impact. Linear regressions showed statistically significant correlation between age and ECOHIS scores in all domains. Therefore, OHRQL was shown to worsen as the child ages.

Conclusion: Families of children with NDDs reported negative impact on their OHRQL. Age-related differences in OHRQL emphasize the importance of early intervention and early establishment of a dental home for children with NDDs.

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1. INTRODUCTION

Neurodevelopmental disorders (NDDs) are a group of disorders in which the development of the central nervous system is disturbed (Springer Nature, 2019). This can impact the acquisition of skills in a variety of developmental domains, including motor function, learning, social, language, and cognition (Jeste, 2015). The most commonly diagnosed NDDs include autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), global developmental delay, intellectual disability, and learning disabilities (Jeste, 2015). Based on parental responses to the National Health Interview Surveys, approximately 15% of children in the United States ages 3 to 17 years are affected by neurodevelopmental disorders (Boyle et al, 2011). The survey indicated the number of children with certain developmental disabilities such as ASD, ADHD, and other developmental delays has increased, creating a demand for more health and education services.

Neuropsychiatric problems associated with NDDs can severely impair a patient's ability to communicate and function in certain environments, such as the dental setting. Individuals with such disorders tend to react differently to various sensations, and as a result, dentists must be aware of and sensitive to these differences. Dentists should provide individualized treatment approaches that focus on a child's abilities and not disabilities (Raposa, 2009). It is important to introduce the child to the dental environment early to tailor individualized interventions to protect the child's oral health and gradually build trust and cooperation.

Part of understanding the oral health of children with NDDs is to understand the child's oral health related quality of life (OHRQL). OHRQL is defined as the impact of oral

health or disease on an individual's daily functioning, well-being, and quality of life (Pahel, Rozier, & Slade, 2007). Oral disease and conditions may produce symptoms among children that give rise to physical, social, and psychological effects that influence their day-to-day lives in addition to their family's day-to-day lives (Gomes, 2014). By assessing OHRQL, communication can be improved between patients, parents, and the dental team to provide a greater understanding and quality of care.

In this descriptive study, oral health related quality of life will be assessed for children with NDDs, as well as and its impact on their caregivers. Collected data will be compared to determine if age-related differences exist among children with NDDs.

2. BACKGROUND AND SIGNIFICANCE

2.1 NEURODEVELOPMENTAL DISORDERS AND DENTAL CARE

Prevalence of certain NDDs, such as ASD and ADHD, has been increasing over the last four decades (CDC, 2009) CDC, 2010). Surveys of educators and pediatricians have reported a rise in the number of children seen in classrooms and exam rooms with behavioral and learning disorders (Kelleher, McInerny, Gardner, Childs, & Wasserman, 2000) (U.S. Department of Education, 2018). Due to this increase in prevalence, dentists need to be more prepared to treat children with these disorders. Surveys of educators and pediatricians have reported a rise in the number of children seen in classrooms and exam rooms with behavioral and learning disorders (Kelleher et al, 2000) (U.S. Department of Education, 2019).

The American Academy of Pediatric Dentistry (AAPD) classifies children with NDDs as children with special healthcare needs (SHCN), which is defined as "any

physical, developmental, mental, sensory, behavioral, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or use of specialized services or programs” (AAPD, 2016). Poorer oral hygiene status has been shown to exist among preschool children with SHCN (Zhou, Wong, & McGrath, 2019). Individuals with SHCN may also be at increased risk for oral disease throughout their lifetime. Oral disease can have a direct and devastating impact on the health and quality of life of these individual. Because of the unmet dental care needs of individuals with SHCN, emphasis on a dental home and comprehensive coordinated services should be established (AAPD, 2016). Patients with an established dental home are more likely to receive appropriate preventive and routine care that is individualized (AAPD, 2016). With routine care, dentists have the opportunity to structure appointments, maintain consistency, and facilitate positive experiences (Grant, Carlson, & Cullen-Erickson, 2004).

2.1.1 AUTISM SPECTRUM DISORDER

Autism spectrum disorder (ASD) is a biologically-based disorder of brain development. It is a serious and complex lifelong disorder that has been defined as the most severe-neuropsychiatric disorder in childhood (Landrigan, 2010). The Center for Disease Control (CDC) reports the prevalence of ASD to be 1 in 68 children (CDC, 2014). Many children with ASD have other co-existing conditions such as cognitive impairment, epilepsy, ADHD, depression/anxiety, bipolar disorder, schizophrenia, and sleep disorders (Autism Speaks, 2019). Individuals with ASD demonstrate difficulties in social interaction, communication, and have repetitive behaviors or limited interests/activities (Landrigan,

2010). These symptoms can hurt the individual's ability to function socially, at school, work, or other areas of life.

Children with ASD, particularly those with communication, cognitive, and behavior difficulties, may encounter difficulty with home oral care and dental visits (Stein et al, 2012). Impaired sensory perception can cause aberrant responses to visual, auditory, tactile, olfactory, and gustatory signals during dental care and treatment (Stein et al, 2011). Communication between child and dentist may also be impaired due to the child's incapability to share information using spoken language, gestures, and eye contact (Barberesi, Katusic, & Voigt, 2006). There may be difficulty in behaving appropriately and cooperatively, communicating their wants and needs, and understanding expectations. This can lead to heightened dental anxiety. Because of these limitations, 15% of U.S. children with ASD had unmet dental care needs compare to 6% of American children overall (Mckinney et al, 2014).

Conflicting results have emerged by the limited number of studies that carried out normative oral health assessment in children with ASD. Some studies have shown that children with autism exhibit higher caries prevalence, poorer oral hygiene, and a higher extent of unmet needs of dental treatment compared to non-autistic healthy children (Jaber, 2011) (Vishnu Rekha, Arangannal, & Shahed, 2012). Other studies have shown that children with ASD are more likely to be caries-free (Loo, Graham, & Hughes, 2008) (Orellana et al, 2012). However, in these studies, it was shown that children with ASD have other significant problems despite their decreased caries rate. More patients with ASD are uncooperative and required general anesthesia to complete dental treatment (Loo et al, 2008), and patients with ASD have frequent oral manifestations such as

bruxism, self-inflicted oral harm, non-nutritive chewing, object biting, and erosion (Orellana et al, 2012) (DeMattei, Cuvo, & Maurizio, 2007). Children with ASD also have eating habits that make them more prone to caries; many pouch food in their mouth for extended periods of time and have a preference for soft, sweet, or sticky foods (Klein & Nowak, 1999). Often times, caregivers of ASD patients use food rewards such as candy to reinforce desired or positive behaviors (Onol & Kirzioglu, 2018). Despite the varied findings in the literature, it can be established that children with ASD have significant oral health problems. All of these factors can make it challenging for ASD patients to receive appropriate dental care.

2.1.2 ATTENTION DEFICIT HYPERACTIVITY DISORDER

Attention deficit hyperactivity disorder (ADHD) is a disruptive behavior disorder characterized by symptoms of inattention (not being able to focus), hyperactivity (excess movement that is not fitting to the setting), and impulsivity (hasty acts that occur in the moment without thought) (APA, 2017). Previous literature has shown that children with ADHD have particular difficulties staying focused at dental examinations. During the dental visit, they make significantly more initiatives that do not focus on the examination or the dentist (Blomqvist et al, 2005). They have been shown to have trouble with communication; Blomqvist et al (2005) also showed children with ADHD had fewer verbal responses and had more missed responses. Their symptoms of restlessness, hyperactivity, and impulsive behavior also make them more prone to serious dental accidents (Alberth et al, 2001). Children with ADHD have also been shown to have higher dental caries rates compared to their peers (Rosenberg, Kumar, & Williams, 2014).

2.1.3 INTELLECTUAL DISABILITY AND LEARNING DISABILITY

Other NDDs that impact child behavior in the dental setting include intellectual and learning disabilities. Intellectual disability is defined as a disability with general mental abilities that affect functioning in two areas: intellectual functioning and adaptive functioning (APA, 2017). These patients have an IQ of less than 70, which impairs life skills such as communication, self care, home living, and social or interpersonal skills (APA, 2017). Learning disability is a general term for a neurological disorder that affects the way in which a child's brain can receive, process, retain, and respond to information (EPA, 2015). In both these disorders, the child may have trouble understanding, communicating, and using certain skills in the dental environment.

2.2 BARRIERS TO DENTAL CARE

Dental caries is the most chronic infectious disease of children, and the burden of oral disease falls disproportionately among individuals in the United States. Some of the most extreme oral health disparities are associated with special-needs patients, especially children with developmental disabilities. (Caplan & Weintraub, 1993). Dentistry has been found to be the most common category of unmet healthcare needs for children with SHCN, and one of the most needed services (Lewi, Robertson, & Phelps, 2005) (Waldman & Perlman, 2001). In addition to the child's physical, sensory, cognitive, and behavioral limitations, there are also various social and environmental factors that influence a child's oral care (Chadwick, Chapman, & Davies, 2018). Barriers include lack of appropriately trained dental providers, decreased access to care, and financial limitations (Milano, 2017).

This population has more treatment complications posed by their medical conditions and more difficulty finding a dentist willing to provide care (Nelson et al, 2011). There is a diminishing number of dental providers comfortable treating populations of children with SHCN (Thikkurissy et al, 2008). The United States has approximately 6000 pediatric dentists (AAPD, 2016). Due to this relatively small number, there is a necessity of broader involvement by general dentists. However, only 10 percent of surveyed general dentists reported that they treat patients with SHCN often or very often, while 70 percent reported that they rarely or never treat patients with SHCN (Casamassimo, Seale & Ruehs, 2004). Because of this, it has become increasingly difficult to transition patients from pediatric dentists to general dentists as they become older and reach adulthood. In addition, when patients reach adulthood and transition into full permanent dentition, their oral health care needs may go beyond the scope of the pediatric dentist's expertise (AAPD, 2016).

Access to care is difficult for patients with SHCN and their families. Parents find it challenging to navigate the healthcare system and determine which interventions are most effective and appropriate for their child (Elder, Kreider, Brasher, & Ansell, 2017). Significantly more parents of ASD children than parents of typically developing children report difficulty in oral care in the home, oral care at the dentist, and access to oral care (Stein et al, 2011). Even when children find dental care, studies have shown that the quality of care can still be negatively affected due to communication breakdowns (Espinoza & Heaton, 2016).

Families with SHCN children also experience much higher health-care expenditures than for healthy children (Sices, Harman, & Kelleher 2007). The burden of

these costs can be magnified when care for the child means loss in parental income due to missed work (Montes & Halterman, 2008).

Dentists must consider these barriers to dental care when individualizing treatment approaches for children with NDDs.

2.3 CAREGIVER BURDEN

To fully understand the oral health of children with NDDs, dentists must also understand the context of their family life. Dentistry for children with NDDs must take a family-centered approach (Schor, 1995). Parents are the experts and advocates for their children in everyday life, so it is important to involve caregivers and have an understanding about the patient's home environment (Raposa, 2009). They may have answers to many potential issues that may arise from a visit to the dentist. It is important to thoroughly interview caregivers to collect this information and assess which behavior management techniques are most effective for these patients (Raposa, 2009). Once communication has been established with the caregiver, dentists are responsible for introducing a practical home care regimen for the caregiver, since they are important in providing supervision and assistance for oral hygiene in children with SHCN (AAPD, 2016). Home oral health practices are also the most effective form of desensitization (Ferguson & Cinotti, 2009). Successful implementation of routine oral care can help the delivery of long, term successful dental care.

Parents of children with SHCN have caregiver burden, despite the presence or absence of functional limitations in this vulnerable population group (Chi, McManus, & Carle, 2014). Therefore, dentists must be understanding of the difficulties that caregivers of children with NDDs face. Compared to parents of typically developing children, parents

of children with NDDs have greater parenting stress, which is defined as the aversive psychological reaction to the demands of being a parent (Craig et al, 2016) (Woodman, Mawdsley, & Hauser-Cram, 2015).

A significant amount of time may be required from caregivers to provide adequate dental care: transportation to appointments, arranging and coordinating care by making appointments, and following up on the child's dental needs (HRSA, 2001). A National Survey of Children with Special Health Care Needs (Waldman & Perlman, 2001) showed that caregivers of over 28% of children who are affected spend more than 11 hours a week providing, coordinating, or arranging care compared to the families of more than 5% of children who are never affected by their conditions. Even something as simple as brushing may be a daily obstacle. Caregivers who assume the nursing role to care for their children have additional responsibilities that can cause social isolation, greater anxiety, and stress in a marriage or relationship (Diehl, Moffitt, & Wade, 1991). These factors can cause negatives effects on the family and parent's overall well-being.

2.4 ESTABLISHING A DENTAL HOME

Because of the difficulties and barriers experienced by children with NDDs and their families, it is essential to establish a dental home early to focus on preventative care and lower disease burden. The AAPD recommends establishing a dental home as early as six months of age and no later than 12 months of age, with two dental checkups per year thereafter (AAPD, 2018). This is especially important in the SHCN population. The AAPD Caries Risk Assessment places patients with SHCN automatically as moderate risk, even if no caries or other risk factors are present (AAPD, 2016).

Strong clinical evidence exists for the efficacy of early professional dental care complemented with caries-risk and periodontal-risk assessment, anticipatory guidance, and periodic supervision (Thompson, McCann, & Schneiderman, 2017). Children who have a dental home are more likely to receive appropriate preventive and routine oral health care, thereby improving families' oral health knowledge and practices, especially children at higher risk (Thompson et al, 2017). Intervening early and tailoring interventions to parents and families are critical ways to protect children and their family's well-being (Elder et al, 2017). If habits are not implemented early, it becomes increasingly harder to maintain a healthy mouth. An early dental home provides earlier diagnosis and treatment intervention before problems occur, which can reduce anxiety and facilitate referral (Nowak & Casamassimo, 2002).

2.5 ORAL HEALTH RELATED QUALITY OF LIFE

Oral Health Related Quality of Life (OHRQL) is a new area of research that has emerged over the past two decades, and recently recognized by the World Health Organization (WHO) in 2013 as an important segment of the Global Oral Health Program (Sischo & Broder, 2011). It is based on the concept that oral health is more than just teeth; oral health affects overall health and well-being. The World Dental Federation (FDI) defines oral health as “multifaceted and includes the ability to speak, smile, smell, taste, touch, chew, swallow, and convey a range of emotions through facial expressions with confidence and without pain, discomfort, and disease of the craniofacial complex” (2015).

2.5.1 A THEORETICAL MODEL OF OHRQL

The theoretical model for OHRQL is based on social science theory and epidemiological findings (Figure 2.1). It incorporates biological, social, psychological, and

cultural factors that are adapted from Wilson and Cleary (1995). This framework links health status or clinical variables, functional status, oral-facial appearance, psychological status, and OHRQL to the effects of environmental/contextual factors and access to care on oral health related perceptions (Baiju, Peter, Varghese, & Sivaram, 2017). Within the environmental factors include the influence of a child’s caregiver, finances, and family structure. The interplay of all these components together shape the overall quality of life (QOL) for an individual (Wilson & Cleary, 1995).

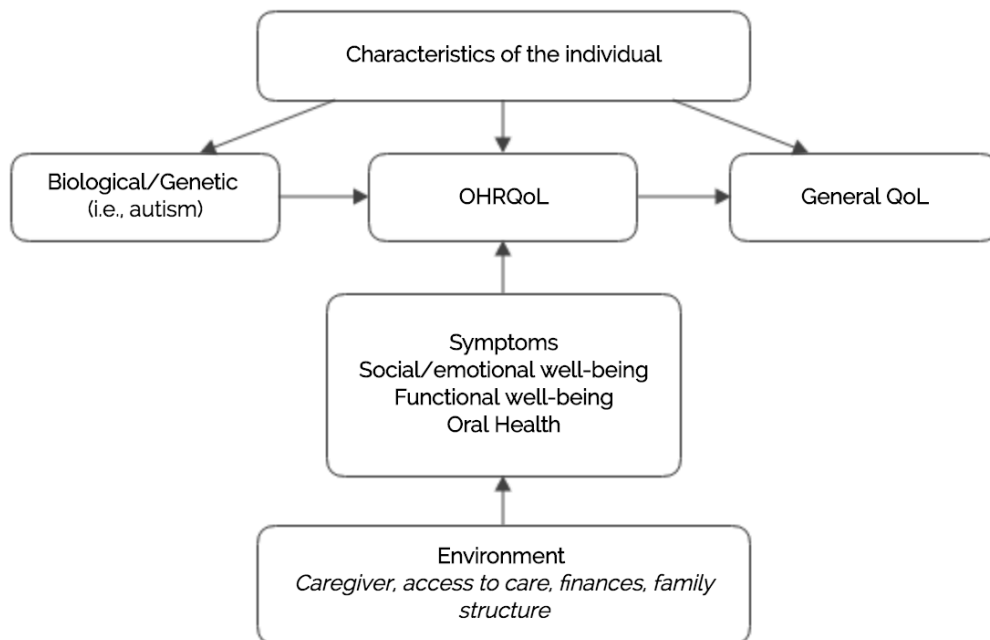


Figure 2.1. Theoretical model of OHRQL: the interplay of components

The concept of OHRQL can become an important tool to understand and shape the state of dental practice. Oral disease and conditions may produce symptoms among children that give rise to physical, social, and psychological effects that influence their day-to-day lives. Assessing OHRQL can help improve communication between patients/parents and the dental team – providing a greater understanding and quality of care.

In addition, by identifying groups who are vulnerable to low OHRQL, investigators can use data from survey research to create programs aimed at improving oral health and develop interventions that care for the “whole” person (Bennadi & Reddy, 2013). OHRQL data can also be an effective mechanism to improve equal access to care for vulnerable populations by communicating with policymakers to reveal the importance of oral health (Al Shamrany, 2006).

2.5.2 QUALITY OF LIFE IN CHILDREN WITH SHCN

Multiple studies have shown that quality of life (QOL) in children with SHCN is lower. A systematic review was completed in 2017 to assess quality of life in childhood mental and behavioral disorders (Jonsson et al, 2017). The majority of these disorders included NDDs such as ADHD, ASD, intellectual disability, and motor disorders. Despite the heterogeneity seen in the 41 studies identified by the systematic review, results were consistent to show that QOL in this population was significantly reduced compared to typical/healthy controls across several dimensions.

Many studies assessing QOL have been completed on populations specific to ASD. A meta-analysis showed that quality of life is lower for people with autism compared to people without autism across their lifespan; in this sample, age, IQ, and symptom severity did not predict quality of life (Heijst & Geurts, 2015). This finding was verified in a separate study; quality of life was found to be lower in high-functioning young adults with autism compared to typically developing peers (Dijkhuis, Ziermans, Van Rijn, Staal, & Swaab, 2017). Another review of 14 studies on quality of life in adults with ASD also demonstrated lower quality of life compared to that of typically developing adults (Ayres et al, 2018).

In ADHD populations, similar findings of lower QOL have been demonstrated. Interestingly, late-onset ADHD has been shown to have more severe impairment at work and poorer family support than early-onset ADHD (Lin, Lo, Yang, & Gau, 2015).

QOL has also been assessed in parents of children with neurodevelopmental disorders. A systematic review of 26 articles demonstrated poorer results of QOL in parents of mentally-ill children; most of these studies included children with ADHD or ASD (Dey, Paz Castro, Haug, & Schaub, 2018). Other studies have verified these findings of lower QOL in caregivers of children diagnosed with ASD (Ozgur, Aksu, & Eser, 2018) (Marsack-Topolewski & Church, 2019) and ADHD (Cappe, Bolduc, Rouge, Saiag, & Delorme, 2017). These findings highlighted the need to provide services and support to alleviate the burden among parents of adult children with developmental disorders.

2.5.3 ORAL HEALTH RELATED QUALITY OF LIFE IN CHILDREN WITH SHCN

Despite the multiple studies on QOL in populations of patients with NDDs, few studies have been completed in pediatric populations, and even fewer studies have been completed on oral health. Only 3 studies have looked at parental perception of OHRQL in children with ASD, with none published in the United States (Eslami, Movahed, & Asadi, 2018) (Richa, Yashoda, & Puranik, 2014) (Pani et al, 2013). Two of the studies reflected poorer OHRQL in ASD populations, and although the other study reflected better overall OHRQL, the study revealed more problems for ASD populations in social and communication issues. A few other studies have been completed in pediatric populations with SHCN: a couple in relation to dental caries (Weckwerth et al, 2016) (Cancio et al, 2018), and a few in relation to treatment under general anesthesia: (Farsi et al, 2018) (EI-

Meligy et al, 2016) (Baens-Ferrer, Roseman, Dumas, & Haley, 2005) (Chang, Patton & Kim, 2014).

2.5.4 MEASURING OHRQL: THE EARLY CHILDHOOD ORAL HEALTH

IMPACT SCALE

Numerous measures have been developed in recent years to assess OHRQL in children. However, until the Early Childhood Oral Health Impact Scale (ECOHIS) was developed, no instrument was designed specifically for use in epidemiological surveys to assess OHRQL in children (Pahel et al, 2007).

The Early Childhood Oral Health Impact Scale (ECOHIS) was developed in 2007 by the University of North Carolina's Public Health Department as an epidemiological survey to assess Oral Health Related Quality of Life (OHRQL) in children (Pahel et al, 2007). The survey was developed using an existing 45-item pool from a previous OHRQL study. These items were rated by health professionals who were experienced in dealing with young children. The resulting 36 items underwent item reduction, and the final 13 items were then piloted to demonstrate that the study had excellent psychometric properties, including construct validity, internal consistency reliability, and test-retest reliability. ECOHIS scores indicating worse quality of life were significantly associated with fair or poor parental ratings of their child's general and oral health (Pahel et al, 2007).

Currently, the ECOHIS is also used internationally and translated into a number of languages including Chinese, German, French, and Arabic. There are over 100 studies on Pubmed related to the ECOHIS. Populations of children with SCHN have been studied, including children with oral clefts (Zeraatkar, Ajami, Nadjmi, & Golkari, 2018), children aged 6 to 14 with cerebral palsy (Abanto et al, 2014), a population of children

with intellectual disabilities (Weckwerth et al, 2016), and a group of children infected with HIV (Buczynski, Castro, Leao, & Souza, 2011).

However, more research is still needed. There is a limited number of studies on OHRQL specific to children with NDDs and their caregivers, and a lack of high-quality data on the clinical oral health of children with NDDs.

2.6 AIMS, HYPOTHESIS, AND SIGNIFICANCE

2.6.1 AIMS

The study's primary aim is to assess differences in oral-health related quality of life (OHRQL) for children with NDDs and their families, based on age.

Other aims of the study are to gain further insight into the dental experience of children with NDDs and to better understand the impact of oral health on the lives of children with NDDs and their families.

2.6.2 NULL HYPOTHESIS

The null hypothesis of the study is that there is no significant difference in oral health-related quality of life between age groups.

2.6.3 SIGNIFICANCE

It is important to assess a child's oral health as a whole. By understanding a child's OHRQL and its impact on a child's family, dentists can become more educated providers. Due to the increase in barriers to dental care for older children with NDDs, assessing OHRQL in this population has become essential. If age-related differences are present within OHRQL, then diagnosis and treatment interventions can be tailored to each child.

This can increase a child's ability to tolerate dental care, leading to a healthier mouth and a more positive OHRQL for children with NDDs and their families.

3 METHODS AND MATERIALS

This study was approved by the Committee on Human Research at the University of California, San Francisco (IRB #18-24806), and all participants completed an informed consent agreement. In this study, a survey was given to primary caregivers for children with NDDs. Medical charts were reviewed to collect social demographic information.

3.1 PARTICIPANTS

A convenience sample was selected for this study. Participants were recruited from a clinic referral population at the Service Training Advocacy Research (STAR) Center for Autism Spectrum Disorders (ASDs) and Neurodevelopmental Disorders (NDDs) at University of California, San Francisco (UCSF). The STAR Center's primary goals are to provide diagnostic assessments and comprehensive evaluations for individuals of all ages with behaviors, signs, and symptoms associated with ASDs or other NDDs; conduct evidence-based treatment for individuals; and to advocate for these patients and their families. This study was conducted from January 2018 to May 2019.

The inclusion criteria included the following:

- Patients referred to the STAR Center for clinical evaluation and treatment
- Ages 0 to 18
- English-speaking
- Patients with co-existing conditions were included (such as Down's syndrome, epilepsy, or other learning disabilities)

- Child must be living with the primary caregiver who completed the survey

The exclusion criteria included the following:

- Non English-speaking
- An incomplete OHRQL questionnaire
- Those children whose parents refused to give their consent

The final sample comprised of 57 subjects and their primary caregiver.

3.2 MEASURES

An Oral Health and OHRQL survey was designed from two previously validated surveys: the World Health Organization (WHO) Oral Health Questionnaire and the Early Childhood Oral Health Impact Scale (ECOHIS).

Both surveys rely on the caregiver to provide assessment for the child and give the caregiver's perception of their child's oral health and OHRQL. Parents are intimately involved in the health and healthcare of their children, and the treatment of children's health problems is as likely to be influenced by parental perceptions of a child's needs as it is by the needs of the child (Schor, 1995). Responsibility for the health of children with special healthcare needs is usually borne by the adults; therefore, in this population, it is appropriate to collect OHRQL information from the child's parent or caregiver.

3.2.1 WORLD HEALTH ORGANIZATION (WHO) QUESTIONNAIRE

The World Health Organization (WHO) has a long tradition of epidemiological survey methodology, which includes a description of the diagnostic criteria that can be readily understood and applied in public health programs worldwide. The oral health questionnaire was taken from the newest edition *Oral Health Surveys: Basic Methods* (2013). Within the survey included measures such as age of first dental visit,

pain/discomfort related to the teeth, frequency of dental visits and reasons for these visits, oral homecare habits, and consumption of sugary foods and drinks.

Caregivers were asked to complete a self-assessment of the status of their child's teeth and gums. They were also asked to assess their comfort level in cleaning their child's teeth and taking their child to the dentist.

3.2.2 EARLY CHILDHOOD ORAL HEALTH IMPACT SCALE (ECOHIS)

The Early Childhood Oral Health Impact Scale (ECOHIS) was used to assess OHRQL (Pahel et al, 2007) (Table 3.1).

Table 3.1. Items on the Early Childhood Oral Health Impact Scale

The Early Childhood Oral Health Impact Scale (ECOHIS)

ECOHIS-Child

1. How often has your child had **pain** in the teeth, mouth or jaws? (*Child symptoms*)
 How often has your child.....because of dental problems or dental treatments? (*Child function*)

2. had **difficulty drinking hot or cold beverages**
3. had **difficulty eating some foods**
4. had **difficulty pronouncing any words**
5. **missed preschool, daycare or school**

How often has your child.....because of dental problems dental treatments? (*Child psychological*)

6. had **trouble sleeping**
7. been **irritable or frustrated**

How often as your child.....because of dental problems or dental treatments? (*Child self-image/social interaction*)

8. **avoided smiling or laughing** when around other children
9. **avoided talking** with other children?

ECOHIS-Family

How often have you or another family member.....because of your child's dental problems or treatments? (*Parental distress*)

10. **been upset**
11. **felt guilty**

How often..... (*Family function*)

12. have you or another family member **taken time off from work**.....because of your child's dental problem or dental treatments?
13. has your child had dental problems or dental treatments that had a **financial impact** on your family?

The ECOHIS consists of 13 items: 9 child-related (ECOHIS-child) and 4 on family impact (ECOHIS-family) (see Table 1). The ECOHIS-child includes one *child symptoms* item, four *child function* items, and two each from the *child psychological* and *child self image/social interaction* domains. The ECOHIS-family includes two *parental distress*

items and two *family function* items. OHRQL was evaluated using 11 out of the 13 items. The two items from the *child self image/social interaction* domain on smiling/laughing and talking with other children were excluded due to the variable social limitations of children with NDDs.

Prior to the 13 items, parents were led with the following:

“Problems with the teeth, mouth, or jaws and their treatment can affect the well-being and everyday lives of children and their families.” For each of the following questions, please check the box next to the response that best describes your child’s experiences or your own. Consider the child’s entire life from birth until now when answering each question.

The ECOHIS has a five-point response format ranging from “very often” to “never” including the option of “Don’t know.” Parents were required to select one option.

3.2.3 CHILD AND CAREGIVER DEMOGRAPHICS

Additional demographic information was verified. Medical records were reviewed to obtain information regarding child’s race, gender, and any concurrent medical diagnoses or medications. Caregiver demographics were also collected, including relationship to child, composition of household, education level, employment status, and household income.

3.3 STUDY DESIGN

Caregivers of children with NDD’s are referred to the STAR Center by other primary care providers. During their first visit at the STAR Center, the parent and the child were given an intake survey. The oral health survey was completed as part of the clinic intake survey.

Data was collected, and subjects were categorized into two groups by age: 1) those under 6 years of age (<6), 2) those 6 years and older (6+). The average age for eruption of the first permanent teeth, the first molars, is age 6. Therefore, age 6 was used due to its significance for indicating the initiation of the dental stage from primary dentition to mixed dentition.

3.4 DATA ANALYSIS

3.4.1 WORLD HEALTH ORGANIZATION (WHO) QUESTIONNAIRE

The four questions focusing on caregivers were extracted from the WHO questionnaire to be analyzed.

Two questions were used to assess the caregiver's perception of the child's dental health: 1) "How would you describe the health of your child's teeth?" and 2) "How would you describe the health of your child's gums?" Each item was scored on a scale from 0 to 5, as follows: very poor=score 5, poor=score 4, average=3, good=2, very good=1, and never=0. A higher score reflected a greater impact on the quality of life. Mean and standard deviation was calculated for each age group.

Two questions were used to assess the caregiver's comfort in providing dental care for the child: 1) "How comfortable are you cleaning your child's teeth?" and 2) "How comfortable are you taking your child to the dentist?" Each item was scored on a scale from 0 to 4, as follows: very uncomfortable=score 4, somewhat uncomfortable=score 3, neither comfortable nor uncomfortable=score 2, somewhat comfortable=score 1, and very comfortable=score 0. A higher score reflected a higher level of discomfort when providing dental care for the child. Mean and standard deviation was calculated for each age group.

3.4.2 EARLY CHILDHOOD ORAL HEALTH IMPACT SCALE (ECOHIS)

Each of the 11 items was scored on a scale from 0 to 4, as follows: very often=score 4, often=score 3, occasionally=score 2, hardly ever=score 1, and never=score 0. With the excluded questions, the total score varied from 0 (no effect) to 44 (severe effect).

The total score, mean, and standard deviation for the whole ECOHIS (ECOHIS-total) were calculated. The same was completed for the child (ECOHIS-child) and family (ECOHIS-family) sections. Within each sub-group (ECOHIS-total, ECOHIS-child, and ECOHIS-family), mean and standard deviation were also calculated for each age group.

3.4.3 STATISTICAL ANALYSIS

Baseline and demographic characteristics were summarized by standard descriptive statistics (mean, standard deviation, and percentages).

The statistical significant difference among the age groups was determined by the non-parametric Wilcoxon rank-sum test. Linear regressions were completed comparing child age to ECOHIS-total, ECOHIS-child, and ECOHIS-family. The level of significance will be set at $p < 0.05$.

4 RESULTS

A total of 57 children/caregiver pairs were recruited for the study. Survey questions on caregiver's perception of oral health, caregiver's comfort providing dental care, and OHRQL were completed at 100% for all 57 participants. Data from all surveys were included in the results.

Some caregivers declined to provide specific information on parental characteristics.

4.1 CHILD DEMOGRAPHICS

The mean age was 5.81 years (SD=3.93), and ages ranged from 0 to 17 years. There were 34 participants under the age of 6 (mean=3.21, SD=1.47), and 23 participants 6 and older (mean=9.65, SD=3.20).

The majority of children were male (87.7%), and primarily white (52.6%) or Asian (28.1%). Demographics are summarized in Table 4.1.

Table 4.1. Child characteristics and clinical data (N=57)

Variable	N (%)
Sex	
Male	50 (87.7%)
Female	7 (12.3%)
Race	
White	30 (52.6%)
Asian	16 (28.1%)
Black or African American	1 (1.8%)
Other (White/Asian or White/Black-African American)	7 (17.4%)
Unknown	3 (5.3%)

4.2 PARENT DEMOGRAPHICS

The questionnaire was completed by mothers (88.7%) and fathers (11.3%). A majority of children came from two-parent households (89.1%). Caregiver characteristics included 89.1% employed full time or part time, 89.3% with a

postgraduate degree, and 52.7% with a household income of \$150,000 or more.

Demographics are summarized in Table 4.2.

Table 4.2. Caregiver Characteristics and clinical data (N=57)

Variable	N (%)
Relationship to Child	
Mother	47 (88.7%)
Father	6 (11.3%)
Race	
White	33 (60.0%)
Asian	20 (36.4%)
Black or African American	1 (1.8%)
Other	1 (1.8%)
Composition of Household	
Two-parent	49 (89.1%)
Single-parent	5 (9.1%)
Other	1 (1.8%)
Employment Status	
Employed full-time or part-time	55 (98.2%)
Un-employed	1 (1.8%)
Highest Level of Education	
Postgraduate Degree	50 (89.3%)
Some college	5 (8.9%)
High School Graduate	1 (1.8%)
Household Income	
\$150,000 or more	29 (52.7%)
\$100,000 to \$149,999	7 (12.7%)
\$50,000 to \$100,000	11 (20.0%)
Less than \$50,000	2 (3.7%)
Unknown	6 (10.9%)

4.3 ORAL HEALTH

The average age of the child’s first dental visit was 4.25 (SD=5.49) years. 63.2% of children went to the dentist 2 times or more during the past 12 months, and 78.9% of children went to the dentist at least once during the past 12 months.

The primary reason for visiting the dentist was for routine check-up of teeth/treatment (87.0%). However, 19.3% had not visited the dentist during the past 12 months.

Brushing habits varied; 40.4% were brushing two or more times a day, and 17.6% were brushing less than once a day. Of those brushing, 93% were using toothpaste, and 68.4% were using toothpaste that contains fluoride. About a third of children were flossing to clean their teeth or gums (31.6%).

4.3.1 CAREGIVER PERCEPTION OF CHILD’S DENTAL HEALTH

Almost half of caregivers rated the health of their child’s teeth as very good to excellent (47.4%), and the health of their child’s gums as very good to excellent (50.9%) (Table 4.3). Only 8.8% rated the health of their child’s teeth as very poor to poor, and 5.3% rated the health of their child’s gums as very poor to poor.

Table 4.3. Percentage distribution of caregiver responses regarding perception of child’s dental health

Caregiver Perception of Child’s Dental Health	Very Poor to Poor N (%)	Average to Good N (%)	Very Good to Excellent N (%)	Don’t Know N (%)
How would you describe...				
...the health of your child’s teeth?	5 (8.8%)	23 (40.3%)	27 (47.4%)	2 (3.5%)
...the health of your child’s gums?	3 (5.3%)	23 (40.3%)	29 (50.9%)	2 (3.5%)

The mean score for perception of health of child’s teeth was 1.54 (SD=1.35), and the mean score for perception of health of child’s gums was 1.46 (SD=1.36).

Although mean scores were higher for the 6+ age group, there were no statistical differences between age groups for either the perception of health of

child's teeth (p=0.1782) or the perception of health of child's gums (p=0.6510).

These results are summarized by age group in Table 4.4.

Table 4.4. Mean scores and age associations for caregiver responses from the WHO questionnaire

	Total Mean (SD)	<6 years Mean (SD)	6+ years Mean (SD)	p-value
Caregiver Perception of Child's Dental Health				
health of child's teeth	1.54 (1.35)	1.35 (1.37)	1.83 (1.30)	0.1782
health of child's gums	1.46 (1.36)	1.38 (1.35)	1.57 (1.41)	0.6510
Caregiver Comfort in Providing Dental Care				
cleaning child's teeth	0.74 (0.90)	0.82 (0.82)	0.61 (0.66)	0.6775
taking your child to the dentist	1.00 (1.27)	1.09 (1.36)	0.85 (1.14)	0.7667

4.3.2 CAREGIVER COMFORT IN PROVIDING DENTAL CARE

Most caregivers reported being somewhat comfortable to very comfortable in cleaning their child's teeth (80.6%) (Table 4.5). Only 5.3% reported being very uncomfortable to somewhat uncomfortable in cleaning their child's teeth.

Table 4.5. Percentage distribution of caregiver responses regarding comfort in providing dental care

Caregiver Comfort in Providing Dental Care	Very Uncomfortable to Somewhat Uncomfortable N (%)	Neither Comfortable nor Uncomfortable N (%)	Somewhat Comfortable to Very Comfortable N (%)	Don't Know N (%)
How comfortable are you...				
...cleaning your child's teeth?	3 (5.3%)	5 (8.8%)	46 (80.6%)	3 (5.3%)
...taking your child to the dentist?	11 (19.2%)	3 (5.3%)	38 (66.7%)	5 (8.8%)

However, an increase of caregivers reported being uncomfortable taking their child to the dentist; 19.2% rated it as very uncomfortable to somewhat uncomfortable. Over half still reported being somewhat comfortable to very comfortable in taking their child to the dentist (66.7%).

The mean score for comfort in cleaning child’s teeth was 0.74 (SD=0.90), and the mean score for comfort in taking child to the dentist was 1.00 (SD=1.27).

Although mean scores were higher for the 6+ age group, there were no statistical differences between age groups for either the comfort in cleaning child’s teeth ($p=0.6775$) or the comfort in taking child to the dentist ($p=0.7667$). These results are summarized by age group in Table 5.

4.4 ORAL HEALTH RELATED QUALITY OF LIFE

The breakdown of baseline ECOHIS scores are shown in Table 4.6. Mean and standard deviation of ECOHIS-total, ECOHIS-child, and ECOHIS-family sub-groups are shown in Figure 4.1 by age group.

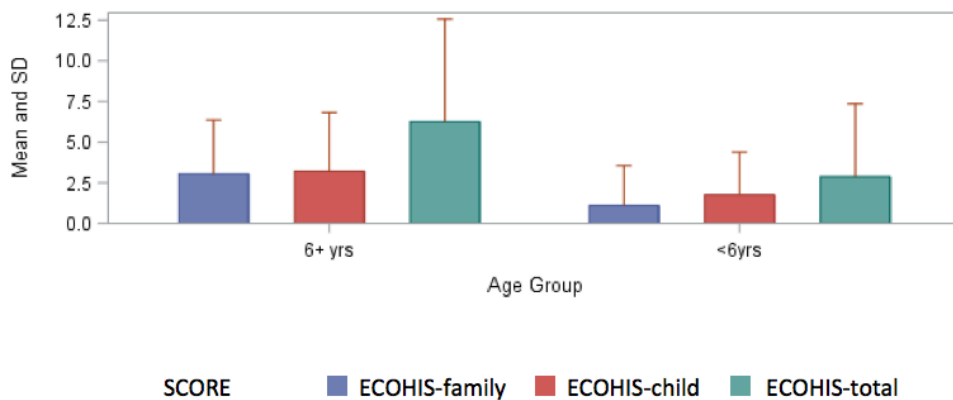


Figure 4.1. Mean and standard deviation for ECOHIS-total, ECOHIS-child, and ECOHIS-family by age group

Table 4.6. Percentage distribution of caregiver responses on the ECOHIS

ECOHIS-total	Never or hardly ever N (%)	Occasionally, often, or very often N (%)	Don't know N (%)
ECOHIS-child			
How often has your child had pain in the teeth, mouth or jaws?	38 (66.7%)	11 (19.3%)	8 (14.0%)
How often has your child.....because of dental problems or dental treatments?			
had difficulty drinking hot or cold beverages	51 (89.5%)	1 (1.8%)	5 (8.8%)
had difficulty eating some foods	46 (80.6%)	5 (8.8%)	6 (10.5%)
had difficulty pronouncing any words	42 (73.7%)	2 (2.5%)	13 (22.8%)
missed preschool, daycare or school	52 (93.0%)	1 (1.8%)	3 (5.2%)
had trouble sleeping	47 (82.5%)	4 (7.0%)	6 (10.5%)
been irritable or frustrated	40 (70.2%)	10 (17.5%)	7 (12.3%)
ECOHIS-family			
How often have you or another family member.....because of your child's dental problems or treatments?			
been upset	47 (82.5%)	8 (14.0%)	2 (3.5%)
felt guilty	38 (66.7%)	15 (26.3%)	4 (7.0%)
taken time off from work	48 (84.2%)	9 (15.8%)	0 (0.0%)
How often has your child had dental problems or dental treatments that had a financial impact on your family?	50 (87.7%)	7 (12.3%)	0 (0.0%)

4.4.1 ECOHIS-TOTAL

Mean ECOHIS-total score was 4.25 (SD=3.93). Within the ECOHIS responses, feeling guilty was reported as having the most impact on OHRQL (26.3%), and difficulty drinking hot or cold beverages and missing preschool, daycare, or school were reported as having the least impact (1.8%). “Difficulty pronouncing any words” had the greatest “don’t know” response rate (22.8%).

For the <6 age group, mean ECOHIS score was 2.88 (SD=4.47). For the 6+ age group, mean ECOHIS score was 6.26 (SD=6.30). ECOHIS-total score was shown to be significantly different by age (p=0.0328).

Age-related associations are shown in Table 4.7.

4.4.2 ECOHIS-CHILD

Mean ECOHIS-child score was 2.35 (SD=3.11). For the <6 age group, mean ECOHIS score was 1.76 (SD=2.62). For the 6+ age group, mean ECOHIS score was 3.22 (SD=3.61). Within the ECOHIS-child items, pain and irritability/frustration were shown to have the greatest impact with 19.3% parents reporting pain in the teeth, mouth or jaws, and 17.5% parents reporting the child being irritable or frustrated due to dental problems or dental treatments.

Although mean scores were higher for the 6+ age group, there were no statistical differences in ECOHIS-child score ($p=0.0939$).

4.4.3 ECOHIS-FAMILY

Mean ECOHIS-family score was 1.89 (SD=2.96). For the <6 age group, mean ECOHIS score was 1.12 (n=2.43). For the 6+ age group, mean ECOHIS score was 3.04 (n=3.32). The ECOHIS-family items had more responses within the “occasionally, often, or very often” category compared to the ECOHIS-child items in all domains. The largest impact was parents reporting feeling guilty (26.3%, n=15).

Table 4.7. Mean scores and age associations for caregiver responses from the WHO questionnaire

	Total Mean (SD)	<6 years Mean (SD)	6+ years Mean (SD)	p-value
ECOHIS-total	4.25 (3.93)	2.88 (4.47)	6.26 (6.30)	0.0328*
ECOHIS-child	2.35 (3.11)	1.76 (2.62)	3.22 (3.61)	0.0939
ECOHIS-family	1.89 (2.96)	1.12 (2.43)	3.04 (3.32)	0.0159*

ECOHIS-family score was shown to be significantly different by age ($p=0.0159$). Age-related associations are shown in Table 4.7.

4.5 LINEAR REGRESSION

Linear regressions were completed comparing age to ECOHIS-total, ECOHIS-child, and ECOHIS-family scores to assess the relationship of age and oral health-related quality of life.

For each year increase in age, ECOHIS-total score increased by 0.5 unit ($p=0.0035$) (Figure 4.2). For each year increase in age, ECOHIS-child score increased by 0.3 unit ($p=0.0057$) (Figure 4.3). For each year increase in age, ECOHIS-family score increased by 0.2 unit ($p=0.0131$) (Figure 4.4). Statistical significance was found in all three categories.

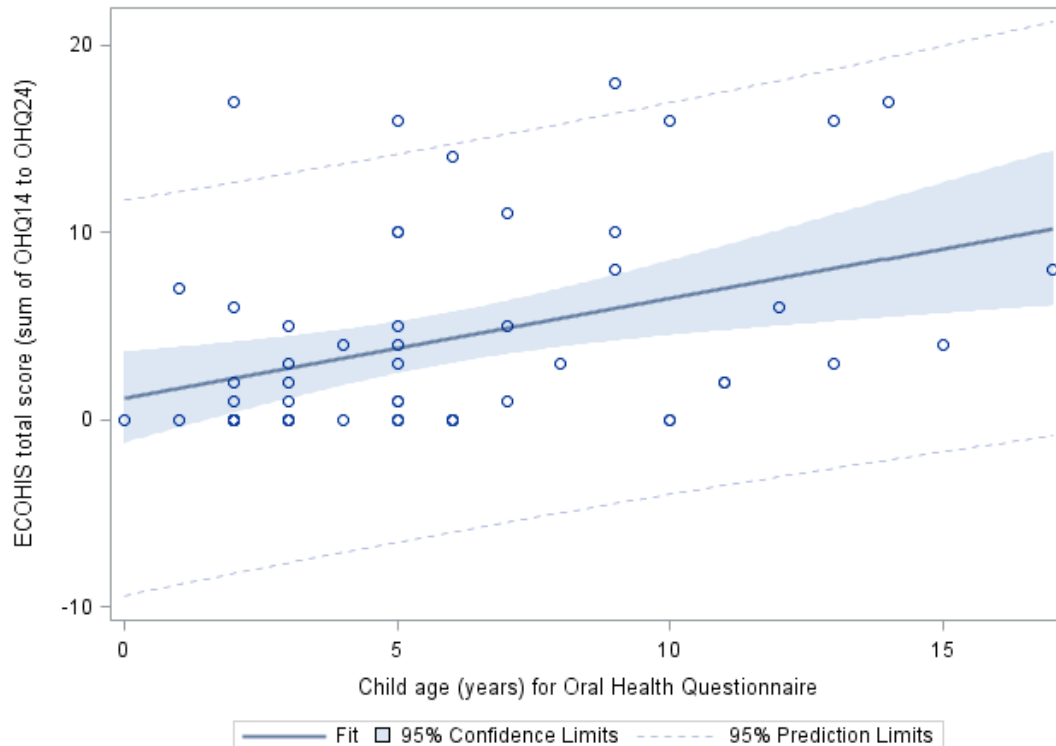


Figure 4.2. Linear regression for child age (years) vs. ECOHIS-total score

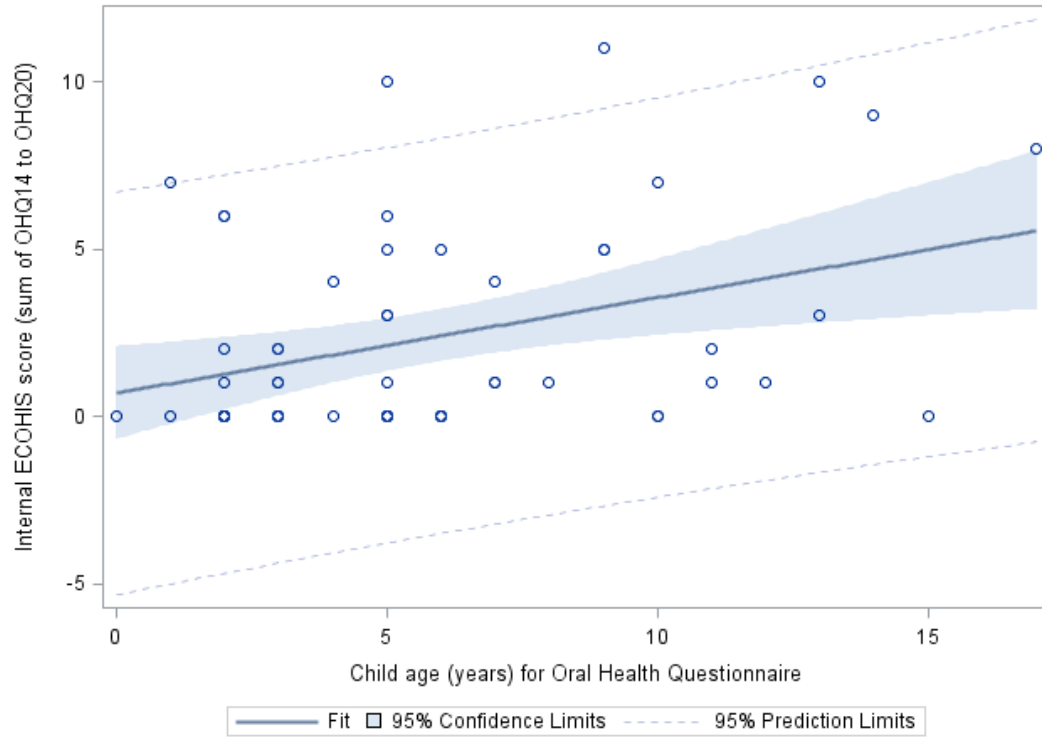


Figure 4.3. Linear regression for child age (years) vs. ECOHIS-child score

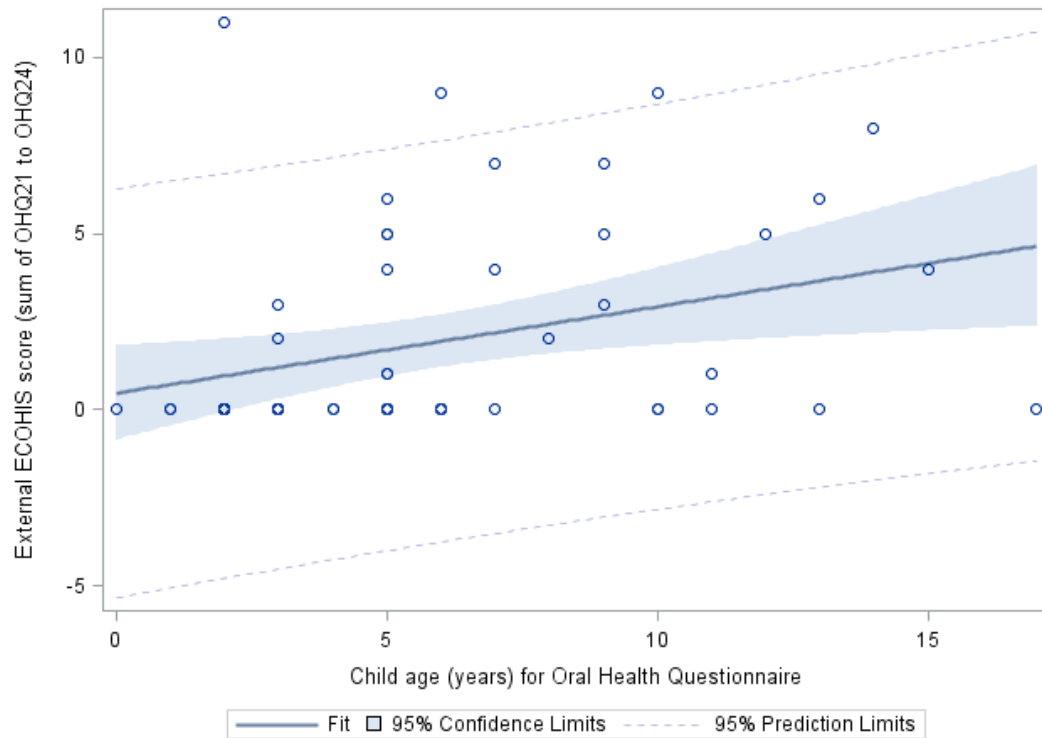


Figure 4.4. Linear regression for child age (years) vs. ECOHIS-family score

5 DISCUSSION

5.1 CHILD AND CAREGIVER DEMOGRAPHICS

In order to receive treatment at the STAR Center, patients are required to have private health insurance or to pay out-of-pocket. The center does not routinely accept Medicaid patients. Most families in our study had high education levels, private health insurance, and above average income. Children were raised in stable family environments and had two-parent households.

Previous studies have demonstrated differences in socioeconomic groups when it comes to dental care. Health disparities exist among different income groups (Waldman & Perlman, 2006) and between children with private insurance and Medicaid (Sarkar, Earley, Asti, & Chisolm 2017). Those with lower income are more likely to report unmet dental care need (Lewis, 2009). Greater barriers to care and an increased financial impact exists in children with developmental disabilities from lower socioeconomic groups aged 2 to 17 (Schultz, Shenkin, & Horowitz, 2001). A difference in QOL has also been shown in relation to parents' education levels. Parents with more years of schooling have been shown to have higher QOL (Cancio et al, 2018).

These differences in socioeconomic status and parent background can greatly affect a child and family's OHRQL. However, due to the relatively homogenous population used in this study, the study is unable to capture these socioeconomic differences.

5.2 ORAL HEALTH

5.2.1 PARENTAL PERCEPTION OF ORAL HEALTH

Over half of our study population's caregivers were comfortable providing dental care for their children (80.6%), and perceived their child's oral health as at least average (87.7% on the health of teeth and 91.2% on the health of gums). Again, this may be due to the fact our study population is well-educated and high-income.

Greater discomfort was reported regarding taking the child to the dentist; only 66.7% were comfortable. This finding is consistent with previous literature. Many parents of children with SHCN have reported the negative impact that dental examinations have had on them as a family; both the anxiety and stress, before, during, and after the dental visits. (Thomas, Blake, Morris, & Moles, 2017).

5.2.2 UNMET DENTAL NEEDS

Interestingly, positive parental perception of oral health and high comfort level providing oral care did not correlate with less unmet dental needs.

Even though most families had high education levels and income, there was still evidence of unmet dental needs in our study population, as indicated by the 19.3% of children who had not visited the dentist during the past 12 months. This finding was also seen in another survey of high-income families of children with SHCN; out of over 1000 responses, 20% of patients had an unmet dental need (Nelson et al, 2011). In this same study, more than 90% of the high-income SHCN children had seen a dentist within the past year, which is higher than what was seen in our study population (78.9%). The dental frequency in our study population was also slightly lower than the national average.

According to the CDC (2017), the percent of children with a dental visit in the past year was 84.6%.

There is also discrepancy in the age of the child's first dental visit. According to a survey on American children's oral health conducted in 2009, the average age of a child's first dental visit is 2.5 (Delta Dental, 2010).

5.3 ORAL HEALTH RELATED QUALITY OF LIFE

The greatest impact items on the ECOHIS in our study population were "pain in the teeth" (19.3%) in the child impact section. Similar results were found in previous ECOHIS studies (Clementino et al, 2015) (Leal, Bronkhorst, Fan, & Frencken, 2012). Dental pain has also been reported as the most frequent specific cause of perceived impact on OHRQL when different evaluation tools are used (Bianco, Fortunato, Nobile & Pavia, 2010) (Easton et al, 2008).

5.3.1 AGE-RELATED DIFFERENCES IN OHRQL

Statistically significant differences were found in ECOHIS-total score and ECOHIS-family score between age groups. The children in the older age group were shown to have poorer OHRQL, and their family impact was also greater. All three linear regressions comparing age and ECOHIS scores (total, child, and family sub-groups) supported this finding. As children with NDDs age, their OHRQL worsens.

Our findings are consistent with findings in the literature. Although age differences and OHRQL have not been assessed in children with NDDs, previous studies have compared age and general QOL. Previous studies demonstrated that older children with SHCN had decreased QOL (Cancio et al, 2018) (Thurston et al, 2010) (Klassen, Miller, &

Fine, 2004). The rates of unmet dental needs due to cost have also been shown to increase with age (HRSA, 2001).

5.3.2 POSSIBLE EXPLANATIONS

Children may be receiving intervention and treatment at a later age. Elder et al (2017) found that the most frequently reported barrier in patients with ASD is the need for better educated providers and more effective and timely means of connecting families of individuals to available resources. Specific to dentistry, parents of children with SHCN may not access dental treatment until later in their child's life due to other pressing medical and developmental concerns (Wright & Kupietzky, 2014). Parents may go through many unsuccessful attempts to find a dentist able to treat their child and accommodate their child's behavioral needs. Because of this delay, there may be a greater likelihood that the child has built up anxiety and a developed fear of the dentist as they age (Wright & Kupietzky, 2014).

Children may also develop extensive avoidance behaviors as they age as a means of coping, repressing, or ignoring stressful stimuli (Bernard, Cohen, McClellan, & Maclaren, 2004). These behaviors can be triggered in the dental setting. In order to eliminate these behaviors to provide comprehensive dental care, it may require a great deal of time and patience.

As children age into adolescence, their dental needs also become more complicated. The adolescent patient has a potentially high caries risk, an increased risk for periodontal disease, and a tendency for poor nutritional habits (AAPD, 2015). Adolescence marks a period of significant caries activity for many individuals, and adolescents have a higher prevalence of gingivitis compared to prepubertal children

(AAPD, 2015). In addition to dental changes, a child with SHCN may need behavioral modifications during dental treatment. Even for routine cleanings, protective stabilization may be necessary.

Physical resistance exhibited by an older child may have far more dramatic consequences than similar behavior in a toddler (Lyons, 2009). Protective stabilization using stabilization devices such as a papoose board during dental treatment is often used in patients with SHCN to decrease the risk of injury while allowing safe completion of treatment (AAPD, 2015). As children age and become stronger and more resistant, they may also face decreased access to care. Clevenger et al (1993) indicated that 80% of dentists surveyed were unwilling to treat patients with developmental disabilities because of their resistance.

All of these factors may negatively impact a child and their family's OHRQL in the dental setting.

5.3.3 CAREGIVER IMPACT

In our study, caregivers report feeling upset and guilty, having to take time off from work, and feeling financial impact due to their child's dental health or dental problems. The highest response was "felt guilty" (26.3%) in the family impact section. Similar results were found in previous ECOHIS studies of normal, healthy children (Clementino et al, 2015) (Naidu, Nunn, & Donnelly-Swift, 2016) (Arrow & Klobas, 2015).

Impact on work and finances has been shown in caregivers of children with SHCN. The National Survey of Children with Special Health Care Needs indicated that 30% of parents had to cut back on work or stop working to care for their children (HRSA, 2001). This can reduce a family's income. In the same survey, more than 20% of families

reported financial problems due to the child's medical conditions (not specific to dental problems). Nearly 40% of families with children of conditions that affect their abilities report experiencing a financial problem, compared to only 9% of children whose conditions never affect their abilities (HRSA, 2001).

Our study's findings further validate the need for dentists to be sensitive to the caregiver's experience. Interventions to improve oral health of children with SHCN should also focus on reducing caregiver burden in order to achieve higher OHRQL.

5.4 STUDY LIMITATIONS

5.4.1 STUDY POPULATION

One of the biggest limitations in this study is the demographics of our study population. Because our study population consists of high income and high level of education participants, the data is not necessarily generalizable to the general population. Future research should focus on assessing socioeconomic differences in OHRQL in children with NDDs and their caregivers.

In addition, when studying children with SHCN, each child is highly variable in their level of skills and abilities; they have their own unique set of strengths and needs. Although children may fall under a single diagnosis, it is still important to avoid stereotypes and generalities when treating children with NDDs. Our study survey was completed during intake of the children to the STAR Center, and prior to full clinical and neurological assessment. Therefore, we were unable to assess the full extent of the child's medical condition.

5.4.2 RELIANCE ON CAREGIVER RESPONSE

Our survey relies on a parental report for oral health. When assessing children and especially children with SHCN, study design must rely on parents to provide responses for the child. However, there are limitations in parents' knowledge of their children's activities and feelings. They cannot assess their child's OHRQL with one hundred percent accuracy.

In previous quality of life studies, the importance of including a "Don't know" option is stressed when respondents are asked to assess someone else's health or quality of life (Jokovic et al, 2003). Especially in a special needs population, a "Don't know" response must be provided for caregivers in order to achieve accurate survey responses. In our study population, the "Don't know" response was utilized frequently.

5.4.3 EXCLUSION OF ECOHIS ITEMS

There is difficulty in fully assessing OHRQL in a special needs population. Variables that contribute to OHRQL such as smiling, social interaction, and speech may be difficult to assess in children with NDDs due to their limited abilities in these domains. In our study, we had to exclude 2 ECOHIS items to account for these differences. This may alter our overall ECOHIS-total score and ECOHIS-child score results.

6 CONCLUSION

Families of children with NDDs have more difficulties compared to children without SHCN. Therefore, dentists need to be sensitive to these children and their families and provide individualized care for each child with NDDs that come to their office. One way to customize care is to understand the patient and family's OHRQL.

Age-related differences in OHRQL further validate the importance of early intervention. In order to avoid the complications that arise from treating an older child, it is essential for children with NDDs to establish a dental home early. Dentists need to intervene early while OHRQL is still high, and before it declines as the child ages. By establishing a dental home early, the child can build a sense of trust and communication with the dentist to avoid lifelong problems that can result from oral disease. The dentist, child, and parent can then work as a team to improve OHRQL outcomes in this vulnerable population and as a result, improve well-being as a whole.

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