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# Oral Health Education and Dental Care Access of Families of Children with Down Syndrome in New Mexico

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# Oral Health Education and Dental Care Access of Families of Children with Down Syndrome in New Mexico

By

**Alayna Marissa Holcomb**

B.S. Dental Hygiene, University of New Mexico, 2022

Thesis

Submitted in Partial Fulfillment of the

Requirements for the Degree of

**Master of Science**

**Dental Hygiene**

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# Dedication

I dedicate this work to my parents Ken and Dina Holcomb, and my brother Aidan Holcomb. I could never have done it without their constant love and support throughout my whole educational journey. You have taught me to be determined, to believe in myself, and to always persevere. I am honored to have you as my parents and brother.

# Oral Health Education and Dental Care Access of Families of Children with Down Syndrome in New Mexico

Alayna Marissa Holcomb

B.S Dental Hygiene, University of New Mexico, 2022

M.S Dental Hygiene, University of New Mexico, 2024

## Abstract

The purpose of this study was to assess the oral health education and dental care access of families of children with Down syndrome in New Mexico. Thirty members of the Rio Grande Down Syndrome Network completed a survey. Most individuals with Down syndrome receive dental services every six months (62.5%) at a regular dental office (54.2%). Caregivers reported individuals take 1-2 prescription medications (54.2%) and are not aware of the correlation between prescription medications and dry mouth (62.5%). Half of the participants are aware of the increased risk for gum disease (50%) even though most have not been diagnosed (70.8%). Most caregivers are not aware Down syndrome can cause prominent grooves on the tongue (66.7%) and have not received instruction to clean the tongue (45.8%). Homecare assistance of some variation was reported at 66.7%. Caregivers reported to have not received education on any of the listed dental topics (58.3%).

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# Chapter I: Introduction

## Introduction

Dental hygiene has evolved throughout many years to become an important preventive care measure within the healthcare system. During the establishment of dental hygiene, many people considered tooth cleaning to be luxury rather than a necessity. Previously it was thought that your teeth only needed to be cared for when a problem had already occurred rather than as a preventive measure. The view of dental hygiene greatly shifted as research on the prevention of poor oral health continued, leading to more people caring for their oral health.

Research has continued to grow, leading to new technologies and advancements. Although it is important for these advancements to take place, it is equally important for them to be adaptive to all populations. Dental needs are apparent in all individuals and not all of them have access to the dental care they need and deserve. The special needs community and the access to dental care they get is important to consider when discussing the future of dental hygiene. All communities of patients must be treated with the same level of care and attention and although advancements have been made in treating the special needs community, there is still a lack of care that needs to be addressed.

As part of the patient care process, dental hygienists provide education on maintaining oral health. Patients must be educated on their current level of oral health and how to improve and maintain it. These patients can, and usually exhibit numerous oral and systemic health problems that must be addressed when discussing the treatment

and counseling plan of the patient. Dental hygienists must be knowledgeable and prepared to treat these patients with the level of care necessary to help maintain their oral health with not only clinical care, but educational counseling as well. Therefore, it is crucial to examine the relationship between families of children with down syndrome and receiving adequate oral health education by conducting a survey of this community.

**Statement of the Problem**

Does a lack of education and access to care play a role in the adequacy of oral health of patients with Down syndrome?

**Significance of the Problem**

Down syndrome is a genetic disorder caused when abnormal cell division results in extra genetic material from chromosome 21. Some characteristics of this syndrome include a small head, flattened facial features, eyes with an upward slant, small unusual, shaped ears, short neck, and poor muscle tone. Most people are able to recognize someone with Down syndrome due to these distinct characteristics, but this condition increases the risk of developing other systemic conditions as well. This includes vision and hearing problems, heart defects, seizures, hypothyroidism, blood disorders, hypotonia, sleeps disorders, digestive problems, celiac disease, nutritional deficiencies, and dental problems. Some of the most common dental problems seen within this community are slower development of teeth, impacted teeth, dental caries, periodontal disease, fissured tongues, and misaligned teeth with class III malocclusion being the most common. Dental hygienists must recognize that these systemic conditions can increase

the risk of developing oral health problems that will lead to a more advanced treatment plan.

In dental hygiene, it is important as providers to not only care for patients through the process of dental cleaning, but also through education and counseling. These factors are crucial when delivering treatment to patients because home care is a part of the maintenance factor of dental hygiene. Without routine dental prophylaxes and good homecare, maintaining a healthy oral cavity becomes increasingly challenging. Not being knowledgeable about the importance of oral health can greatly impact the outcome. If the caregiver of persons with down syndrome does not understand why maintaining a healthy oral cavity is important, then it decreases the chances of these individuals getting routine care. People with Down syndrome often rely on their caregivers to schedule routine dental visits. This shows how vital oral health educational counseling is for this community of patients.

**Operational Definitions**

Hypotonia- abnormally decreased tonicity or strength.

Periodontal Disease (PD)- a group of diseases that affect the periodontal tissues.

(gingiva, alveolar bone, periodontal ligament).

Fissured tongue- a benign condition characterized by deep grooves (fissures) in the dorsum of the tongue.

Malocclusion- a problem in the way the upper and lower teeth fit together in biting or chewing.

Xerostomia- abnormal dryness of the mouth due to insufficient salivary secretions.

# Chapter II: Review of Literature

## Introduction

This literature review will increase the understanding of the relationship between families of children with down syndrome and adequate oral health education. These topics must first be explored independently to explain the concepts' importance in dental hygiene before building a correlation between the two. The literature will define key concepts such as down syndrome, periodontal disease, dental hygiene counseling, and special care clinics. The literature will discuss the need to further research on the relationship between people with Down syndrome and adequate oral health education. *PubMed* and *The National Institute of Health* databases were searched for keywords such as Down syndrome, access to care, oral health, counseling, and oral manifestations.

## Down Syndrome Defined

"Trisomy 21, the presence of a supernumerary chromosome 21, results in a collection of clinical features commonly known as Down syndrome (DS)."[1] This genetic disorder is characterized by physical growth delays, facial features, developmental, and intellectual disabilities ranging from mild to moderate. Although trisomy 21 is the most commonly known type of down syndrome, there are two other forms that are equally important to know and understand due to the similar systemic and oral health effects seen between all types. Trisomy 21, also known as nondisjunction, accounts for almost all Down syndrome cases. Translocation is a type of Down syndrome that is indicated when only part of an extra copy of chromosome 21 attaches to another chromosome. Although there is an additional copy of chromosome 21, the total number remains at 46 due to the

attachment property. Mosaicism accounts for less than 5% of Down syndrome cases and is indicated when a mixture of two types of cells occurs, some containing 46 chromosomes, and others containing 47.[2]

**Vitamin Deficiencies**

Nutritional counseling is taught in dental hygiene education as an important factor of oral health counseling due to the relationship between nutritional deficiencies and decreased oral health. Families of children with down syndrome are at an increased risk for nutritional deficiencies due to poor eating habits, nutrient absorption for individuals who also have celiac disease, and hormone regulation for those who also have endocrine disorders.

Celiac disease is a condition where the body is unable to properly digest barley, rye, and wheat products, causing damage to the walls of the intestine and preventing the body from getting nutrients from food. The diagnosis of celiac disease can further result in malnutrition, decreased growth, and more rarely intestinal cancer.

Evidence has shown that individuals with Down syndrome are diagnosed with celiac disease more frequently than those without the disorder.[3] Because of this, it is also important to examine the relationship between oral health and nutritional deficiencies. Ostermaier et al. researched the correlation between Down syndrome and celiac disease by determining the incidence of celiac disease among children with Down syndrome. The study examined medical records of 39,893 patients and 49 were diagnosed with Down syndrome.[3] Of the 49 patients, 45 were chosen for the study and had non-disjunction (trisomy 21), with 27 being female. Three of the 45 patient selected were diagnosed with

positive celiac serology (anti-endomysial antibody positive and antitissue transglutaminase antibody levels in the 90 to 250 range, with levels <20 indication a positive result).[3] A biopsy was also done on these three patients for confirmation. Due to these findings, the researchers concluded that 6.7% of children with Down syndrome have celiac disease, which is an overall incidence of 325 per 100,000 persons.[3] This percentage also led the researchers to conclude that it is more than 18 times the previously published incidence rate.

The association between celiac disease and Down syndrome has been continuously researched due to the strong frequency seen in earlier studies. Gale et al. concluded that there is evidence of an increased prevalence of celiac disease in Down's syndrome due to the results of their study. The participants were 59 adults with Down's syndrome from New South Wales, Australia. Blood samples were collected from 55 of the 59 participants, and a control group was matched based on age and sex. Biopsies were also performed on those who exhibited a positive antigliadin antibody test in both groups, and the specimens were taken from the far distal section of the duodenum. The antigliadin and antibody test results showed that 21 of the 55 patients with Down's syndrome, had an increase in both IgA and IgG antibodies, and one patient had IgA deficiency and raised IgG antibodies.[4] The biopsy specimen results were from 17 of the 22 patients of these two had unequivocal appearances of celiac disease, two had giardiasis, five showed evidence of lymphocytic infiltration of the lamina propria, and eight were histologically normal.[4]

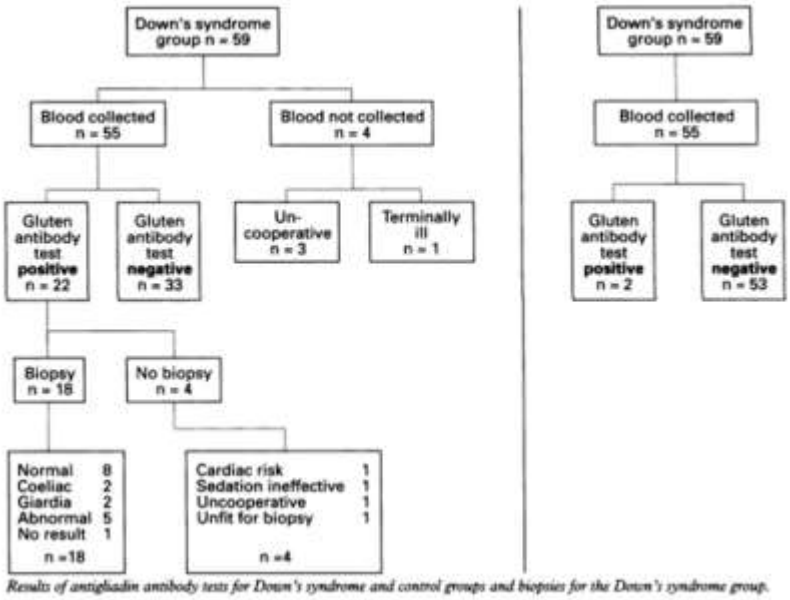


*Figure 1. Results of antigliadin antibody tests for Down syndrome and control groups and biopsies for the Down syndrome group*

Gale L, Wimalaratna H, Brotodiharjo A, Duggan JM. (1997, April). Down's syndrome is strongly associated with coeliac disease. Retrieved September 14, 2023, from https://pubmed.ncbi.nlm.nih.gov/9176077/

Gale et al. concluded that the presence of celiac disease was seen in at least two and probably seven of 18 patients biopsied and of 51 of the entry cohort, resulting in a prevalence of at least 3·9% and as much as 13·7%, which is about $29/10^5$ to show an increase of more than 100-fold.[4]

The prevalence of celiac disease in Down syndrome patients in the United States was studied to determine if screening for celiac disease should be implemented into routine health visits for all children with Down syndrome. Zachor et al. studied seventy-five patients with Down syndrome who underwent serologic tests for celiac disease. These tests included screenings with serum IgA-anti endomysium antibodies (EMAs) and IgA-antigliadin antibodies (AGAs). Serum IgA was measured in each patient to exclude IgA deficiency for more accurate results. The results showed that sixty-two (83%) of the

children with Down syndrome showed negative screening results but 42% of them had gastrointestinal symptoms.[5] These symptoms included constipation, gastroesophageal reflux, failure to thrive, and diarrhea. Lab results also showed IgG-AGA levels in 69 patients with thirty-six of these being positive for IgG-AGA.[5] Zachor et al. concluded to confirm an increased prevalence of celiac disease in Down syndrome individuals with a 35-to 500-fold increase.[5] It also showed the prevalence of this disease with the Down syndrome population being 1 in 20.[5]

Various vitamin deficiencies may be common in individuals with celiac disease, meaning it is important to discuss how these deficiencies may also cause harm to the oral cavity. Deficiencies of vitamin B12 can produce oral manifestations including glossitis, angular cheilitis, recurrent oral ulcers, oral candidiasis, and diffuse erythematous mucositis. Vitamin A is important for a healthy oral mucosa and assists in the formation of ameloblasts and odontoblasts, which are important for tooth development. Vitamin D is a major source for tooth and bone remineralization. Vitamin E deficiency does not cause harm to the oral cavity; however, it is necessary for hormone regulation which is important for this community due to the number of endocrine abnormalities that can exist.

Endocrine abnormalities are prevalent in individuals with Down syndrome and thyroid disorders are shown to be the most common. Within this spectrum of thyroid disorders, persons with Down syndrome may be diagnosed with congenital hypothyroidism, subclinical hypothyroidism, acquired hypothyroidism, both autoimmune and non-autoimmune, and hyperthyroidism.[6] Although each of these disorders are

important and must be understood, congenital hypothyroidism has caused great concern of some researchers due to the many effects this disorder can further cause.

Congenital hypothyroidism is diagnosed by examining the plasma TSH levels. An elevation greater than 10 mIU/1 associated with low plasma T4 at birth is diagnosed as congenital hypothyroidism.[6] This disorder is seen in individuals with Down syndrome 28-35 times more than that of the general population.[6] This disorder also caused greater risk of other systemic conditions including congenital cardiac disease, respiratory distress syndrome, and gastrointestinal anomalies.[6]

Thyroid gland dysfunction is associated with Down syndrome individuals resulting in the best method and frequency of thyroid monitoring to remain controversial. Calcaterra et al. sought to better characterize the timing, prevalence, and dynamics of thyroid dysfunction in children and adolescents with Down syndrome. Data was collected from 91 children and adolescents with Down syndrome from January 2002 to September 2019. Congenital hypothyroidism, autoimmune thyroid diseases (such as Hashimoto's Disease and Graves' Disease), and subclinical hypothyroidism were assessed for by using their respective methods. The results showed that congenital hypothyroidism was detected in 15 subjects, autoimmune thyroid diseases in 23 subjects, and subclinical hypothyroidism in 29 subjects.[7] Calcaterra et al. concluded that more than 70% of their Down syndrome patients had thyroid disease which included congenital hypothyroidism, autoimmune thyroid diseases, and subclinical hypothyroidism, which led to the recommendation of screenings being done every 6 months for this population.[7]

## Oral Health Defects

Oral health defects are also quite common in individuals with Down syndrome. Delayed tooth eruption of both primary and permanent teeth is common, and this delay can vary between a couple of months to a couple of years. Oftentimes, tooth eruption does not follow the normal tooth eruption pattern. Smaller than average teeth, missing teeth, and teeth with roots that are smaller than average can also be seen with this community.

Individuals with down syndrome may have a larger tongue than average, or they may have a small upper jaw that makes the tongue appear and feel larger. The tongue may also have prominent fissures and grooves, which can increase the risk of accumulating bacteria. This accumulation of bacteria causes bad breath and can lead to gum disease.

Malocclusion is also predominately seen in individuals with Down syndrome. Some of these occlusion defects are crowding, underbite, and overbite, with the most common occlusion defect being characterized as class III malocclusion. Class III malocclusion is present when the mandible, or lower jaw, is protruded. It can also be exhibited when the maxilla, or upper jaw, is underdeveloped.

When examining the cranial base, maxillary and mandibular morphology of individuals with Down syndrome, varying degrees of abnormal morphologies can be seen. These abnormalities include a smaller than average maxilla and mandibular ramus and body, severely proclaimed and under erupted maxillary incisors, under erupted mandibular incisors, reduced alveolar heights, anterior open bite, forward rotation of

maxillary and mandibular planes, and hypodontia of permanent teeth.[8] There was a 17.4% smaller than average length of the maxilla and a 6.9% smaller length of the mandible.[8] The maxillary incisors were 6.29 mm more under erupted than average.[8] Alveolar heights of the mandible in both the posterior and anterior regions were smaller in the Down syndrome group by 25.5%.[8] An anterior open bite was largely seen in the DS group with 48% exhibiting this trait and 52% of the patients having an overbite of less than 1 mm.[8] Hypodontia of one or more permanent teeth was seen in 92% of the patients with Down syndrome.[8]

**Periodontal Disease**

Periodontal disease refers to both gingivitis and periodontitis. Periodontitis, a progressed state of gingivitis, involves the destruction of supporting structures around the teeth including the periodontal ligament, bone, and soft tissue. This disease is argued to be commonly seen in individuals with Down syndrome not only due to a decrease in oral health maintenance, but also due to the decreased immune system. Because of this, it is especially important for these individuals to receive oral health education, including homecare instructions.

Nuernberg et al. examined the periodontal status of individuals with Down syndrome and how factors such as sociodemographic and behavioral characteristics are associated.[9] The oral health status of 82 individuals with Down syndrome was examined and a questionnaire regarding the sociodemographic and behavioral factors and family perception was done through a direct interview prior to the clinical examination. The clinical examination was done using the following clinical parameters: visible plaque

index, bleeding on probing (BOP), probing pocket depth (PPD), clinical attachment loss (CAL), and number of missing teeth.

The results showed an overall number of participants presented with high levels of plaque at 66.58%, a median number of bleeding sites reached 30.6%, a median number of sites with PPD and CAL >4 mm were 3.1% and 5.9% respectively, 70.3% of participants had one or more sites with a PPD >4 mm, and 43.75% of participants had at least one site >7mm of PPD.[9] The results of periodontal diagnosis showed that 18 (28.1%) had gingivitis, and 46 (71.9%) had localized or generalized periodontitis.[9]

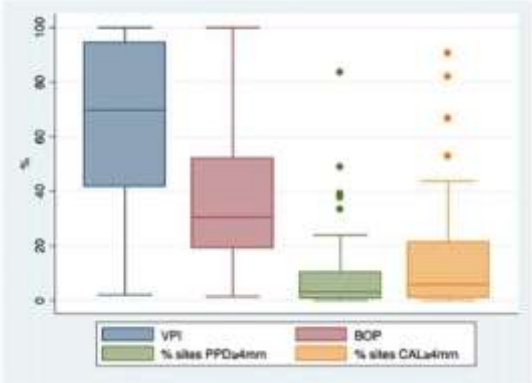


*Figure 2. Boxplot for the percentage of sites with VPI, BOP, PPD, and CAL*

Nuernberg MAA, Ivanaga CA, Haas AN, Aranega AM, Casarin RCV, Caminaga RMS, Garcia VG, Theodoro LH. (2019, May). Periodontal status of individuals with Down syndrome: sociodemographic, behavioural and family perception influence. Retrieved July 2, 2023, from https://pubmed.ncbi.nlm.nih.gov/31062454/

The results of this study show that a high number of individuals with Down syndrome are diagnosed with periodontal disease and adequate oral health maintenance is needed to stop the progression of the disease.[9]

The prevalence of periodontal disease in individuals with Down syndrome was studied by specifically examining defective neutrophil chemotaxis. Izumi et al. argued

that this defect in neutrophils was correlated to an increase in periodontal disease within this community. The results of this study showed that the chemotactic index of the DS patients was significantly lower compared to that of the healthy participants.[10] There was a direct correlation between the incidence of bone loss and the chemotactic index with them being inversely proportional to each other. [10]

| | DS patients mean ± S.D. | Healthy volunteers mean ± S.D. |
|---|---|---|
| Agarose plate method (×20) | (N = 14) | (N = 14) |
| Chemotaxis (A) | 26.6 ± 7.6 | 36.1 ± 6.9 |
| Random migration (B) | 16.9 ± 4.7 | 18.8 ± 4.2 |
| Chemotactic index (A/B) | 1.58 ± 0.25* | 1.94 ± 0.21 |
| Boyden chamber method (×400) | (N = 10) | (N = 9) |
| | 33.2 ± 19.1* | 67.4 ± 26.5* |

* $P < 0.01$ (Mann-Whitney U test)

*Table 1. Neutrophil chemotaxis*

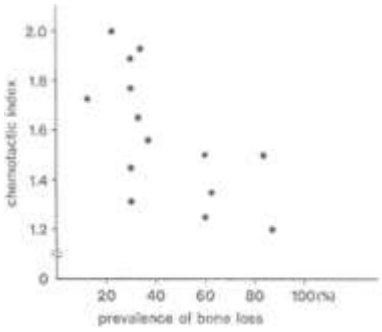


*Figure 3. Relationship between the prevalence of bone loss and the chemotactic index of the patient*

Izumi Y, Sugiyama S, Shinozuka O, Yamazaki T, Ohyama T, Ishikawa I. (1989, May). Defective neutrophil chemotaxis in Down's syndrome patients and its relationship to periodontal destruction. Retrieved July 2, 2023, from https://pubmed.ncbi.nlm.nih.gov/2525619/

**Xerostomia**

Xerostomia is a common condition seen in oral healthcare amongst many communities of patients. It is defined as a decrease of saliva production also commonly known as "dry mouth." One of the most common causes of xerostomia is the use of prescription medications. This can greatly impact the Down syndrome community due to the various systemic conditions they may present that requires use of multiple medications. Guggenheimer and Moore researched the etiology of this condition and concluded that the risk for xerostomia increases with the number of drugs being taken.[11] They also found a wide range of drugs to have a xerostomia incidence of 10 percent or more which include category drugs such as anticholinergic agents, antidepressant/antipsychotic agents, diuretic agents, antihypertensive agents, sedative/anxiolytic agents, muscle relaxant agents, analgesic agents, antihistamines, and miscellaneous medications.[11] This loss of salivary flow can cause multiple oral health complications such as an increased risk of caries and susceptibility to infections. The reduction of saliva leads to the inability to effectively remove food from the oral cavity and a decrease in the proteins and electrolytes that inhibit cariogenic microorganisms and buffer acids.[11] According to Guggenheimer and Moore, patients are more at risk for developing oral infections such as oral candidiasis when salivary flow is reduced.[11]

According to Tanasiewicz et al. research has been found to conclude that more than 500 agents cause or increase xerostomia as a side effect.[12] This research has led researchers to conclude that the interactions between certain

medications can lead to an increased risk of developing dry mouth. According to this research, an increased risk of xerostomia can be caused from drugs such as diuretics, antidepressants, antihistamine agents, neuroleptics, bronchodilators, anxiolytics, cholinolytic agents, hypotensive agents, opioids, immunostimulants, appetite suppressants, and antimigraine drugs.[12] Tanasiewicz et al. also discussed findings found at the University of Reims that revealed the number of drugs administered is more significant than their type to the cause of xerostomia.[12]

**Oral Health Instruction**

Oral health counseling is a major component in the process of patient care. Patients must be educated on oral diseases, how they develop, how to prevent them, and how to maintain good oral health after treatment is done. Without counseling, there is a major increase in the risk of patients not fully benefiting from care, or further developing diseases. This element of patient care can be argued to be more important in patients with Down syndrome due to the various systemic and oral health effects already present from the disorder. A subject that can be discussed within oral health counseling from a dental hygienist is the importance of correct toothbrushing technique. This may be necessary to discuss with all ages of patients with Down syndrome due to the range of intellectual disabilities.

Shyama et al. examined the effectiveness of supervised toothbrushing and an oral health education program for children and young adults with Down syndrome in Kuwait.[13] The study discussed the importance of effective toothbrushing techniques and how it can and must be taught to the disabled community due to the occurrence of heavy

plaque accumulation, gingivitis, and periodontal disease seen within this community.[13] Shyama et al. theorized that the inclusion of family into dental health programs as well as in-service teacher education programs and materials to modify the student's hygiene for school-age children with disabilities, would better the oral health of these individuals.[13] The study was conducted with 112 children with Down syndrome and ages ranged from 11 to 22 years old.[13] Clinical examines were performed on all children, which included gingivitis scoring of PI and GI indices and assessment of plaque thickness. Multiple educational tools and counseling were utilized with the students for the study which included dental health posters, an oral health practices videotape was shown, dental health slogans were sung, and painting sessions of dental health messages and pictures. Teachers also demonstrated proper toothbrushing techniques and assisted those who needed help, which was conducted twice a week. Stars were awarded to students for encouragement and other forms of prizes were given to those who demonstrated proper toothbrushing techniques and performed well during other oral health related activities.

The results of this study showed an improvement in oral hygiene with emphasis on plaque and gingivitis scores.[13] The mean plaque score decreased from 1.93 to 0.95 and the mean gingivitis score decreased from 2.00 to 0.83.[13] These results show that the majority of the subjects had a significant reduction in plaque and gingival indices.[13] The researchers of this study concluded that most of the students within the study showed a significant improvement in their competence and dexterity in brushing, as well as a positive change in attitude towards oral hygiene procedures.[13]

Mean (± SD) of plaque and gingival indices at the baseline and in the final examinations according to age group.

| | Plaque Index | | | Gingival Index | | |
|---|---|---|---|---|---|---|
| Age Group (years) | Baseline | Final | *p*-vaule | Baseline | Final | *p*-value |
| 11-13 | 1.69 (±0.42) | 0.74 (±0.48) | <0.001 | 1.76 (±0.44) | 0.64 (±0.49) | <0.001 |
| 14-16 | 2.01 (±0.39) | 1.04 (±0.50) | <0.001 | 2.05 (±0.46) | 0.86 (±0.52) | <0.001 |
| 17-22 | 2.18 (±0.33) | 1.14 (±0.54) | <0.001 | 2.28 (±0.34) | 1.13 (±0.56) | <0.001 |
| Total | 1.93 (±0.43) | 0.95 (±0.53) | <0.001 | 2.00 (±0.47) | 0.83 (±0.56) | <0.001 |

*Table 2. Mean of plaque and gingival indices at the baseline and in the final examinations according to age group*

Shyama M, Al-Mutawa SA, Honkala S, Honkala E. (2003). Supervised toothbrushing and oral health education program in Kuwait for children and young adults with Down syndrome. Retrieved August 12, 2023, from https://pubmed.ncbi.nlm.nih.gov/14650557/

## Special Care Clinics

Special care dental clinics are essential for the special needs community to receive dental care. They provide comprehensive dental care to patients with severe physical, mental, and medical disabilities. They provide a way for these patients to receive dental care in a safe and helpful environment where they can receive the necessary care they deserve. These clinics are particularly important for the Down syndrome community; however, these clinics are very scarce worldwide which causes a barrier to access. Due to this, it can be argued that all dental care providers, including dentists and dental hygienists, must be educated, and prepared to treat the community of special needs patients who have the ability to be treated at non-special care clinics.

Factors that impact access and experiences of dental care for the Down syndrome community was examined by conducting a quantitative study through a questionnaire that investigated experiences and expectations of dental care for adults with DS.[14] Kaye et al.

investigated questions pertaining to demographic characteristics of respondent, expressions of concern regarding oral health, access to dental services, experience of dental treatment, desirable qualities of dentist, and information requirements.[14] This study showed important information regarding the expressions of concern about oral health and how they were receiving this information.[14]

For this study, 200 people who were caregivers to an individual with DS were randomly selected and 117 of those responded to the questionnaire.[14] Eight-three (65%) participants responded they were concerned about ongoing oral diseases which included periodontal disease, caries, and oral infections.[14] One hundred and three (81%) participants responded they had concern about prevention issues, which included how to maintain oral hygiene, and 17 (13%) responded they assisted in cleaning the teeth of the individual with DS.[14]

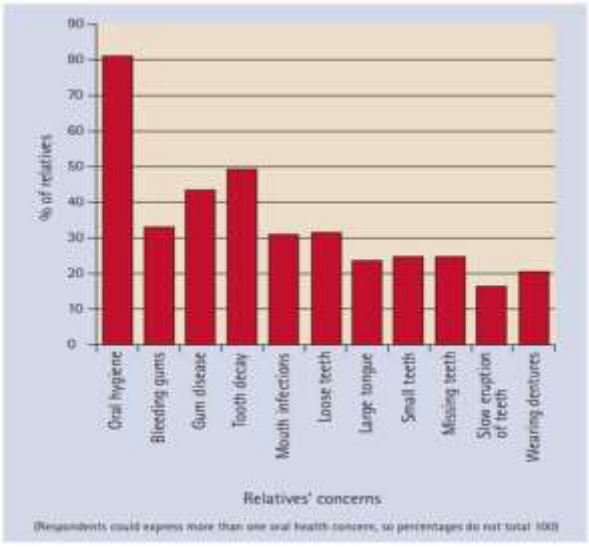


*Figure 4. Percentage of relatives and their concerns*

Kaye PL, Fiske J, Bower EJ, Newton JT, Fenlon M. (2005, May). Views and experiences of parents and siblings of adults with Down Syndrome regarding oral healthcare: a qualitative and quantitative study. Retrieved August 14, 2023, from https://pubmed.ncbi.nlm.nih.gov/15895058/

According to Kaye et al., a high number of these individuals are concerned about the oral health of the child they are caring for.[14] The results also showed a low number of participants were receiving useful information regarding the oral health of the individual with DS. Only 27 (21%) of the respondents were given advice by either a social worker or healthcare professional, to take the individual to the dentist.[14] Seventy-two (56.5%) respondents received the most useful information from speaking to other parents of people with DS, 76 (60%) from charity organizations, and only 37 (29%) received useful information from asking health professionals.[14]

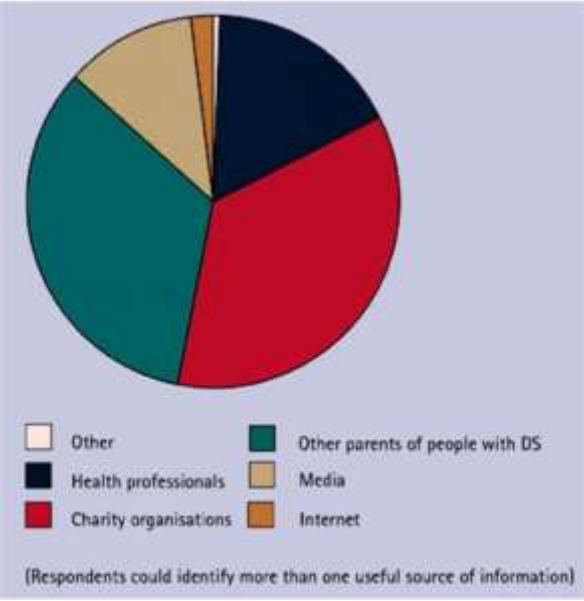


*Figure 5. Most useful sources of learning about DS*

Kaye PL, Fiske J, Bower EJ, Newton JT, Fenlon M. (2005, May). Views and experiences of parents and siblings of adults with Down Syndrome regarding oral healthcare: a qualitative and quantitative study. Retrieved August 14, 2023, from https://pubmed.ncbi.nlm.nih.gov/15895058/

These results show that a high number of participants are worried about the oral health of the individual with DS but only a small number receive information regarding this from a healthcare professional.

D'Addazio et al. examined the dental health of people with disabilities to understand if their oral health needs are met, as well as identify their most critical issues as per dentists.[15] The study used a questionnaire for dentists that asked questions regarding the type of disabilities they provide service to which included physical disabilities, collaborating people with cognitive disabilities, and non-collaborating people with cognitive disabilities.[15] Collaborating people with cognitive disabilities was defined as, "people who, due to the fragility and health vulnerability or psychic or sensory disability, have lost the ability to take care of their own oral health."[15] Non-collaborating people with cognitive disabilities was defined as, "[people] who are unable to collaborate in dental treatments, with severe psychic or sensory disabilities."[15] A questionnaire was also done for people with disabilities and these questions included frequency of visits to the dentist, types of treatment received, barriers they experienced, main difficulties encountered during treatments, habits related to oral hygiene, and if treatment was done in a dedicated facility or a private practice.[15]

The results were obtained from 91 participants of dentists with 55 being male.[15] Of these 91 participants, 73.5% responded they treat less than 10 patients per year with physical disabilities, 76.5% treat less than 10 patients with cognitive and collaborative disabilities, and 93% treat less than 10 patients with non-collaborative disabilities.[15] In addition, over 50% of dentists who have treated an individual with a disability never or almost never plan to include them in follow-up programs even though 73.1% believe that

individuals with physical disabilities do not have good oral hygiene.[15] Eighty percent of dentists reported the need for attending courses or training days regarding the oral health treatments of this community.[15]

The results from the questionnaire of individuals with a disability included 61 respondents.[15] Of the 61 respondents, 30 (49.1%) people reported they never go to the dentist, 29 (47.54%) people reported difficulty finding a specialized dentist able to treat them, and 37 (60%) people reported going to the dentist only when needed.[15]

D'Addazio et al. concluded that although a high number of dentists agree that this community lacks good oral hygiene, a small percentage treat them and plan to do follow-up programs.[15] It also showed that a high percentage of dentists believe they need more education, and attending training courses on how to treat these individuals would benefit them.

**Special Care Courses**

Dental care providers must be educated about the relationship between patients with special needs and oral health. Individuals with down syndrome present many systemic and oral health problems due to the disorder, which are necessary to understand to ensure quality dental care. Dental and dental hygiene programs require a special needs class to be taught, however, it is not required for the students to see patients with special needs in clinic.[16] Due to this, dental care providers graduate their programs with no clinical experience on how to treat this population of patients. Although students do gain education on how to counsel these patients, the lack of clinical experience may still create a barrier.

Casamassimo et al. examined dentists' overall care of children with special health care needs (CSHCN), with emphasis on how educational and environmental factors may affect their practice patterns.[17] A survey was sent to 4,970 dentists in which 1,251 responded.[17] Some of the questions asked pertained to the frequency they treat CSHCN, the education they received in school in how to treat these individuals, their desire for additional training in how to treat this community, and how they perceived various factors as barriers to willingness to provide care to CSHCN.[17]

The results show that only about 10% of dentists see CSHCN "very often" or "often."[17] Approximately one-fourth of the participants stated they had hands-on education with CSHCN in dental school and more than 40% desire additional training to treating CSHCN.[17] Over 60% of dentists agreed that the greatest barrier to willingness of care was patient behavior.[17]

*(Responses expressed as percentages)*

| | I do this procedure in my practice... (N=1237) | | | Dental school education was... (N=1157) | | | I desire more training... (N=1133) | | |
|---|---|---|---|---|---|---|---|---|---|
| | VO/O | S | R/N | HL | LO | N | VD/D | SD | ND |
| Cerebral Palsy | 6 | 19 | 68 | 23 | 47 | 23 | 41 | 23 | 30 |
| Mental Retardation | 10 | 32 | 52 | 27 | 46 | 19 | 41 | 22 | 29 |
| Medically Compromised | 10 | 34 | 50 | 26 | 48 | 18 | 43 | 21 | 28 |

VO/O = Very Often/Often
S = Sometime
R/N = Rarely/Never

HL = Hands-on/Lecture
LO = Lecture/Lab Only
N = None

VD/D = Very Desirable/Desirable
SD = Somewhat Desirable
ND = Not Desirable

*Table 3. Responses about how frequently practitioners treat disabled children, how they were educated in dental school to treat disabled children, and their desire for additional training.*

Casamassimo PS, Seale NS, Ruehs K. (2004, January). General dentists' perceptions of educational and treatment issues affecting access to care for children with special health care needs. Retrieved October 24, 2023, from https://pubmed.ncbi.nlm.nih.gov/14761169/

| | (Responses expressed as percentages) High | Med | Low | No |
|---|---|---|---|---|
| Patient's behavior | 64 | 20 | 6 | 4 |
| Level of disability | 45 | 28 | 12 | 8 |
| Level of disease | 33 | 32 | 17 | 12 |
| My level of training | 30 | 35 | 21 | 7 |
| Office staff training | 24 | 34 | 23 | 13 |
| Availability of funds | 23 | 32 | 27 | 12 |

*Table 4. Practitioners' perceptions of issues as barriers to their willingness to treat disabled children*

Casamassimo PS, Seale NS, Ruehs K. (2004, January). General dentists' perceptions of educational and treatment issues affecting access to care for children with special health care needs. Retrieved October 24, 2023, from https://pubmed.ncbi.nlm.nih.gov/14761169/

Casamassimo et al. also concluded that dentists who did not receive any educational experience in treating CSHCN during school were significantly more likely to report they have never treated patients with special health care needs.[17] This study shows that an increase in education for dentists may also lead to an increase in access to care for the special needs community.[17] Although these healthcare professionals are required to receive a level of education about these individuals, it may be necessary to keep examining if it is enough.

| | Cerebral Palsy | Mentally Retarded | Medically Compromised |
|---|---|---|---|
| Level of disability (N=1023) | p<0.0001 | p<0.0001 | p<0.0001 |
| Level of dental disease (N=1022) | p<0.0001 | p<0.0001 | p<0.0001 |
| Patient behavior (N=1018) | p<0.0001 | p<0.0001 | p<0.0001 |
| Level of staff training (N=1013) | p<0.0001 | p<0.0001 | p<0.0001 |
| Availability of funding (N=993) | p<0.05 | p<0.001 | p<0.0001 |
| Current level of training (N=905) | p<0.0001 | p<0.0001 | p<0.0001 |
| *Chi-square test* | | | |

*Table 5. General practitioners who often or very often treat disabled children perceive the following issues less frequently as barriers to their willingness to treat them as compared with general practitioners who rarely or never treat disabled children*

Casamassimo PS, Seale NS, Ruehs K. (2004, January). General dentists' perceptions of educational and treatment issues affecting access to care for children with special health care needs. Retrieved October 24, 2023, from https://pubmed.ncbi.nlm.nih.gov/14761169/

## Summary

Oral health education for the Down syndrome community is an important factor in providing adequate patient care. This counseling leads to a better understanding of how to achieve a state of health and maintain it. Due to the various systemic and oral health conditions this community faces, it is necessary to educate why the relationship between Down syndrome and poor oral health exists. Having dental professionals who are knowledgeable about this relationship and can provide proper care is essential for this community.

# Chapter III: Methods and Materials

## Introduction

The extent of knowledge caregivers possess about oral health and Down syndrome is important to understand. This will help dental hygienists provide education tailored to the needs of this population. Increasing the knowledge and understanding of caregivers of individuals with Down syndrome can prevent conditions that may arise from lack of oral health care. By assessing the knowledge of this community, an understanding of where education is deficient and how to close these gaps of knowledge to improve the oral health of those with Down syndrome will be evaluated. Caregivers of individuals with Down syndrome were asked to report their dental visit frequency and knowledge of the correlation between oral health and Down syndrome.

## Sample Description

An electronic survey was sent to all members of the Rio Grande Down Syndrome Network, through the bi-monthly newsletter. The intended population for this study is caregivers of individuals with Down syndrome, who are members of the Rio Grande Down Syndrome Network. Members of the network can include those with Down syndrome, caregivers, or supporters of the community who live in New Mexico.

## Research Design

The survey sent to all members of the Rio Grande Down Syndrome Network asked various questions assessing the level of knowledge on the relationship between Down syndrome and oral health, as well as questions relating to the frequency of dental

visits and other individual characteristic variables. The survey contained qualitative and quantitative questions. The survey asked participants to answer several demographic questions such as age, gender, frequency of dental visits, type of dental office seen at, and level of oral home-care achievable. Types of demographic questions asked are, "how often does your child receive dental cleanings," and "what type of dental office do they go to for dental cleanings." These questions assessed the level of knowledge the participants have on the frequency of dental cleanings needed per year for an individual with Down syndrome, as well as the level of accessibility these individuals must receive dental cleanings. Questions such as, "are you aware that Down syndrome is directly correlated to an increased risk of developing periodontal disease," and "are you aware Down syndrome can cause the tongue to have prominent grooves which causes bacteria to get trapped?" assessed the level of knowledge of the direct correlation between Down syndrome and oral health. Each question assessed if an increase in education is needed for parents/ guardians of individuals with Down syndrome. The survey link was emailed to participants via the bi-monthly newsletter. Participants gave consent by opening the survey link. The newsletter contained information regarding the study, what it will consist of, how it will be performed, and the role of who is conducting it. The newsletter posting also contained the survey link and contact information of the Principal Investigator.

**Data Collection**

The Rio Grande Down Syndrome Network newsletter sent out on a bi-monthly basis, reaches approximately 350 recipients. Consent of the survey was attained when the subject opens the survey link. The electronic survey was conducted and sent out through Microsoft Forms. This software allowed for the data to be collected in the required format

and analyzed accordingly. After the survey was sent out, participants had 14 days to complete. After the 14-day completion period, the data from the surveys was collected and analyzed. The survey contained a total of 13 questions that took approximately 5-10 minutes to complete. Participants of the survey had a complete voluntary choice to not participate or end the survey at any time. No personal identification information was collected. They survey was approved to be conducted by the University of New Mexico's Human Research Protections office, HRRPO # 23-497.

**Data Analysis**

The data of the surveys was analyzed through Microsoft Forms. Once all of the surveys were completed, the data were divided into categories that match according to the questions asked. Percentages were used to calculate the responses to each question asked within the survey and in their respective categories. A statistician reviewed all the data collected and questions that were able to form hypotheses were analyzed for further analysis. Chi-square tests were then used to determine if an association or relationship between two means existed. A total of nine questions were tested using a Chi-square test. This was a descriptive study and descriptive statistics were used to present data collected.

# Chapter IV: Results, Discussion, and Conclusion

## Results

The survey was sent out to all members of the Rio Grande Down Syndrome Network on Tuesday January 16, 2024, in their bimonthly newsletter and remained open for 14 days. The survey closed on Monday, January 29, 2024. A total of 30 (n=30) surveys were received.

Of the thirty responses received, 90% (n=30) of the participants reported caring for an individual with Down syndrome while 10% (n=3) do not care for an individual with Down syndrome.

Of the thirty responses, 20% (n=6) reported another caregiver for the same individual completed the survey, thus, their participation in the study ended. The reported data will include the 24 participants who reported a survey had not yet been completed for the individual they care for.

Of the 24 participants, 41.6% (n=10) reported caring for an individual up to 14 years of age. While 20.8% (n=5) and 37.5% (n=9) reported caring for individuals 15-24 years of age and 25-64 years of age, respectively. None of the participants cared for individuals 64 years and above.

| What is the age of the individual in your care? ***(N=24)*** | N | % |
|---|---|---|
| 0-14 years | 10 | 41.6 |
| 15-24 years | 5 | 20.8 |
| 25-64 years | 9 | 37.5 |
| 64 years and above | 0 | 0 |

*Table 6. Age of individual*

Of the 24 participants, 8.3% (n=2) reported the individual in their care gets their teeth professionally cleaned and examined every 3-4 months. While 62.5% (n=15) reported every 6 months, 16.6% (n=4) reported once per year, and 12.5% (n=3) reported the individual has never had their teeth professionally cleaned and examined. None of the participants reported the individual to receive dental care every 2+ years.

| How often does the individual in your care get their teeth professionally cleaned and examined? ***(N=24)*** | N | % |
|---|---|---|
| Every 3-4 months | 2 | 8.3 |
| Every 6 months | 15 | 62.5 |
| Once per year | 4 | 16.6 |
| Every 2+ years | 0 | 0 |
| Has never had their teeth professionally cleaned and examined | 3 | 12.5 |

*Table 7. Frequency of cleaning/exam*

Of the 24 participants, 54.2% (n=13) reported the individual in their care to receive dental treatment from a regular dental office. While 12.5% (n=3) reported receiving care from a special needs' office, 37.5% (n=9) from a pediatric office, and 4.2% (n=1) from a public health/tribal health office.

| What kind of dental office does the individual in your care receive treatment from? ***(N=24)*** | N | % |
|---|---|---|
| Regular dental office | 13 | 54.2 |
| Special needs office | 3 | 12.5 |
| Pediatric office | 9 | 37.5 |
| Public health/tribal health office | 1 | 4.2 |

*Table 8. Type of dental office*

Of the 24 participants, 37.5% (n=9) reported the individual in their care does not take any prescription medications. While 54.2% reported the individual takes 1-2 prescription medications and 8.3% (n=2) take more than 3 prescription medications.

None of the participants reported they were unsure how many prescription medications the individual in their care are taking.

| How many prescription medications does the individual in your care take? ***(N=24)*** | N | % |
|---|---|---|
| 0 | 9 | 37.5 |
| 1-2 | 13 | 54.2 |
| 3+ | 2 | 8.3 |
| Unsure | 0 | 0 |

*Table 9. Number of prescription medications taken*

Of the 24 participants, 37.5% (n=9) reported they are aware most prescription medications can cause dry mouth, leading to a higher incidence of tooth decay and plaque build-up while 62.5% (n=15) are not aware.

Of the 24 participants, 50% (n=12) reported they are aware individuals with Down syndrome are at a higher risk for developing gum disease. Equally, 50% (n=12) reported they are not aware.

Of the 24 participants, 12.5% (n=3) reported the individual in their care has been diagnosed with gum disease. While 70.8% (n=17) reported the individual has not been diagnosed with gum disease and 16.6% (n=4) reported they are unsure.

| Has the individual in your care been diagnosed with gum disease? ***(N=24)*** | N | % |
|---|---|---|
| Yes | 3 | 12.5 |
| No | 17 | 70.8 |
| Unsure | 4 | 16.6 |

*Table 10. Diagnosed gum disease*

Of the 24 participants, 29.2% (n=7) reported they are aware Down syndrome can cause the tongue to have prominent grooves which causes bacteria to get trapped while 66.7% (n=16) are not aware.

Of the 24 participants, 8.3% (n=2) reported a dental provider has instructed the individual in their care to use a tongue scraper. While 41.7% (n=10) reported brushing the tongue with a toothbrush, and 50% (n=11) reported not being instructed to use either method.

| Has a dental provider instructed you to clean the tongue through any of the following methods? Select all that apply. ***(N=24)*** | N | % |
|---|---|---|
| Use a tongue scraper | 2 | 8.3 |
| Brush tongue with toothbrush | 10 | 41.7 |
| None | 12 | 50 |
| Other | 0 | 0 |

*Table 11. Methods of cleaning tongue*

Of the 24 participants, 20.8% (n=5) reported they assist the individual in their care with brushing. While 8.3% (n=2) reported they assist with flossing, 33.3% (n=8) do not assist with any activities listed, 12.5% (n=3) assist with brushing and flossing, 16.7% (n=4) assist with brushing, flossing, and cleaning the tongue, and 8.3% (n=2) assist with brushing and cleaning the tongue.

Of the 24 participants, 66.7% (n=16) reported they assist with some variation of brushing, flossing, and cleaning the tongue and 33.3% (n=8) reported they do not assist with any homecare.

| Do you assist the individual in your care with the following homecare? Select all that apply. ***(N=24)*** | N | % |
|---|---|---|
| Brushing | 5 | 20.8 |
| Flossing | 2 | 8.3 |

| | | |
|---|---|---|
| Cleaning tongue | 0 | 0 |
| I do not assist with these activities | 8 | 33.3 |
| Brushing, flossing | 3 | 12.5 |
| Brushing, flossing, cleaning tongue | 4 | 16.7 |
| Brushing, cleaning tongue | 2 | 8.3 |

*Table 12. Assistance of homecare*

Of the 24 participants, 8.3% (n=2) reported a dental provider has discussed the effects of gum disease on oral health. While 4.2% (n=1) reported the provider discussed the effects of vitamin deficiencies on oral health, 4.2% (n=1) the effects of dry mouth on oral health, 12.5% (n=3) the effects of plaque on oral health, 58.3% (n=14) received no education on any of the topics listed, 8.3% (n=2) the effects of gum disease on oral health and the effects of plaque on oral health, and 4.2% (n=1) the effects of gum disease on oral health, the effects of vitamin deficiencies on oral health, and the effects of plaque on oral health.

Of the 24 participants, 41.7% (n=10) reported a dental provider has discussed any of the following topics listed and 58.3% (n=14) have not had a dental provider discuss any of the topics listed.

| Has a dental provider discussed any of the following topics with you? Select all that apply. ***(N=24)*** | N | % |
|---|---|---|
| The effects of gum disease on oral health | 2 | 8.3 |
| The effects of vitamin deficiencies on oral health | 1 | 4.2 |
| The effects of dry mouth on oral health | 1 | 4.2 |
| The effects of plaque on oral health | 3 | 12.5 |
| I have not received education on any of these topics | 14 | 58.3 |
| The effects of gum disease on oral health, the effects of plaque on oral health | 2 | 8.3 |
| The effects of gum disease on oral health, the effects of vitamin deficiencies on oral health, the effects of plaque on oral health | 1 | 4.2 |

*Table 13. Dental topics*

**Analysis**

1. **A chi-squared test for the relationship between caring for individuals with Down syndrome and the age of the individuals cared for.**

Hypothesis:

Null Hypothesis ($H_0$): There is no association between caring for individuals with Down syndrome and the age of the individuals in care.

Alternative Hypothesis ($H_a$): There is an association between caring for individuals with Down syndrome and the age of the individuals in care.

The null hypothesis was rejected with *p* value of .138 at a significance level of $\alpha = 0.05$.

It was found that there was a significant association between caring for individuals with Down syndrome and the age of the individuals in care. Those who care for individuals with Down Syndrome to be more than those who do not with the age range 0-14 years being more of the age of the individuals they care followed by age range 25-64 years old and finally 14-24 years, *X*^2 (N=24, 2) = 3.97, *p*=.138 (Figure 1).

2. **Chi-squared test for the relationship between caring for individuals with Down syndrome and whether another caregiver for the same individual has completed the survey in the past.**

Hypothesis:

Null Hypothesis ($H_0$): There is no association between caring for individuals with Down syndrome and whether another caregiver for the same individual has completed the survey in the past.

Alternative Hypothesis ($H_a$): There is an association between caring for individuals with Down syndrome and whether another caregiver for the same individual has completed the survey in the past.

With a p-value of 0.033, we reject the null hypothesis at a significance level of $\alpha = 0.05$

It was found that less or fewer caregivers for the same individual had completed this survey in the past, X^2(N=30, 1) = 4.45, p=.033 (Figure 2).

3. **Chi-squared test for the relationship between caregiver awareness of individuals with Down syndrome being at higher risk for developing gum disease and the frequency of professional dental examinations for the individuals in their care.**

Hypotheses:

Null Hypothesis ($H_0$): There is no association between caregiver awareness of individuals with Down syndrome being at higher risk for developing gum disease and the frequency of professional dental examinations for the individuals in their care.

Alternative Hypothesis ($H_a$): There is an association between caregiver awareness of individuals with Down syndrome being at higher risk for developing gum disease and the frequency of professional dental examinations for the individuals in their care.

With a p-value of 0.334, we fail to reject the null hypothesis at a significance level of $\alpha = 0.05$.

It was found that there was a significant difference of caregivers of individuals with Down Syndrome aware of the higher risks for developing gum diseases of individuals under their care in how often they get them professional dental examination, $X^2(N=24, 3) = 3.40$, $p = .334$.

4. **A chi-squared test for the relationship between caregiver awareness of individuals with Down syndrome being at higher risk for developing gum disease and the type of dental office used for the individual's dental care.**

Hypotheses:

Null Hypothesis ($H_0$): There is no association between caregiver awareness of individuals with Down syndrome being at higher risk for developing gum disease and the type of dental office used for the individual's dental care.

Alternative Hypothesis ($H_a$): There is an association between caregiver awareness of individuals with Down syndrome being at higher risk for developing gum disease and the type of dental office used for the individual's dental care.

With a p-value of 0.70, we fail to reject the null hypothesis at a significance level of $\alpha = 0.05$.

It was observed that regular dental office was a significantly more likely to be used by care givers of individuals with Down Syndrome aware of the higher risks of developing gum disease than any other dental offices, $X^2(N= 24, 4) = 2.22$, $p = .70$ (Figure 4)

5. **A chi-squared test for the relationship between the diagnosis of gum disease in individuals under the care of caregivers and the number of prescription medications they take.**

Hypotheses:

Null Hypothesis ($H_0$): There is no association between the diagnosis of gum disease in individuals under caregivers' care and the number of prescription medications they take.

Alternative Hypothesis ($H_a$): There is an association between the diagnosis of gum disease in individuals under caregivers' care and the number of prescription medications they take.

With a p-value of 0.80, we fail to reject the null hypothesis at a significance level of $\alpha = 0.05$.

It was found after diagnosis that a significant number of individuals are not diagnosed with gum diseases and those diagnosed the number of 1-2 mediations is significantly higher, $X^2(N=24,4) = 1.63$, $p = .80$.

6. **A chi-squared test for the relationship between caregiver awareness of the oral health implications of Down syndrome and whether they assist the individual in their care with homecare dental treatment.**

Hypotheses:

Null Hypothesis ($H_0$): There is no association between caregiver awareness of the oral health implications of Down syndrome and whether they assist the individual in their care with homecare dental treatment.

Alternative Hypothesis ($H_a$): There is an association between caregiver awareness of the oral health implications of Down syndrome and whether they assist the individual in their care with homecare dental treatment.

With a p-value of 0.818, we fail to reject the null hypothesis at a significance level of $\alpha = 0.05$.

It was observed that there was a significant lack of knowledge of the care givers of that Down Syndrome can cause the tongue to have prominent grooves which causes bacteria to get trapped and therefore a significantly higher number do not assist in homecare dental treatment, $X^2(N=23,6) = 2.93$, $p = .818$.

7. **A chi-test to analyze the relationship between caregiver awareness of medication-induced dry mouth and whether a dental provider has instructed the individual in their care to clean the tongue.**

Hypotheses:

Null Hypothesis ($H_0$): There is no association between caregiver awareness of medication-induced dry mouth and whether a dental provider has instructed the individual in their care to clean the tongue.

Alternative Hypothesis ($H_a$): There is an association between caregiver awareness of medication-induced dry mouth and whether a dental provider has instructed the individual in their care to clean the tongue.

With a p-value of 0.217, we fail to reject the null hypothesis at a significance level of $\alpha = 0.05$.

It was found that most caregivers were not aware of the effects of medications and a significant number did not receive dental instructions from a dental provider to clean the tongue, $X^2(N=24,3) = 4.45$, $p=.217$.

8. **A chi- test showing the relationship between caregiver awareness of individuals with Down syndrome being at a higher risk for developing gum disease and whether a dental provider has discussed this topic with them.**

Hypotheses:

Null Hypothesis ($H_0$): There is no association between caregiver awareness of individuals with Down syndrome being at a higher risk for developing gum disease and whether a dental provider has discussed this topic with them.

Alternative Hypothesis ($H_a$): There is an association between caregiver awareness of individuals with Down syndrome being at a higher risk for developing gum disease and whether a dental provider has discussed this topic with them.

With a p-value of 0.20, we fail to reject the null hypothesis at a significance level of $\alpha = 0.05$.

It was observed that there was no significant difference of awareness of how prone individuals with Down Syndrome are to gum disease due to little or no formal instructions provided from a dental provider, $X^2(N=24,7) =9.90$, $p=.20$

**Discussion**

The knowledge caregivers of children with Down syndrome possess is essential to the degree of oral health these individuals have. Individuals with Down syndrome may have a wide variety of systemic and oral health conditions which leads to a greater need for consistent and quality oral healthcare. This level of oral care is firstly achieved

through possessing the knowledge to understand why it is needed and how to attain it. The access to care these individuals have can also decrease their oral health. This access to care takes into consideration not only the facility, but also the access to knowledgeable oral health professionals who can and will successfully educate these caregivers about the correlation between down syndrome and oral health. The results of the survey overall show a need for an increase in education or access to care for the individuals with Down syndrome. Most caregivers reported that the individual in their care receives dental cleanings and exams every six months, which is a longer recall interval than preferred for patients with or who are at a greater risk for poor oral health. The results also showed that only 12% (n=3) of individuals with Down syndrome receive dental care in a special needs clinic. Most individuals are reported to be receiving dental care from a regular dental office at 50%. This number can be influenced by the lack of access to dental care from special needs clinics in New Mexico.

More than half of the individuals with Down syndrome were reported to be taking at least one prescription medication while the same number of caregivers reported not knowing the negative effects it has on oral health. While 71% of the individuals have not been diagnosed with gum disease, only 50% of caregivers were aware that individuals with Down syndrome are at a higher risk for developing the disease. Most caregivers, 70%, were not aware that Down syndrome can cause prominent grooves in the tongue leading to bacteria getting trapped, and almost half reported that the individual in their care has not been instructed to clean their tongue with any of the following methods listed, including a toothbrush or tongue scraper. Although more than half of the individuals have been instructed to effectively clean their tongue, most were not educated

on why this is especially important for someone with Down syndrome. Most caregivers reported that they assist the individual in their care with some variation of homecare at 66.7%.

Unfortunately, more than half of the caregivers, 58%, reported they had not received education on the various topics listed which included: the effects of gum disease on oral health, the effects of vitamin deficiencies on oral health, the effects of dry mouth on oral health, and the effects of plaque on oral health. This shows that a large number of individuals with Down syndrome and their caregivers could not be getting the oral health education they need. The results show that in every category, except one, more than half of the caregivers do not have adequate knowledge on the effects of Down syndrome on oral health. Further research should be done to assess whether these results are the same across other regions and if the lack of oral health education for the individuals and their caregivers is due to the dental professionals willingly not providing this care or if they themselves do not feel educated enough on this topic to provide the necessary care. Previous research done, as discussed in the literature review, shows positive outcomes on oral health when satisfactory education is done. The results of this study show a small glimpse into a huge problem that can be existing for this community and research must continue to be done to prove that advancements and changes are needed to improve and maintain the oral health of these individuals.

**Limitations**

The survey was sent out in a bi-monthly newsletter which consisted of x number of pages. The posting was included on the last page, and ideally, would have been included on the first page for optimal viewing. The position of the posting could have

contributed to the limited number of responses received. Future studies should consider a stand-alone email promoting the survey in an attempt to increase the response rate.

Additionally, the survey contained a flaw in the design. The first question asked if the participant of the survey was a caretaker of an individual with Down syndrome and included two choices, “yes” or “no.” However if the participant answered “no” it did not end the survey which should have been done. This led to three participants answering “no,” the survey did not end, and the participant was able to answer the remaining questions which could have altered the results of the data. The recruitment posting should have contained the language “for only caregivers of an individual with Down syndrome” to ensure the targeted sample population was reached.

**Future Studies**

The results support caregivers having inadequate knowledge on the effects of Down syndrome on oral health. Further research should be done to assess whether these results are the same across other regions. Additionally, research could investigate the level of education dental professionals have. Previous research done, as discussed in the literature review, shows positive outcomes on oral health when satisfactory education is done. The results of this study show a small glimpse into a huge problem that can be existing for this community and research must continue to be done to support advancements and necessary changes to improve and maintain the oral health of these individuals. In addition, seminars could be created for caregivers to receive information on oral health education specific to Down syndrome.

**Conclusion**

There is a need for increased oral health education for individuals with Down syndrome and their caretakers. Down syndrome causes many systemic and oral health conditions that can lead to an increased risk for developing many oral diseases and conditions. It is important for these individuals and their caretakers to be properly educated on the correlation between Down syndrome and oral health and how to effectively maintain a healthy periodontium. Many members of the Rio Grande Down Syndrome Network do not have a complete understanding and knowledge of how this disorder is affecting the individuals in their care nor how to properly help them. Dental professionals should be well educated on this issue to provide quality dental health care for all members of their community, regardless of limitations or not. The access to special needs clinics can greatly impact the quality of care these individuals are receiving. More research must be done to conclude where this lack of access to care and education is developing from.

# Chapter V: Article for Submission - Journal of Dental Hygiene

## Title Page

Oral Health Education and Dental Care Access of Families of Children with Down Syndrome in New Mexico

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Keywords: Dental hygiene, Down syndrome, Education

ABSTRACT

**Purpose:** The purpose of this study was to assess the oral health education and dental care access of families of children with Down syndrome in New Mexico.

**Methods:** The data were gathered from a survey available to members of the Rio Grande Down Syndrome Network for 14 days containing 13 questions.

**Results:** The most reported age range for the individuals in care were 0-14 years at 41.6%. Most individuals with Down syndrome receive dental services every six months (62.5%) at a regular dental office (54.2%). Caregivers reported the individuals are taking 1-2 prescription medications (54.2%) and not aware of the correlation between prescription medications and dry mouth (62.5%). Half of the participants are aware of the increased risk for gum disease (50%) even though most have not been diagnosed with the disease (70.8%). Most caregivers are not aware Down syndrome can cause prominent grooves on the tongue (66.7%) and have not been instructed to clean the tongue (45.8%).

Homecare assistance of some variation was reported at 66.7%. Caregivers reported to have not received education on any of the listed dental topics (58.3%).

**Conclusion:** There is a need for increased oral health education for individuals with Down syndrome and their caretakers. Many participants do not have a complete understanding and knowledge of how this disorder is affecting the individuals in their care nor how to properly help them. More research must be done to determine the source of lack of access to care and education.

## INTRODUCTION

Dental hygiene has evolved throughout many years to become an important preventive care measure within the healthcare system. During the establishment of dental hygiene, many people considered tooth cleaning to be luxury rather than a necessity. Previously it was thought that your teeth only needed to be cared for when a problem had already occurred rather than as a preventive measure. The view of dental hygiene shifted as research on the prevention of poor oral health continued, leading to more people caring for their oral health.

Research has continued to grow, leading to new technologies and advancements. Although it is important for these advancements to take place, it is equally important for them to be adaptive to all populations. Dental needs are apparent in all individuals and not all of them have access to the dental care they need and deserve. The special needs community and the access to dental care they get is important to consider when discussing the future of dental hygiene. All communities of patients must be treated with the same level of care and attention and although advancements have been made in

treating the special needs community, there is still a lack of care that needs to be addressed.

As part of the patient care process, dental hygienists provide education on maintaining oral health. Patients must be educated on their current level of oral health and how to improve and maintain it. These patients can, and usually exhibit numerous oral and systemic health problems that must be addressed when discussing the treatment and counseling plan of the patient. Dental hygienists must be knowledgeable and prepared to treat these patients with the level of care necessary to help maintain their oral health with not only clinical care, but educational counseling as well. Therefore, it is crucial to examine the relationship between families of children with down syndrome and receiving adequate oral health education by conducting a survey of this community. By assessing the knowledge of this community, an understanding of where education is deficient and how to close these gaps of knowledge to improve the oral health of those with Down syndrome will be evaluated.

## METHODS AND MATERIALS

An electronic survey was sent to all members of the Rio Grande Down Syndrome Network, through the bi-monthly newsletter. The intended population for this study is caregivers of individuals with Down syndrome, who are members of the Rio Grande Down Syndrome Network. The survey asked various questions testing the level of knowledge on the relationship between Down syndrome and oral health, as well as questions relating to the frequency of dental visits and other individual characteristic variables. An explanation of the study as well as the link to the survey, was sent through

email to the president of the Rio Grande Down Syndrome Network, which was then included in the network's monthly newsletter that is sent to all members which includes approximately 350 people, as well as being posted on the network's online website. The president of the network also posted a brief explanation of the survey and callout for participation via their social media pages. Consent of the survey was attained when the subject participates in the survey. The electronic survey was conducted and sent out through Microsoft Forms. This software allowed for the data to be collected in the required format and analyzed accordingly. After the survey was sent out, participants had 14 days to complete. After the 14-day completion period, the data from the surveys were collected and analyzed. The survey contained a total of 13 questions that took approximately 5-10 minutes to complete. Participants of the survey had a complete voluntary choice to not participate or end the survey at any time. No personal identification information was collected. They survey was approved to be conducted by the University of New Mexico's Human Research Protections office.

## RESULTS

Thirty responses were collected in total for question one, and twenty-four responses were collected for the remaining twelve questions. Twenty-seven (90%) of the participants reported caring for an individual with Down syndrome and twenty-four (80%) reported that another caregiver had not already completed the survey. The most reported age range for the individuals in care were 0-14 years at (41.6%). Most individuals with Down syndrome are receiving dental services every six months at (62.5%) and at a regular dental office (54.2%). Caregivers reported the individual in their care are taking 1-2 prescription medications at (54.2%), and most are not aware of the correlation between

prescription medications and dry mouth (62.5%). Half of the participants are aware of the increased risk for gum disease in Down syndrome individuals (50%), and most have not been diagnosed with the disease at (70.8%). Most caregivers are not aware Down syndrome can cause prominent grooves on the tongue (66.7%) and have not been instructed to clean the tongue at (45.8%). Brusing is the highest reported care to be assisted with at (58.3%). Caregivers reported to have not received education on any of the listed dental topics at (58.3%).

## DISCUSSION

The knowledge caregivers of children with Down syndrome possess is essential to the degree of oral health these individuals have. Individuals with Down syndrome may have a wide variety of systemic and oral health conditions which leads to a greater need for consistent and quality oral healthcare. This level of oral care is firstly achieved through possessing the knowledge to understand why it is needed and how to attain it. The access to care these individuals have can also decrease their oral health. This access to care takes into consideration not only the facility, but also the access to knowledgeable oral health professionals who can and will successfully educate these caregivers about the correlation between down syndrome and oral health. The results of the survey overall show a need for an increase in education or access to care for the individuals with Down syndrome. Most caregivers reported that the individual in their care receives dental cleanings and exams every six months, which is a longer time interval than wanted for patients with or at a greater risk for poor oral health. The results also showed that only 3 (12%) caregivers reported that the individual with Down syndrome receives dental care from a special needs clinic. Most individuals are reported to be receiving dental care from

a regular dental office at 50%. This number can be influenced by the lack of access to dental care from special needs clinics in New Mexico. More than half of the individuals with Down syndrome were reported to be taking at least one prescription medication while the same number of caregivers reported not knowing the negative effects it has on oral health. While 71% of the individuals have not been diagnosed with gum disease, only 50% of caregivers were aware that individuals with Down syndrome are at a higher risk for developing the disease. Most caregivers at 70% were not aware that Down syndrome can cause prominent grooves in the tongue leading to bacteria getting trapped, and almost half reported that the individual in their care has not been instructed to clean their tongue with any of the following methods listed, including a toothbrush or tongue scraper. Although more than half of the individuals have been instructed to effectively clean their tongue, most were not educated on why this is especially important for someone with Down syndrome. Most caregivers did report that they assist the individual in their care with homecare such as brushing and flossing at 76%. Unfortunately, more than half of the caregivers at 58% reported that they have not received education on the various topics listed which included: the effects of gum disease on oral health, the effects of vitamin deficiencies on oral health, the effects of dry mouth on oral health, and the effects of plaque on oral health. This shows that a large number of individuals with Down syndrome and their caregivers could not be getting the oral health education they need. The results show that in every category, except one, more than half of the caregivers do not have adequate knowledge on the effects of Down syndrome on oral health. Further research should be done to assess whether these results are the same across other cities and if the lack of oral health education for the individuals and their caregivers is due to

the dental professionals willingly not providing this care or if they themselves do not feel educated enough on this topic to provide the necessary care. Previous research done, as discussed in the literature review, shows positive outcomes on oral health when satisfactory education is done. The results of this study show a small glimpse into a huge problem that can be existing for this community and research must continue to be done to prove that advancements and changes are needed to improve and maintain the oral health of these individuals.

## CONCLUSION

There is a need for increased oral health education for individuals with Down syndrome and their caretakers. Down syndrome causes many systemic and oral health conditions that can lead to an increased risk for developing many oral diseases and conditions. It is important for these individuals and their caretakers to be properly educated on the correlation between Down syndrome and oral health and how to effectively maintain a healthy periodontium. Many members of the Rio Grande Down Syndrome Network do not have a complete understanding and knowledge of how this disorder is affecting the individuals in their care nor how to properly help them. Dental professionals should be well educated on this issue to provide quality dental health care for all members of their community, regardless of limitations or not. The access to special needs clinics can greatly impact the quality of care these individuals are receiving. More research must be done to conclude where this lack of access to care and education is developing from.

# Appendix A: HRPP Approval Letter


Human Research Protections Program

January 4, 2024
Christine Nathe
(505) 272-8147
Fax: (505) 272-5584
CNathe@salud.unm.edu

Dear Christine Nathe:

On 1/4/2024, the HRRC reviewed the following submission:

| | |
|---|---|
| Type of Review: | Initial Study |
| Title of Study: | Oral Health Education and Dental Care Access of Families of Children with Down Syndrome in Albuquerque. |
| Investigator: | Christine Nathe |
| Study ID: | 23-497 |
| Submission ID: | 23-497 |
| IND, IDE, or HDE: | None |
| Submission Summary: | Initial Study |
| Documents Approved: | • Consent Letter from RGDSN<br>• HRP-507- Consent Template for Survey Final.pdf<br>• HRP-583 - Survey Template 3.pdf<br>• Survey Draft Final.pdf |
| Review Category: | EXEMPTION: Categories (2)(i) Tests, surveys, interviews, or observation (non-identifiable) |
| Determinations/Waivers: | Provisions for Consent are adequate.<br>HIPAA Authorization Addendum Not Applicable. |
| Submission Approval Date: | 1/4/2024 |
| Approval End Date: | None |
| Effective Date: | 1/4/2024 |

The HRRC approved the study from 1/4/2024 to inclusive. If modifications were required to secure approval, the effective date will be later than the approval date. The "Effective Date" 1/4/2024 is the date the HRRC approved your modifications and, in all cases, represents the date study activities may begin.

Because it has been granted exemption, this research is not subject to continuing review.

HEALTH SCIENCES

## Human Research Protections Program

Please use the oonsent doooments that we.re approved by the HRRC. The approved consents are avaHable for your retrieval in theoocuments tab of the parent study.

If **the study meets the definition of an -NIH Clinical Trial, the study must be registered** ·tn **the CllnlcalTrlals,gov database. Addltlonally, the approved consent document(s} must be uploaded to the Cllnlcaffrlats.gov database.**

This determination applies only to the activities described i,nthis submission and does not apply should you make any changes to these documents. If changes are being considered t,hese must be submitted for r-eview in a study modification to he HRRC fOf' a determination prior to implementation. If there are questions about whether HRRC rev,iew is needed, contact the HRPO before implementing changes without .approval. A change in the research .may disqualify this research f11om the current revie category. You may submit a modification by navigating to the active study and clic ing thecreate Modification/CR· button.

If this study is approved for a waiver of HIPAA authorization the IRB had determined the use or disclosure of protected health information in this study involves no more than a minimal ,r.is,kto the pliivacy of individuals because the study contains a plan to protect the identifiers from ,improper use and disclosure, a process to destroy the identifiers at the earliest opportunity consistent ·th conduct of the research and there are written assurances that the protected health information ill not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for othe,research for which the use or disclosure of protected health information would be permitted. The IRB reoognizes that the research could not practicably be conducted without the waiv-er, and could not practicably be conducted withou access to and use of the p.rotected health information.

If your submission indicates you will translate mater,iats post.approval of English materials, you may not ,recruit or enroll participants in another l'anguage, until a'll translated materials are reviewed and approved.

In conducting this study you are required to follow the !Investigator Manual (HRP-103) hich can 1be found by navigating to the IRB Library.

Sincerely,

Thomas F. Byrd, MO
HRRC Executive Chair

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## Appendix B: Informed Consent

**The University of New Mexico Health Sciences Center**

**Consent and Authorization to Participate in a Research Study**

Dear Prospective Participant,

Researchers at the University of New Mexico are inviting you to take part in a survey about oral health education and dental care access of families of individuals with Down syndrome in Albuquerque. The purpose of this survey is to assess the knowledge of parents/guardians of an individual with Down syndrome about oral health and how the disorder of Down syndrome affects it, as well as frequency of dental visits and the type of dental offices these individuals are receiving care from.

The information gained from this study can help increase dental professionals' knowledge about the disorder and how their patient care can be improved for this community. It can also lead to increased advocacy for improved access to dental care for the Down syndrome community. Due to the lack of previous research done on this issue, the results of this study can greatly impact how these individuals receive dental hygiene care in the future.

Although you may not get personal benefit from taking part in this research study, your responses may help us understand more about the correlation between Down syndrome and oral health, and if a lack of education plays a role. There are no known risks to participating in this study. The survey should take about 10 minutes to complete.

Your response to the survey is anonymous, which means no names will appear or be used on research documents or be used in presentations or publications. The research team will not know that any information you provided came from you, nor even whether you participated in the study.

We hope to receive completed questionnaires from about 50 people, so your answers are important to us. Of course, you have a choice about whether or not to complete the survey/questionnaire, but if you do participate, you are free to skip any questions or discontinue at any time.

If you have questions about the study, please feel free to ask; my contact information is given below. If you have questions regarding your legal rights as a research subject, you may call the UNM Human Research Protections Office at (505) 272-1129.

Thank you in advance for your assistance with this important project. To ensure your responses/opinions will be included, please submit your completed survey/questionnaire by January 29, 2024. By clicking on the link below, you will be agreeing to participate in the above-described research study.

Survey Link

Sincerely,

Christine Nathe

University of New Mexico Health Sciences Division of Dental Hygiene

PHONE: 505-272-8147

E-MAIL: CNathe@salud.unm.edu

HRRC ID#23-497

## Appendix C: Survey

| Question | Response |
|---|---|
| 1. Do you care for an individual with Down syndrome? | a. Yes<br>b. No |
| 2. Has another caregiver for the same individual completed this survey? | a. Yes > End Survey<br>b. No |
| 3. What is the age of the individual in your care? | a. 0-14 years<br>b. 15-24 years<br>c. 25-64 years<br>d. 64 years and above |
| 4. How often does the individual in your care get their teeth professionally cleaned and examined? | a. Every 3-4 months<br>b. Every 6 months<br>c. Once per year<br>d. Every 2+ years<br>e. Has never had their teeth professionally cleaned and examined |
| 5. What kind of dental office does the individual in your care receive treatment from? | a. Regular dental office<br>b. Special needs office<br>c. Pediatric office<br>d. Public health/tribal health office<br>e. Other |
| 6. How many prescription medications does the individual in your care take? | a. 0<br>b. 1-2<br>c. 3+<br>d. unsure |
| 7. Are you aware most prescription medication can cause dry mouth, which leads to a higher incidence of tooth decay (cavities) and plaque build-up? | a. Yes<br>b. No |
| 8. Are you aware individuals with Down syndrome are at a higher risk for developing gum disease? | a. Yes<br>b. No |
| 9. Has the individual in your care been diagnosed with gum disease? | a. Yes<br>b. No |

| | |
|---|---|
| 10. Are you aware Down syndrome can cause the tongue to have prominent grooves which causes bacteria to get trapped? | a. Yes<br>b. No |
| 11. Has a dental provider instructed you to clean the tongue through any of the following methods? Select all that apply. | a. Use a tongue scraper<br>b. Brush tongue with toothbrush<br>c. None<br>d. Other: _____ |
| 12. Do you assist the individual in your care with the following homecare? Select all that apply. | a. Brushing<br>b. Flossing<br>c. Cleaning tongue<br>d. I do not assist with these activities |
| 13. Has a dental provider discussed any of the following topics with you? Select all that apply. | a. The effects of gum disease on oral health<br>b. The effects of vitamin deficiencies on oral health<br>c. The effects of dry mouth on oral health<br>d. The effects of plaque on oral health<br>e. I have not received education on any of these topics |

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