Self-Reported Oral health Assessment and Attitudes Toward Oral Health for Adults With Cystic Fibrosis

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SELF-REPORTED ORAL HEALTH ASSESSMENT AND ATTITUDES TOWARD ORAL HEALTH FOR ADULTS WITH CYSTIC FIBROSIS

by

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B.S.D.H. June 2013, Al Baha University, Saudi Arabia

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ABSTRACT

SELF-REPORTED ORAL HEALTH ASSESSMENT AND ATTITUDES TOWARD ORAL HEALTH FOR ADULTS WITH CYSTIC FIBROSIS

Ahmed Ali Almuntashiri
Old Dominion University, 2018
Director: Dr. Susan Daniel

Purpose: Cystic fibrosis (CF) is a chronic genetic disorder that an individual has at birth. Cystic fibrosis impacts equally all races, gender and becomes worse over time. The aim of this current study was to evaluate oral health status, interaction with the oral health system, and oral health awareness in adults with cystic fibrosis. Methods: A validated survey consisting of 27 questions was distributed online through cystic fibrosis Facebook pages. Individuals with CF who were 18 years old or older, residing in the U.S. and having English as their primary language were asked to respond to the survey. Independent variables were demographic categories, whereas the dependent variables were oral health assessment, interaction with the oral health system, and oral health awareness. Results: Out of 350 sample sizes, a total of 133 responses were received; 87 met inclusion criteria. Respondents were 75% female, 50% were single, and 58.6% were employed. Seventy percent reported an annual household income more than $35,000. Good to very good conditions of the mouth and the teeth were reported by respondents with four-year college degree or higher. Married respondents were more likely to have dental insurance, visit a dental office and to have visited a dentist within 12 months. Female 33 and older scored higher on the oral health awareness scale than younger respondents. Conclusion: Although most respondents reported good or very good oral health, 52.7% reported dry mouth, 31% reported difficulty chewing food, and 29.1% reported seeing blood on their toothbrushes. Better oral health habits with additional education for CF adults are needed.
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CHAPTER I

INTRODUCTION

Oral health is a window into overall health and effects each aspect of our lives. Thus, a human’s ability to speak, smile, smell, taste, touch, chew, swallow, and make facial expressions to show feelings and emotions require good oral health (Evans et al., 2000). The mouth includes not only the teeth and gingiva, but also the hard and soft palate, throat, tongue, lips, salivary glands, muscles of mastication, and upper and lower jaws (Evans et al., 2000). An individual with optimum oral health is free of oral pain, oral and pharyngeal cancers, birth defects such as cleft lip and palate, and other diseases (Evans et al., 2000). The oral cavity exhibits symptoms of deficiencies or concerns in other organ systems. Systemic diseases that affect the body, such as diabetes and Sjögren’s syndrome may appear first as signs or symptoms in the oral (Evans et al., 2000). Relationships between chronic oral infections and systemic illnesses have been identified in the cardiovascular system with stroke and coronary disease, the respiratory system and premature low weight births (Evans et al., 2000). While today’s dentistry has been sophisticated and comfortable with many advances in diagnosis and treatment, the majority of people believe that dental visits are necessary only if they experience pain or something abnormal. For instance, 100 million people in the United States fail to visit a dental clinic annually (“Oral Health”, 2018).

Each person has a unique genetic composition. The genetic pattern of human development has a strong relationship with oral tissue that surrounds the mouth (Evans et al., 2000). Genotypic variations have shown an impact on both the dentitions and surfaces of one’s teeth, which can increase susceptibility to dental caries (Shimizu et al., 2012). Indicators of genetic influences on oral health have been correlated with gender differences (Rintakoski,
Kaprio, & Murtomaa, 2010). Cystic fibrosis is a recessively inherited, lethal genetic disorder that affects males and females equally; specifically, Caucasians. Of the 70,000 individuals with cystic fibrosis worldwide, around 30,000 live in the United States of America.; approximately 1000 individuals are diagnosed with cystic fibrosis in the U.S annually (Strausbaugh & Davis, 2010). It has been reported that individuals with special health care needs have higher risk of poor oral hygiene and oral problems. Such oral problems include dental caries and periodontal disease (Tesini, 1981).

**Statement of the Problem**

The mouth is occupied with countless bacteria, some of which are linked to dental and oral diseases. The silent epidemic of dental and oral diseases is affecting lives and health of various population groups (Evans et al., 2000). Such population groups include vulnerable adults and disabled or medically compromised individuals (Evans et al., 2000). Furthermore, oral health issues in employed healthy adults result in loss of 164 million hours of work annually (Evans et al., 2000). Thus, the restrictions of school, work, and home activities causes more oral health concerns in population.

Socioeconomic factors impact oral health. Socioeconomic factors in some groups of people make it difficult to obtain transportation, finances, or time from work to attend to health needs (Evans et al., 2000). In a survey conducted on adults to measure their oral health status based on their families’ incomes, adults from poor families had 28% worse oral health status while adults in non-poor families had less issues with oral health status by 13% (Bloom, Simile, Adams, & Cohen, 2012). In the same survey, the prevalence of ignored dental visits was 42% in adults aged 18 to 64. This is because they could not afford the treatment (Bloom at al., 2012). An oral health comparison among ethnicities reported a good oral health was higher in Non-
Hispanic white and Non-Hispanic Asian by 37% compared to Hispanic or non-Hispanic black by around 25% (Bloom et al., 2012).

A lack of understanding and awareness of the importance of oral health is another reason for the silent epidemic. Higher education level is associated with awareness of the importance of oral health, such as the importance of preventive dental visits. Adults with higher levels of education had a better oral health (39%) than those who had a high school diplomas ([20%]; Bloom at al., 2012).

**Significance of the Problem**

Cystic fibrosis patients suffer from multiple affected organ systems, such as lungs, gastrointestinal tract, pancreas, and sinuses (Fernald & Roberts, 1990). While cystic fibrosis patients focus on the primary genetic disorder and are concerned about their body health, they may ignore their oral health (Sarvas, Chi, & Kim, 2016). Cystic fibrosis patients struggle with surprising and frequent hospitalizations; making visits for dental care less likely (Sarvas et al., 2016). These medical visits leave families with few finances and other resources to seek dental care (Ditto et al., 2010; Sarvas, Huebner, Scott, Aps, & Chi, 2015). Medicaid-enrolled CF children are also less likely to seek dental care due to competing demand on time and resources (Sarvas et al., 2015). Cystic Fibrosis Centers often provide teams consisting of physicians, pulmonologists, nurses, physical therapists, nutritionists, social workers, genetic counselors, pharmacists, psychologists, and infectious disease specialists; yet oral health professionals are not part of the team (Sarvas et al., 2016). It is thought that historically individuals with cystic fibrosis had a short life expectancy and concern for oral health may not have received much attention (Ersin et al., 2006). Enamel defects on maxillary incisors of those with CF have been reported to range from 28.4% to as high as 56%. (Ferrazzano et al., 2012). The abnormal cystic
fibrosis transmembrane conductance regulator gene affects salivary glands; reducing salivary flow rates needed to offset damage from dietary sugars (Kinirons, 1983). There has been an increase in life expectancy for cystic fibrosis individuals from a mean of 29.4 years in 1991 to age 50-60 (Cystic Fibrosis Foundation [CFF], 2012; Jackson et al., 2011). With the increased longevity of CF patients, more attention to regular preventive oral health care is needed.

Individuals with a weak immune system may develop an infection in organs. Periodontitis has been associated with systemic diseases such as: cardiovascular disease, diabetes, bacterial pneumonia and preterm low-birth-weight infants (Boπnjak, CuriloviÊ, & PlanÊak, 2001; Bruck, Cianciola, Genco, Mosovich, & Park, 1982; Christiansen et al., 2006; Ellis, Seymour, Steele, Thomason, & Preshaw, 2003; Emrich, Genco, & Shlossman, 1991; Scannapieco, 1999). Individuals with CF need to maintain respiratory health. A number of medications are required to lower bacterial disease, improve lung function, and increase hydration of airway surfaces (Halfhide, Evans, & Couriel, 2005; Flume et al., 2007); making them more at risk for developing oral diseases from daily medication.

With improvements in the management of cystic fibrosis including increase in life expectancy, oral health providers must address the oral health of those with CF. Results from this study will provide needed data on self-reported oral health status, interaction with the oral health system, and oral health awareness in individuals with cystic fibrosis.

Research Questions

1. How do adults with cystic fibrosis evaluate their oral health status?
   1a. To what extent does oral health assessment in adults with cystic fibrosis vary by demographic categories?

2. To what extent do adults with cystic fibrosis interact with the oral health care system?
2a. To what extent does interaction with the oral health care system vary by demographic categories in adults with cystic fibrosis?

3. To what extent are adults with cystic fibrosis aware of good oral health?

3a. To what extent are demographic categories related to level of awareness in adults with cystic fibrosis?

**Hypotheses**

H1. There will be a statistically significant difference in self-reported oral health assessment of adults with cystic fibrosis based on demographic categories as measured by oral health assessment variables.

H2. There will be a statistically significant difference in the interactions with the oral health care system based on demographic categories in adults with cystic fibrosis as measured by oral health system variables.

H3. There will be a statistically significant difference in the relationship between demographic categories and awareness of good oral health in adults with cystic fibrosis as measured by oral health awareness variables.

**Definition of Terms**

The framework consists of seven components: Cystic fibrosis, oral health status, teeth function, teeth aesthetic, attitude toward oral health system, oral health awareness, people with cystic fibrosis, and polymorphism.

**Cystic Fibrosis:** a progressive, genetic disease that causes persistent lung infections and limits the ability to breathe over time (CFF, 2012).

**Individuals with cystic fibrosis:** a defective gene causes a thick, sticky buildup of mucus in the lungs, pancreas, and other organs (CFF, 2012).
Oral Health: It is a state of being free from mouth and facial pain, oral and throat cancer, oral infection and sores, periodontal (gum) disease, tooth decay, tooth loss, and other diseases and disorders that limit an individual’s capacity in biting, chewing, smiling, speaking, and psychosocial wellbeing (World Health Organization [WHO], 2012). This study will be based only on the participant’s experience at the highest level such as pain and discomfort, ability to chew and speak, satisfaction with mouth function and aesthetics.

Polymorphism: defined as two or more variant alleles occur at one locus (Kim & Misra, 2007).

Assumptions

All participants will be adults with cystic fibrosis. The participants will answer the questionnaire in an honest and candid manner.
CHAPTER II
REVIEW OF THE LITERATURE

This chapter includes relevant research and theory development through the following content areas: cystic fibrosis, quality life of individual with cystic fibrosis, oral health problems and general health, oral health status in general adult population, oral health status and socioeconomic factors, genetics and oral health, oral health and cystic fibrosis, interaction with the oral health system, and oral health awareness.

Cystic Fibrosis

Cystic fibrosis (CF) is a chronic genetic disorder that an individual has at birth. Cystic fibrosis is not caused by bacteria, viruses, chemicals, or radiation. Cystic fibrosis impacts equally all races, ethnicities, gender, and becomes worse over time (CFF, 2012). About 1 in every 20 to 25 Americans is a carrier of cystic fibrosis. In 2016, there were roughly 29,497 people in the U.S. reported to have CF. Approximately, 15,000 were adults aged 18 years old or older (CFF, 2016). The disease prevalence in White Americans is 1 in 3,000; in Latin Americans, 1 in 4,000 to 10,000; and in African Americans, 1 in 20,000 (Walters, Mehta, Hodson, Geddes, & Bush, 2007). According to the Cystic Fibrosis Foundation Patient Registry 2016, approximately 1,000 new cases are identified yearly and 75% of cases are diagnosed by the age of two. The median age of death of individuals with cystic fibrosis was 29.5 years; whereas, the rate of mortality per 100 individuals with cystic fibrosis was 1.3. These data indicate that the life span median of those with cystic fibrosis had increased from 11.6 years in 1986 to 19.0 years in 2016 (CFF, 2016). Individuals contract cystic fibrosis by inheriting a mutated cystic fibrosis allele from each parent. Scientists have discovered that the gene called the cystic fibrosis transmembrane conductance regulator (CFTR) is found on Chromosome 7 (Riordan et al., 1989; Rommens et al.,
A mutation in the CFTR gene produces an abnormal protein that the common mutant allele is the F508del ([ΔF508]; Kerem et al., 1989). This abnormal protein affects the movement of sodium chloride in and out of cells. The role of chloride’s movement is to keep mucus thin and slippery by balancing the salt and water inside and outside the cell. Mucus must be kept thin and slippery because it lines the borders between body organs, particularly the lungs and pancreas. The CFTR also prevents the transport of sodium in the epithelial and calcium-activated chloride channels and regulates intracellular vesicle transport and acidification of organelles (Mehta, 2005; Reisin et al., 1994; Schiebert et al., 1995; Stutts et al., 1995; Vankeerberghen, Cuppens, & Cassiman, 2002).

The number of unique CFTR mutations is greater than 1,500, but only a small number of CFTR functions is known. Based on the molecular mechanisms behind mutations obstructing normal protein synthesis, cystic fibrosis has six mutation classes. Class I mutations show an absence of CFTR functions to reach the cell membrane due to the presence of either a premature stop codon that results in shortened proteins or splicing defects that result in no protein production. Class II mutations affect the CFTR’s ability to keep some chloride channels open and produce misfolded proteins. Class III mutations allow the CFTR to assume the correct position at the cell surface to regulate ion transport, but the CFTR fails to be activated by adenosine triphosphate and cyclic adenosine monophosphate. Class IV mutations reduce chloride transport. Class V mutations cause a decrease in the production of normal CFTR proteins at the cell surface due to a splicing defect, but the proteins can effectively transport chloride. Class VI mutations result in short-lived protein, even though the molecule may reach the cell surface (Gallati, 2014; Mickle & Cutting, 1998; O’Sullivan & Freedman, 2009; Tsui, 1992; Welsh & Smith, 1993).
The prevalence of CF mutations may vary from one region to another. This might be a result of the difference of ethics and known genetics between regions. The thoroughness of DNA analysis also might reflect the difference of CF mutations (Boeck, Zolin, Cuppens, Olesen, & Viviani, 2014). In a study conducted on 25,394 individuals from 23 European countries who had cystic fibrosis of various mutation classes, researchers found that 80% of participants from 18 countries had a class II mutation. Meanwhile, the class I mutation affected 16.4% of patients, and classes III, IV, and V affected 3.9%, 3.3%, and 3.0% of patients, respectively (Boeck et al., 2014).

The signs and symptoms of cystic fibrosis can differ based on the individual’s age. In general, individuals with cystic fibrosis may have salty skin, abnormal fingers and toes, cough with phlegm, and mucoid pseudomonas aeruginosa. In neonatal cases, individuals may have meconium ileus, protracted jaundice, abdominal or scrotal calcifications, and intestinal atresia. Children with cystic fibrosis may develop chronic pansinusitis or nasal polyposis, steatorrhea, rectal prolapse, distal intestinal obstruction syndrome or intussusception, idiopathic recurrent or chronic pancreatitis, and liver disease. Adults may develop symptoms such as allergic bronchopulmonary aspergillosis, chronic pansinusitis or nasal polyposis, bronchiectasis, haemoptysis, portal hypertension, and delayed puberty (CFF, 2016; De Boeck, 2006; Farrell, 2008).

Diagnosis of this disease can be confirmed through various tests. One such test checks for the concentration of chloride in sweat, which must be no more than 60 mmol/L, and is available and clinically useful. Techniques used to scan and analyze specific CFTR gene mutations are dot-blot, reverse dot-blot, allele specific oligonucleotide (ASO), amplification refractory mutation (ARMS), and an oligo-ligation assay. Methods for extensive mutations of the CFTR
gene are sequencing, single strand conformation polymorphism (SSCP) assay, denaturing gradient gel electrophoresis (DGGE) and denaturing high pressure liquid chromatography ([DHPLC]; McGrowder, 2012; Mishra, 2008).

Cystic fibrosis affects several organs and systems: the respiratory, digestive, and reproductive systems and the sweat glands. In those with cystic fibrosis the respiratory system’s mucus is thick, which may cause bacteria to become trapped in and clog respiratory tubes. Therefore, people with thickened mucus are at risk for bacterial infections, which is the cause of at least 80% of thickens related deaths (CFF, 2011). Such bacterial infections include Pseudomonas aeruginosa, Burkhalter cepacia, stenotrophomonas, Stenotrophomonas maltophilia, Staphylococcus aureus, and atypical mycobacteria (Beringer & Appleman, 2000). A study in 12 cystic fibrosis centers focused on the identification of emerging bacteria in 145 patients. The following bacteria were identified: stenotrophomonas maltophilia was predominant in 106 patients, followed by klebsiellae in 36 patients, B. cepacia complex in 31 patients, A. xylocopids in 16 patients, mycobacteria in 11 patients, and Methicillin-resistant Staphylococcus aureus (MRSA) in 11 patients (Steinkamp, 2005).

Proper digestive system function is essential for the breakdown of food to provide the body with nutrients necessary for growth and development. The small intestine in individuals with cystic fibrosis does not have contain adequate enzymes for normal digestion. With cystic fibrosis food’s nutrition cannot be absorbed, leading to fat-soluble vitamin deficiency, and malnutrition unless they receive treatment. Over time, patients with cystic fibrosis will develop other comorbidities including: insulin insufficiency and carbohydrate intolerance (Elder, Wooldridge, Dolan, & D’alessio, 2007; Marshall, 2005), and osteoporosis (Marquette & Haworth, 2016).
Meanwhile, sweat glands help to keep the body’s temperature normal and remove the body’s waste. People with cystic fibrosis lose two to five times the salt and minerals of a person without CF and can develop problems when they sweat, exercise, have a high fever, or are in hot weather. These problems include fatigue, fever, muscle weakness, irregular heart rhythms, and fainting. Finally, females with cystic fibrosis may have difficulties becoming pregnant because thicker mucus can prevent sperm from reaching the egg. Males, on the other hand, may be sterile and have azoospermia because their transport tubes usually do not develop and may require special surgery (Boyle, 2003; Marquette & Haworth, 2016).

Quality of Life in Individuals with Cystic Fibrosis

Because the lives of individuals with cystic fibrosis (CF) have gradually improved, adults with cystic fibrosis can now focus on establishing their careers and families. According to Cystic Fibrosis Centers 2010, 45% of adults with cystic fibrosis work full- or part-time, and about 40% have families. However, the quality of life for individuals with cystic fibrosis is associated with the classification of their cystic fibrosis. Adults with mild cystic fibrosis generally have better quality of life than those with severe cystic fibrosis (George et al., 2010).

The greatest issue in adults with cystic fibrosis is treatment. Adults with cystic fibrosis must engage in different treatments for 2 hours per day, which impact other organs. For instance, data obtained every 2 years from 1998 to 2010 revealed that the health-related quality of life for adults with cystic fibrosis significantly decreased after their lung functions collapsed (Abbott, Hurley, Morton & Conway, 2013; George et al., 2010). Adults with CF also struggle with treatment adherence. Depending on the drugs that they take, adults with CF adhere to their treatments between 31% -79% of the time (Burrows, Bunting, Masell, & Bell, 2002; Eakin, Bilderback, Boyle, Mogayzel, & Riekert, 2001). In CF patients, reduced treatment consistency
leads to worse health outcomes, namely pulmonary exacerbations and decreased baseline lung function (Eakin et al., 2001). Such inconsistencies are due to barriers involving time and self-management. From interviews with 25 older adolescent and adult patients, researchers discovered that 64% had difficulty with self-management; and 56% claimed their treatments were time-consuming (George et al., 2010).

In addition, CF patients do not experience the same health-related quality of life due to differences in age and gender. Patients may experience health complaints, depression, and psychosocial problems. Health complaints generally increase as CF patients’ age. In some restricted studies in Europe, female adolescents and adults have reported poorer perceptions of their health and more total life problems than males (Cavallo, 2006; Gisela, Bisegger, Daniela, & Thomas, 2009; Torsheim et al., 2006; Verhulst et al., 2003).

Adults with CF suffer from depression and anxiety as they age. Likewise, adults with CF experience psychological burdens similar to those of the general population as they age (Cystic Fibrosis Foundation Patient Registry [CFFPR], 2011). In a German study, 14% of CF patients between the ages of 31 and 50 experienced depression, compared to 11% of individuals between the ages of 21 and 30 (Goldbeck, Besier, Hinz, Singer, & Quittner, 2010). In 2016, the median of depression screening performed in CF individuals between 12 to 17 years was 71.3 compared to 76 in CF individuals 18 years and older. Further, the median of anxiety screening performed in CF individuals between 12 to 17 years was 69.1 compared to 69.9 in CF individuals 18 years and older (CFFPR, 2016).

Psychosocial issues in adults with CF impacted their school attendance, work, and both family and peer relationships (Dill, Dawson, Sellers, Robinson, & Sawicki, 2013). In a 21-month study at 10 CF centers in the United States, more than 300 adults participated in a follow-up
survey, revealing that individuals with CF were less psychosocial than other individuals (Dill et al., 2013). The main factors for lower quality of life include pneumothorax, hemoptysis, lung transplantation (Goldbeck et al., 2010), and financial independence—the latter of which is a psychological stressor (Burker, Sedway, & Carone, 2004).

**Oral Health Status in General Adult Population**

According to the World Health Organization (2012), “Oral health is essential to general health and quality of life.” Ignoring oral health can lead to oral diseases that impact overall health, as the mouth is home to bacteria, viruses, and fungi. Oral diseases have various stages; they can begin with dental caries and then proceed to periodontal disease and missing teeth (Evans et al., 2000). Furthermore, poor oral health is associated with many systemic diseases, and it varies from one individual to another based on life factors (Evans et al., 2000). Some individuals are more susceptible or resistant to oral diseases because of genetic differences in structures such as enamels, proteins, and crystals (Evans et al., 2000). In addition, the body’s immune defense mechanisms, the quality and quantity of saliva are also associated with the prevalence of oral diseases (Evans et al., 2000; Slavkin, 1988). The most common oral diseases in all age groups are dental cavities, gingival disease, periodontal disease, oral cancer, oral infectious diseases, and hereditary lesions (WHO, 2012).

Dental caries is a chronic condition among individuals of all ages. It entails loss of enamel and dentin minerals commonly caused by bacteria. Dental caries are 7 times more prevalent in adults than children in the U.S. (Dye, Li, & Beltrán-Aguilar, 2012). Seventy-nine percent of adults between the ages of 20 and 44 from years 2005-2008 have dental restorations, and 25% had have untreated caries (Dye et al., 2012). Nearly 92% of adults between the ages of 45 and 64 have dental restorations, and 20% of the same group had untreated caries (Dye et al.,
Dye, Evans, Li, and Iafolla (2015) used 2011–2012 data to assess dental caries and tooth loss among U.S. adults, finding that, among adults between the ages of 20 and 64, 91% had dental restorations, and 27% had untreated dental caries. Furthermore, with regard to ethnicity, Dye et al. (2015) found caries in 94% of Caucasian adults, which was higher than the rates for adults of Hispanic, Asian, and African descent (85%, 85%, and 86%, respectively). In addition, the prevalence of untreated tooth decay in African American adults was 42%, compared with 36%, 22%, and 17% for Hispanic, Caucasian, and Asian adults, respectively (Dye et al., 2015).

Periodontal disease is caused by bacteria in the biofilm. Periodontitis destroys the soft tissue and alveolar bone (Evans et al., 2000). It also causes gingival bleeding, halitosis, and infections to other organs. The disease has two forms. The foremost form progresses moderately, but the less common form progresses rapidly and is resistant to treatment (Evans et al., 2000).

Periodontal diseases result from Gram-negative bacteria, including Porphyromonas gingivalis, Prevotella intermedia, Bacteroides forsythus, Treponema denticola, and Actinobacillus actinomycetemcomitans. These bacteria generate products that affect tissues and the body’s immune response (Genco, 1996). Although several hundred inflammatory markers cause periodontal disease, it is particularly associated with multiple-serum cytokines such as interleukin-1 (Aiuto et al., 2004; Bodet, Chandad, & Grenier, 2006), interleukin-6 (Aiuto et al., 2004; Loos, Craandijk, Hoek, Wertheim-Van, & Van, 2000), C-reactive protein (Aiuto et al., 2004; Wu et al., 2000), and tumor necrosis factor ([TNF-α]; Bretz et al., 2005; Roberts, McCaffery, & Michalek, 1997).

**Oral Health Problems and General Health**

Oral health problems can lead to infection or diseases that may affect other organs. Periodontal disease, the foremost oral health problem, is associated with several systemic
diseases such as Down syndrome, type 1 diabetes, type 2 diabetes, HIV infection, preeclampsia, Chediak-Higashi syndrome, cardiovascular disease, bacterial pneumonia, preterm births, and low-birth-weight infants (Caton, 1989; Genco, 1996; Bošnjak et al., 2001; Bruck et al., 1982; Christiansen et al., 2006; Ellis et al., 2003; Emrich et al., 1991; Horton et al., 2010; Scannapieco, 1999).

Cardiovascular disease and stroke have also been correlated with oral health. The results of a meta-analysis of prospective and retrospective studies concluded that 20% of cardiovascular disease risk was related to periodontal diseases (Meurman, Sanz, & Janket, 2004). In the same study, the relationship between periodontal disease and stroke was higher. The relationship varied from 2.85 (95% CI [1.78, 4.56]) to 1.74 (95% CI [1.08, 2.81]; Meurman et al., 2004). Moreover, Vettore (2004) analyzed cohort studies with a sample size over 100 that were published between 1980 and February 2001. Vittore demonstrated that there is a greater risk for individuals with cardiovascular disease who had periodontal disease by 1.19 times (95% CI [1.08, 1.32]) than those without periodontal disease. Additionally, the results of 22 case-control and cross-sectional studies found that 34% of individuals with periodontal diseases were at risk of developing cardiovascular disease than those without (Blaizot, Vergnes, Nuwwareh, Amar, & Sixou, 2009).

Periodontitis affects pregnancy more than alcohol consumption or smoking. Periodontal disease and advanced pregnancy outcome have been found to be related. Severe periodontal disease in pregnant females increased the risk of going into premature labor by 7.5 times (Offenbacher et al., 2006). The case study of a 29-year-old pregnant woman showed evidence of the dangers of this disease. Although this woman’s record was fine, amniotic fluid leakage occurred at 19 weeks due to periodontitis (Babalola & Omole, 2010). One possibility might be
the lower level of PGE2 and IL-1 beta in gingival crevicular fluid, which is helpful to fight infection. Another possibility also might be an increase of oral bacteria, such as Bacteroides forsythus, Porphyromonas, and Fusobacterium nucleatum (Babalola & Omole, 2010).

Additionally, Jeffcoate et al. (2003) conducted a pilot trial on 366 women to determine how the treatment of periodontitis reduced spontaneous preterm birth risk at <35 weeks. This study randomized each woman to one of three treatment groups for one week: dental prophylaxis with placebo capsule, scaling and root planning and placebo capsule, and scaling and root planning with metronidazole capsule. An extra group of 723 pregnant women were used as a reference group. The study found that the first group reduced its preterm birth risk to 4.9% compared to 0.8% and 3.3% in the second group and third group respectively. The reference group was at 6.3% compared to all three trial groups.

Diabetes mellitus increases the susceptibility of patients to certain infections (Clark & Lee, 1995). Adults with diabetes mellitus experience common chronic periodontal diseases more often (Kiran, Arpak, Ünsal, & Erdoğan, 2005). The chance of developing destructive periodontal disease in individuals with diabetes mellitus is 2.8-fold greater (Emrich et al., 1991), while it is 4.2-fold greater in progressive alveolar bone loss (Taylor, Burt, Becker, Genco, & Shlossman, 1998).

Furthermore, loss of the alveolar supporting bone and the teeth occurs because of the impact of diabetes on gingival fibroblasts ability to synthesize collagen and glycosaminoglycan (Rommens et al., 1998). In a study conducted on two random groups to identify effect of improved Non-surgical periodontal health in type 2 diabetes mellitus patients. The study measured fasting plasma glucose (FPG), triglyceride (TG), HDL-cholesterol 2-h post-prandial glucose (PPG), glycated haemoglobin (HbA1c), total cholesterol (TC), LDL-cholesterol and
microalbuminure before and after non-surgical periodontal treatment. Forty-four patients with diabetes mellitus participated. The treatment group was the only group that had full-mouth scaling and root planning. Gingival index, plaque index, probing pocket depth, bleeding on probing, clinical attachment levels, and gingival recession were obtained at baseline, 30 and 90 days. There was significant improvement in the treatment group compared to the control group. Non-surgical periodontal treatment was associated with overall improvement in type 2 diabetes (Kıran et al., 2005)

The relationship between dental diseases and respiratory diseases have been identified (Mojon & Bourbeau, 2003). Oral bacterial species include Capnocytophaga species, Actinobacillus actinomycetemcomitans, Prevotella intermedia, Porphyromonas gingivalis, Actinomyces israelii, Eikenella corrodens, and Streptococcus constellatus (Scannapieco & Mylotte, 1996). The hypothesis of entry of oral bacteria into the airway of individuals with periodontitis can lead to the development of pneumonia more quickly than those without periodontitis. First, the aspiration of oral pathogens into the lung can lead to pneumonia, such as Porphyromonas gingivalis. Second, the adhesion and colonization of mucous surfaces may be altered by salivary enzymes. Change in mucosal surface enhanced adhesion as the following: a) through modifying mucosal epithelium because periodontal bacteria; b) loss of protein that cavers the mucosa caused de-masking of surface receptor; c) release of cytokines or removal of surface protein. Third, periodontal disease may cause the destruction of pathogenic bacteria in salivary pellicles. Thus, pathogenic bacteria would adhere to mucosal receptors in the respiratory resulting in smaller amount non-specific host defense mechanisms. Fourth, cytokines that are formed by periodontal tissue may modify the respiratory epithelium to promote infection. This
might be a result of a large variety of cytokines and biologically active molecules, which promote colonization in respiratory (Gomes-Filho, Passos, & Seixas da Cruz, 2010).

**Oral Health Status and Socioeconomic Factors**

Socioeconomic factors have been associated with oral health status. Epidemiologic researchers have discovered that age, education level, income, race, and ethnicity affect the prevalence of oral health problems. This socioeconomic effect is related to oral hygiene, professional prophylaxis, and routine dental care (Evans et al., 2000; Reid, Hyman, & Macek, 2004; Sabbah, Tsakos, Sheiham, & Watt, 2009; Smaje, 1996). Reid et al. (2004) conducted a study to determine the impact of race on oral health status, finding that untreated caries occurred more frequently in Mexican Americans and African Americans than in Caucasian Americans.

In addition, data from “Third National Health and Nutrition Examination Survey conducted in the USA (1988–94)” based on the income and level of education was evaluated. Sabbah et al., (2009), concluded that the prevalence of poorer oral health was generally higher in African–Americans and Mexican–Americans compared to other ethnic groups. African–Americans had higher tooth loss (67%) compared to other races. Gingival bleeding was present among 65% of Mexican–Americans higher than bleeding in other groups. Mexican–Americans are also 1.8 times more likely to have tooth loss associated with level of education. Individuals with low levels of education and income have been found to have more oral health problems, including a higher prevalence of edentulism. This emphasizes that socioeconomic status is associated with the prevalence of oral health problems (Sabbah et al., 2009).

**Genetics and Oral Health**

Environmental factors, such as diet can lead to dental caries. While diet can be caries producing, diet does not often show a difference in lesions between populations. Therefore,
individuals differ on susceptibility to oral diseases, such as dental caries because the difference of small inherited variations in genes (Gao, 1990; Gustafsson et al, 1954).

In families, for example, susceptibility to dental caries in both boys and girls strongly correlates with familial factors (Gao, 1990; Gustafsson et al, 1954). A possible factor, as an explanation, is the involvement of genetic influences (Gao, 1990; Gustafsson et al, 1954). Other environmental factors between individuals, such as social and educational conditions, can be easily found; however, prominent conditions in environment can strongly determine the features of generation. A possible way of equaling the scales in the respective effects of nature and nurture would be a genetic study of twins. Twins provide valued significances for the further clarification of genetic influences (Galton, 2012). A reason for twins’ studies in the possibility of genetic effects is the unavoidable similarity of environmental factors, particularly diet as a main source of caries experience. Another reason is, while monozygous twins have an identical hereditary constitution and dizygous twins are ordinary siblings, each possess a different genotype, twins studies will identify whether the caries variety is the involvement of environment or genetic influences (Bouchard, 1984).

Although there have been advancements in human genetics and molecular biology, monozygous “identical” and dizygous “fraternal” twins continue to play an important role in the research of caries, tooth size, and morphology (Boraas, Messer, & Till, 1988; Conry, Messer, Boraas, Aeppli, & Bouchard, 1993; Kabban, Fearne, Jovanovski, & Zou, 2001; Race, Townsend, & Hughes, 2006; Shuler, 2001; Townsend et al., 2006). Oral health is highly associated with genetic components. In a study of nine sets of monozygotic twins and 21 sets of dizygotic twins, researchers found that dizygotic twins experienced fewer instances of dental caries, periodontal disease and malocclusion by 9.5%, 23.8%, and 9.5%, respectively, while monozygotic twins
experienced higher instances of dental caries, periodontal disease and malocclusion by 88.9%, 77.8%, and 100% respectively (Lovelinaa, Shastrib, & Kumar, 2012). Caries incidence in twins was studied in 96 monozygotic and 128 dizygotic pairs of twins. (Mansbridge, 1959). This study established less similarity in dizygotic twins, whereas higher similarity was shown in monozygotic twins (Mansbridge, 1959). Gingivitis in Swedish twins was examined in a study consisting of 10,000 participants interviewed by the phone (Mucci, Bjorkman, Douglass, & Pedersen, 2005). The genetic component of gingivitis in females was 36% while the genetic component of gingivitis in men was 22% (Mucci et al., 2005). Rintakoski at al. observed oral health in different-gender twins (2010). In five birth studies conducted on twins, caries differed between males (49%) and females (68%) in the average 24.6-year-old (Rintakoski et al., 2010). Oral microorganisms such as streptococci as well as salivary flow rate, salivary amylase and salivary pH were reported as heritable characteristics of 38 like-sex monozygotic and dizygotic twin pairs (Goodman, Luke, Rosen, & Hackel, 1959).

Genetics has been linked to dental caries (Gustafsson et al., 1954). Gustafsson et al. (1954) suggest that one or more genotypic, phenotypic, or environmental influences can increase or decrease the likelihood of dental caries in an individual. In regard to genetics, the occurrence of dental caries has been linked with heredity in several scientific studies. In 1946, one of the earliest Japanese studies of 1,150 families reported that decayed, missing, or filled teeth (DMF) occurred in offspring (Klien, 1946). The study found both father and mother with a high DMF rate produced a high DMF in sons and daughters (Klien, 1946). Book and Grahnen claimed as a result of their study that high resistance to dental caries is plausible in parents with lower caries (1953). In addition, a link has been established between caries, genetics, and gender. Loci 5q13.3, 14q11.2 and Xq27.1 have linked to low caries versus loci 13q31.1 and 14q24.3 for high
caries experience (Vieira, Marazita, & Goldstein, 2008). The mean of low caries occurrence and loci 5q13.3, 14q11.2, and Xq27.1 were significantly different between fathers and mothers: 10.96 versus 14.45 in 46 Filipino families (Vieira et al., 2008).

Periodontitis is a complex and infectious inflammatory disease (Kim & Misra, 2007). Periodontitis affects periodontium and leads to tooth loss (Kim & Misra, 2007). Variation of genes with consideration for environmental factors (gene-environment interactions) has a strong influence on oral diseases, such as periodontitis. Relationship between genes and their variants as a cause of periodontitis was investigated through the use of single nucleotide polymorphism (Kim & Misra, 2007). Single nucleotide polymorphism (SNPs) may affect directly or indirectly a gene’s encoded protein. Polymorphism is defined as two or more variant alleles occur at one locus (Kim & Misra, 2007). Single nucleotide polymorphism (SNPs) has been studied in relation to the association of genes and periodontitis (Goncalves et al., 2017). Goncalves et al. summarized all SNPs that have been associated with severe periodontitis in African Americans (2017). As a result, Interleukin genes (IL1A rs1800587, & IL1B rs1143634), Fc gamma receptor genes (FCGR3B rs403016), Formyl peptide receptor gene (FPR1 rs2070745, FPR1 rs5030879, FPR1 rs2070745, & FPR1 rs2070745), lactoferrin (LTF rs1126478 & LTF rs1126477), Cytochrome B-245 Alpha Chain (CYBA rs4673), glycosyltransferase 6 domain containing (GLT6D1 rs1537415), toll- like receptor 4 ([TLR4 rs4986790]; Goncalves et. al., 2017).

Furthermore, the relationship between periodontitis and diabetes mellitus has been linked (Guzman, Karima, Wang, & Van Dyke, 2003). A study evaluated the relationship between periodontitis and diabetes mellitus through investigating different interleukin(IL)-1 genotypes. One-hundred American diabetic patients, with different ethnicities and ages, were screened for periodontitis and analyzed for genotyping of IL-1A (+4845), IL-1B (+3954), IL-1B (~511), and
IL-1RN (+2018) polymorphisms. The study found significant association between periodontitis and IL-1B (−511) allele 1 in diabetic African Americans IL-1A (+4845), and a borderline significant relationship between periodontitis and IL-1B (+3954) allele 1 (Guzman et al., 2003).

**Oral Health and Cystic Fibrosis**

Cystic fibrosis patients are frequently considered to be at high risk for oral problems (Aps & Martens, 2004). Because there is more attention on the primary genetic disorder, especially with an increase in age, the quality of oral health was measured on 39 children and adolescents with cystic fibrosis. The children felt better about their teeth than the adolescents ([p = .02]; Jonathan et al., 2016). In addition, Aps and Martens (2004) compared the higher impact of genetics on cystic fibrosis oral health by comparing cystic fibrosis homozygotes and heterozygotes. They discovered, based on caries experience and gingival bleeding, cystic fibrosis homozygotes had better oral health status than cystic fibrosis heterozygotes (Aps & Martens, 2004). Several presumptions, such as the salivary mechanism and less pathogenic plaque flora due to antibiotics, play important roles in why cystic fibrosis homozygotes had better oral health status than cystic fibrosis heterozygotes (Aps & Martens, 2004). Aps and Martens (2004) also studied the higher impact of genetics on cystic fibrosis oral health by comparing cystic fibrosis heterozygotes to the healthy control. They found that, based on extraction and restoration teeth, cystic fibrosis heterozygotes had more extraction and restoration teeth than the healthy control (Aps & Martens, 2004).

Carbohydrates is main dietary components to supply energy to humans’ bodies, but, they are cariogenic agent. Due to thickened mucous of individuals with CF, absorption of nutrients from food is reduced resulting in pancreatic insufficiency. Up to 200% of the daily recommended calories for those with cystic fibrosis is needed for people with cystic fibrosis to
ensure proper weight (Smyth et al., 2014; Woestenenk, Castelijns, Van der Ent, & Houwen, 2012). Thus, without insufficient oral hygiene, it is predictable that high carbohydrate diet might lead to caries and enamel demineralization in cystic fibrosis populations.

Additionally, treatments of cystic fibrosis have focused on reducing the development of the disease. Such treatments include oral antibiotics, hypertonic saline, β-adrenergic, and albuterol. These treatments loaded with several aliments from many organs. Oral antibiotics, for example, are usually dosed in sugary suspensions to change the taste. Individuals with cystic fibrosis must consume different treatments multiple times in a day. Therefore, these treatments have been linked to increased xerostomia, and predisposes to malocclusions, caries risk, oral mycosis, and periodontitis while they are associated with the decrease in salivary flow and increase Streptococcus mutans and in lactobacilli (Flume et al., 2007; Halfhide et al., 2005; Kargul, Tanboga, Ergeneli, Karakoc, & Dagli, 1998; Milano, Lee, Donovan, & Chen, 2006). Kargul et al. stated that a β2 agonist inhaler lead to a significant decrease in pH to be around 5.5, which affects flow rates of whole and parotid saliva (1998).

Saliva is a liquid that protects teeth by defending against harmful material. Due to the impact of the CFTR gene, salivary glands in persons with cystic fibrosis are affected (Jajels & Sweeney, 1976). Individuals with cystic fibrosis experience a lower flow rate of saliva than individuals who do not have cystic fibrosis (Blomfield, Warton, & Brown, 1973). Inorganic components of submandibular saliva were measured in people with cystic fibrosis. Magnesium, for example, was higher in those with CF during the intermediate flow rate of saliva (Blomfield et al., 1973). Other inorganic components of submandibular saliva are sodium and chloride concentration, as they both are increased in those with cystic fibrosis (Blomfield et al., 1973). Moreover, calcium and nitrogen concentration were compared between 12 children with cystic
fibrosis and 12 children without cystic fibrosis, as a control group (Chernick, Barbero, & Parkins, 1961). The results showed a significant difference in calcium and nitrogen concentration between both groups. The mean calcium concentration was 12.43 mg in children with cystic fibrosis, compared to 7.51 mg in the control group of children. A higher mean was observed in the nitrogen concentration of the cystic fibrosis group by 0.480 mg/ml to 0.219 mg/ml in the control group (Chernick et al., 1961). Calcium and phosphorus in sublingual saliva were compared among three groups (Mandel et al., 1969). The three groups were 20 children with cystic fibrosis, 20 control children, and old samples taken from asthmatic children. The results showed a significant difference in both calcium and phosphorus in submaxillary saliva. The mean of calcium in submaxillary saliva in children with cystic fibrosis was 13.6 Mg/ml, compared to 10.4 Mg/ml in asthmatic children, and 7.1 Mg/ml in the control group of children. The mean of phosphorus in submaxillary saliva was higher in children with cystic fibrosis than in children with asthma and the control group of children, as 12.4 Mg/ml, 10.5 Mg/ml, and 8.1 Mg/ml respectively (Mandel et al., 1969).

Dental caries and cystic fibrosis studies have stated different indications. Due to long-term oral antibiotics, especially in children, some studies have concluded that patients with cystic fibrosis had less prevalence of caries than individuals without cystic fibrosis (Aps, Van, & Martens, 2002; Jagels & Sweeney, 1975; Kinirons, 1989; Littleton & White, 1964; Primosch, 1980). In contrast, some studies indicated that cystic fibrosis patients experienced a high prevalence of dental caries (Dabrowska et al., 2006; Storhaug, 1985; Storhaug & Holst, 1987). Twenty-three patients with cystic fibrosis were retrieved from Podlasie Province (Dabrowska et al., 2006). Those patients—who were between 2.5 and 24 years old—were evaluated for caries incidence, caries intensity—based on decayed, missing, filled teeth, and oral hygiene (DMFT).
Participants were assigned to three groups based on their age: 1 to 5, 6 to 12, and 13 to 24 years. The incidence rate of caries was very high in all three groups, while the mean of caries intensity was 3.55 in Group 2 and 10.9 in Group 3. Cystic fibrosis patients in Group 3 had higher rates of dental plaque (Dabrowska et al., 2006). Disabled preschool children in 436 families with either asthma, congenital heart disease, cystic fibrosis, or juvenile rheumatoid arthritis were interviewed in order to learn about habits and problems applicable to dental health (Storhaug, 1985). A multiple classification analysis was used to determine the mean number of decayed, missing, or filled teeth (DMFT) based on sociocultural, medical, and habitual variables. Children with cystic fibrosis had a DMFT score of 8.6, which was higher than that of children with juvenile rheumatoid arthritis, at 6.4; but less than that of children with asthma, at 10.0; and of children with congenital heart disease, at 9.0 (Storhaug, 1985). At the Frambu Health Center in Norway, a study was conducted to identify caries occurrence in disabled children (Storhaug & Holst, 1987). Children between the ages 7-16 were selected to participate (189 girls and 226 boys). Disabilities in these participants included juvenile rheumatoid arthritis, cystic fibrosis, asthma, cerebral palsy, congenital heart disease, epilepsy, hemophilia, intellectual disability, spina bifida, and osteogenesis imperfecta. Children with cystic fibrosis and rheumatoid arthritis had a higher DMFT than the other groups. The mean DMFT of the 22 children with cystic fibrosis was 6.45; the second-most affected group in this study (Storhaug & Holst, 1987).

Dental enamel defects are classified as involving opacity or hypoplasia. Enamel opacity is a characterization of enamel with white color or discoloration, with a smooth or thick surface; whereas, defect enamel hypoplasia is characterized by grooves and a partial or complete absence of enamel (Clarkson & O’Mullane, 1989). Causes of enamel defects are sometimes due to unknown factors. Some of the known factors that correlate with enamel defect, however, are
genetic disorders, including amylogenesis defects, tuberous sclerosis, and cystic fibrosis (“Commission on Oral Health”, 1992). Other known factors include severe malnutrition, neonatal hypocalcemia, fluoride, tetracycline, premature birth or low birth weight, and vitamin D deficiency (“Commission on Oral Health”, 1992). Narang, Maguire, Nunn, and Bush (2003) compared enamel defects in 39 girls and 35 boys with cystic fibrosis to those of 52 boys and 54 girls’ with chronic respiratory disorders. The patients with cystic fibrosis were between the ages of 2.5 and 16.5 years, while the patients with chronic respiratory disorders ranged in age from 3.0 to 16.5 years. Cystic fibrosis patients had more defects of enamel than other chronic respiratory disorders (Narang et al., 2003). In Italy, 88 children, ranging in age from 4 to 12, with cystic fibrosis were compared to 101 age-matched children without cystic fibrosis, randomly selected from 10 public schools (Ferrazzano et al., 2012). Examining permanent teeth only, enamel defects in the group without cystic fibrosis were lower, at 22%, compared to patients with cystic fibrosis, at 56% (Ferrazzano et al., 2012). In a study comparing 36 cystic fibrosis patients and their siblings. Those with cystic fibrosis had mildly, moderately, or severely stained incisors, while their siblings did not (Jajels & Sweeney, 1976). In 1967, Swaalow, Haller, and Young identified side effects of antibiotics in people with cystic fibrosis. Antibiotics used by children with cystic fibrosis were tetracycline, oxytetracycline, and chlortetracycline. The prevalence of discolored teeth was assessed in 63 children. After the incisors were examined, 24% of the children had discolored teeth that were mostly affected; whereas, moderately-affected discolored teeth occurred in 13% of the children, and minimally-affected discolored teeth occurred in 63% of the children. The presence of fluorescence occurred in only 19% of the children. Those who experienced more fluorescence had tetracycline, and children who
experienced less fluorescence used either oxytetracycline, chlortetracycline, or a mixture of the two (Swaalow et al., 1967).

Periodontal health depends on patient demographics, social class, and general health. Furthermore, periodontal health is associated with saliva components and saliva concentration (Narang et al., 2003). Individuals with cystic fibrosis experience more calculus deposits ($M=0.11$) and gingival bleeding than those with respiratory disorder ($[M=0.13]$; Narang et al., 2003). Jonathan et al. (2016) reported that adolescents with cystic fibrosis experienced gingival bleeding more often.

**Interaction with the Oral Health System**

The American Dental Association (ADA) and American Academy of Pediatric Dentistry (AAPD) recommend a dental checkup every 6 months. Dental checkups have benefits beyond evaluating the need for any treatment; a dental checkup is an opportunity to assess oral health, monitor growth and development, and increase awareness to reduce the risk of cavities (Evans et al., 2000). Oral examinations can help to identify the early signs of nutritional deficiencies, human immunodeficiency virus (HIV), and other kinds of systemic disease (Evans et al., 2000). Dental visits can protect an individual’s teeth through the use of pit-and-fissure sealants and topical fluoride applications (Hale, 2003). Individuals from different ethnic and racial backgrounds exhibit distinctive patterns of interaction with the oral health system. A study that assessed the oral health status of adults (between 18 and 64 years of age) found that stained teeth, crooked teeth, bleeding gums, broken or missing teeth, and broken or missing fillings were more prevalent among non-Hispanic Black, non-Hispanic White, and Hispanics; such conditions were less likely to have an impact on non-Hispanic Asian individuals (Bloom et al., 2012).
Medicaid is the primary dental coverage among individuals with low incomes or disabilities (Shapiro, 2008). Children are the first beneficiaries of Medicaid, under which they receive comprehensive dental services; however, adults’ dental insurance varies from state to state (Shapiro, 2008). Unfortunately, more than 85,000,000 adults have no dental insurance (National Academy for State Health Policy, 2007). Thus, Medicaid coverage does not provide adequate coverage for adults. For instance, 19% of adults with Medicaid coverage exhibited oral health that was four times worse than the 4% of adults with private health insurance (Bloom et al., 2012). Among elderly individuals, Medicaid is not an adequate form of dental insurance, as it only provides coverage for extremely limited hospital visits, leaving 70% of Americans over the age of 65 without dental coverage (Shapiro, 2008). Therefore, individuals without dental insurance consult and seek help from emergency departments. In 2008, 124,000,000 emergency department visits were related to dental pain (Centers for Disease Control and Prevention, 2011).

At a minimum, an individual suffering from acute oral pain should be covered for treatments such as a nerve block, abscess drainage, a temporary filling or tooth extraction. While individuals without coverage benefit from the law that requires emergency departments to relieve pain, physicians are not as highly trained to provide dental interventions as oral health professionals (Wallace, Carlson, Mosen, Snyder, & Wright, 2011).

Individuals with special needs may experience greater difficulties with oral self-care (Nelson et al., 2011). McIver (2001) cited five key barriers preventing children with special health care needs (CSHCN) from accessing dental care: the medical care system, the child’s special needs, the child’s parents, the dentist, and payment. In Alabama, a survey of families with CSHCN found that 35% of such families had trouble finding dentists willing to treat their children (Al Agili, Roseman, Pass, Thornton, & Chavers, 2004). The survey found three main barriers to
accessing dental care: Medicaid insurance being insufficient to cover the cost, a severe disability such as cerebral palsy, and dentists lacking experience in the provision of care for CSHCN (Al Agili et al., 2004). Another survey to identify barriers and unmet dental needs in Massachusetts families with CSHCN included 214 families by mail and 400 families by telephone (Nelson et al., 2011). The children’s disabilities within this sample included cystic fibrosis, autism disorders, Down syndrome, developmental delay/neurological disorders, and cerebral palsy. The study found three high-impact barriers: dental care being too expensive, no dentists being willing to treat the child, and the child’s medical conditions. Of the children in the survey sample, 20% had needs that were not being met under the current system of dental coverage. Within that 20% of children whose needs were not being met, 5% had cystic fibrosis, 23% had Autism, 21% had Down syndrome, 32% had developmental delays/neurological disorders, and 22% had cerebral palsy (Nelson et al., 2011). A study based on Iowa’s Medicaid program focused on comparing interactions with the oral health care system between children with cystic fibrosis and non-cystic fibrosis Medicaid-enrolled children between the ages of 3 and 17 years. After analyzing 156,183 enrolled in Iowa’s Medicaid, a significant difference was found between the groups. Children with cystic fibrosis were less likely to use any dental care (50.6%) than children without cystic fibrosis ([69.7%]; Sarvas et al., 2015).

**Oral Health Awareness**

Awareness and advices are essential in the improvement of oral health. Poor awareness of oral care leads to an increase in oral and total health difficulties (Petersen, 2003). Awareness of oral health includes many behaviors, such as: oral hygiene, dietary habits, dental clinic visits, and use of fluorides (Petersen, 2003). Oral health awareness can decrease oral health burdens in society. In 1988, a survey was sent in the United Kingdom after previous national survey to
assess the improvement in adult oral health. As a result, the percentage of natural teeth in adults increased from 70% to 79% (Downer, 1991). Oral health awareness is associated with the level of a mother’s education. Around 300 children’s teeth were examined and compared to their mothers’ education. Less caries prevalence was observed in children whose mothers had higher education compared to mothers with some education and non-education 10.6%, 38.1% and 46.8% respectively (Kinirons & McCabe, 1995).

In contrast, an increase of oral health problems is associated with less or no oral health awareness. Based on the difference between Medicaid dental insurance and private dental insurance, adults with Medicaid dental insurance had less interaction with a dental clinic compared to adults with private dental insurance 21% versus 12% in more than 5 years (Bloom et al., 2012). In Sweden, oral self-care and self-perceived oral health questionnaire compared between 102 patients with type 2 diabetes to non-diabetic control (Sandberg, Sundberg, & Wikblad, 2001). Eighty-five percent of type 2 diabetic group had never been aware about the relation between oral health and diabetes. (Sandberg et al., 2001). Furthermore, around 14 general medical practices that have adults with type 2 diabetes were surveyed to assess oral health awareness (Hancocks & Preshaw, 2011). More than two hundred adults with type 2 diabetes participated. Only 15% flossed daily. Of the sample, 69.1% had never received information about oral health and diabetes (Hancocks & Preshaw, 2011).
CHAPTER III
METHODOLOGY

Research Design

The study was a non-experimental, cross-sectional descriptive design. The study was posted on some cystic fibrosis Facebook pages, such as Cystic fibrosis parent support group, Cystic fibrosis parents, Dear cystic fibrosis, and Parenting with cystic fibrosis. The survey design collected data at a single point in time, and all responses were anonymous. The quantitative data was collected directly through Qualtrics, a web-based survey tool. Qualtrics website allows for respondents’ identities to remain anonymous. The subjects’ identification was stored on a separate database within Qualtrics. Respondents never provided names when they completed the survey.

The questionnaires stated the purpose of the research and voluntary participation. Participants accessed the link to the web-based survey which also provided information on how to respond to items on the questionnaire. A close-ended questionnaire included the following information about demographic characteristics, oral health assessment, interaction with the oral health care system, and oral health awareness for adults with cystic fibrosis were formulated into Qualtrics. The questionnaire was categorized into subgroups with simple headings to increase the reliability and degree of anonymity with less interviewer and social desirability bias.

The survey was initially launched for four days, followed by a second launch four days later, and a third launch which was available for two days. The survey was available for 10 days. If a participant becomes inactive during the survey for more than four minutes, the participant was logged out automatically.

Sample Size and Sampling Method

The target population was adults with cystic fibrosis. The sample size needed for this
study was 350 participants. Participants were recruited using a non-probability purposive
sampling technique from distributing and posting the survey on some cystic fibrosis Facebook
pages. This technique increased the probability of selection; and all responses were anonymous.
All followers of cystic fibrosis social media were able to see the invitation to this study.

**Instrument Design**

A survey adapted from the American Dental Association’s Survey (Appendix A) was
modified to identify oral health status, interaction with the oral health care system, and oral
health awareness (Yarbrough, Starkel, Vujicic, Aravamudhan, & Meyer, 2015). The modified
survey can be seen in appendix B. The ADA Survey consisted of 29 of which questions (#1, #3,
and #26) were excluded as they related to personal life or residency in other countries. Simple
language was used in the current survey to enhance participants’ understanding. Measurements
in this study were a combination of the following: 14 nominal scale, five ordinal scale, and three
interval scales.

The ADA survey was validated in two pre-pilot studies. The first pre-pilot was to test the
survey through phone interviews between April 2, 2015 and April 13, 2015 with ten participants.
Next, the survey was conducted on 86 adults in Montana and 150 adults in New York through an
online pilot survey to assess respond to the questions. Further, the ADA survey was launched
June 23 through August 7, 2015 to more than 14,000 individuals randomly selected to participate
(Nasseh, 2015).

Additionally, content validity of the instrument was assessed using three steps. First,
survey items were placed in a blueprint under categorical headings (Appendix C). Second, a
panel of experts from the School of Dental Hygiene and Department of Statistics at Old
Dominion University reviewed these instruments to enhance content validity. Next, a pilot test of
the survey was conducted using five student participants to ensure understanding of items; two were international students. Demographics data obtained were age, sex, race, ethnicity, culture, education and socio-economic status. The three dependent variables were: 1) Oral Health Assessment, 2) Interaction with the Oral Health System; and 3) Oral Health Awareness. Next are descriptions of data gathered for each dependent variable.

Oral Health Assessment

Self-Reported Oral Health Assessment was one of the study outcomes. Oral Health Assessment was based on the participant’s experience at the highest level, such as pain and discomfort, ability to chew and speak, satisfaction with mouth function and aesthetics. This dependent variable did not describe the presence of dental diseases, number of missing teeth and number of restorations. Information about the participants’ oral health assessment was collected using question one through five (Appendix B).

Interaction with the Oral Health System

Interaction with the Oral Health System was another outcome. The questionnaire identified how often adults with cystic fibrosis visit the dentist; their insurance status; their source of insurance; and potential issues with access to oral health services. Information about interaction with the oral health system was collected through questions 6, 7, 8, 9, 10, 11, 12, 15, 16, and 17 (Appendix B).

Oral Health Awareness

Oral Health Awareness was the third outcome of this study. This dependent variable described the extent of oral health awareness of adults with cystic fibrosis and frequency of dental visits. Oral health awareness data was gathered through questions 13 and 14 (Appendix B).
Inclusion and Exclusion Criteria

To be eligible for the study, each participant must have cystic fibrosis, be 18 years-old or older, live in the U.S. and English-speaking (Appendix D).

Data Collection Procedure

Data gathering took place following approval by the Old Dominion University Health Science Human Subject Research Review Committee (Appendix E). Format for the independent variables consisted of demographic categories and the dependent variables were likert scale responses for oral health assessment, interaction with the oral health care system, and oral health awareness. The survey was posted and distributed through some cystic fibrosis pages on Facebook to all their members, and responses were anonymous.

Eligibility of this study, which required each participant to have cystic fibrosis, be 18 years-old or older, live in the U.S. with English as the primary language (Appendix D). The questionnaire stated the purpose of the research and voluntary participation. Participants accessed the web-based survey through a link posted on the cystic fibrosis sites. Instructions on how to answer the questions were provided. Anonymity was maintained for participants throughout the study. No questions were asked about the participants’ names, addresses or contact information. Completion of the questionnaire took approximately 15 minutes. Participation in the survey was completely voluntary and the participant might refuse to participate at any time by closing the browser. If a participant became inactive during the survey for more than four minutes, the participant was logged out automatically.

Data was stored on Qualtrics, which is password protected and behind extensive firewall protections. Data were downloaded into SPSS for analysis and only accessed by the research team. All data analysis was through the investigator’s laptop, which was password protected.
Finally, dissemination of the study findings will be through a thesis, presentations and journal manuscript.

**Statistical Analysis**

The Statistical Package for the Social Sciences (SPSS) version 24 software was used for data analysis. Descriptive statistics (means, standard deviations, percentages, and frequencies) were used to determine levels of oral health assessment, interaction with oral health system, and oral health awareness among the study participants. One-way analysis of variance (ANOVA) was used to compare the means of each dependent variables (Appendix F).

**Protection of Human Subjects**

Prior to implementation, this study was submitted for approval to Old Dominion University College of Health Science Human Subjects Research Review Committee. Cystic fibrosis is a genetic disorder that damages the lungs and digestive system, so cystic fibrosis does not impact ability to consent. This study was minimal risk to human subjects. Also, this study had respect for persons through comprehension, voluntariness (participants could refuse to participate in the study or withdraw from the study at any time), and privacy. The questionnaire was distributed though Qualtrics website tool, which stored the data on a separate secured site. Anonymity of participants was maintained as no questions were asked about the participants’ names, addresses or contact numbers. Only the research team accessed data from the survey.
CHAPTER IV

RESULTS

The way adults with cystic fibrosis (CF) assess their oral health and perceive access to oral health services was investigated. The assessment was conducted through using a survey instrument. Descriptive statistics (means, standard deviations, and percentages) and one-way analysis of variance (ANOVA) were used for the statistical analyses with an alpha of \( p \leq 0.05 \) to test for significance.

Descriptive Statistics

Inclusion criteria for participants were subjects with cystic fibrosis who were 18 years-old or older, living in the U.S., and spoke English. The total number of responses to the survey was 133; however, 46 were excluded due to incomplete survey responses or participants who lived outside of the U.S., resulting in 87 responses for analysis. Male respondents comprised 20.7% of the sample with females making up 75.9%, and 1.1% was other (See Table 1). Almost 70% of the participants were of non-poor status with an annual household income more than $35,000. The majority of participants were white 95.4% and half of the participants were single in terms of their marital status. Approximately 57% of the participants were between the ages of 18 and 32 years, and 40.2% of the participants were \( \geq 33 \)-years or older. Educated CF respondents comprised 71.3% of the sample, which included those who had completed college or graduate school; and 58.6% were employed.
Table 1

*Frequencies and Percentages for Demographics*

<table>
<thead>
<tr>
<th>Demographics</th>
<th>n</th>
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</tr>
</thead>
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<td></td>
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<tr>
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<td>20.7</td>
</tr>
<tr>
<td>Female</td>
<td>66</td>
<td>75.9</td>
</tr>
<tr>
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<tr>
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<td>2.3</td>
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<td>Total</td>
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<td>100</td>
</tr>
<tr>
<td>Age</td>
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<td></td>
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<td>Young adults or Adulthood</td>
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<td>57.5</td>
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<td>40.2</td>
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<td>White</td>
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<tr>
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<td>College or Graduate College</td>
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<td>Income</td>
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<tr>
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<tr>
<td>Total</td>
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</tr>
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</table>
Primary Analysis

The following research questions were evaluated and tested at alpha 0.05 level of significance:

**Research question one. How do adults with cystic fibrosis evaluate their oral health status?**

Of the 87 respondents with CF, most respondents ($n=56$) reported their mouth health as good or very good ($M=2.80$). Only 29 respondents described their mouth as being between fair to poor condition (Figure 1). Likewise, most subjects ($n=53$) rated their teeth as being in good or very good condition (Figure 2). Only 33 respondents described their teeth as being in fair or poor condition (See Table 2). When asked if “Life in general was less satisfying because problems with your mouth and teeth” only 31 responded, “never”. Most ($n=60$) indicated that the condition of their teeth played no role in their job interviews.
Table 2

_Frequencies, Percentages, Means and Standard Deviations for Mouth and Teeth Health Variables_

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
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<td>Adults’ mouth health</td>
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<td></td>
<td>2.80</td>
<td>.96</td>
</tr>
<tr>
<td>Poor (1)</td>
<td>10</td>
<td>11.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td>19</td>
<td>22.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>34</td>
<td>40.0</td>
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<td></td>
</tr>
<tr>
<td>Very Good (4)</td>
<td>22</td>
<td>25.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
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<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults’ teeth health</td>
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<td></td>
<td>2.74</td>
<td>.98</td>
</tr>
<tr>
<td>Poor (1)</td>
<td>11</td>
<td>12.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td>22</td>
<td>25.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>31</td>
<td>36.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Good (4)</td>
<td>22</td>
<td>25.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life was less satisfying because of problems with your teeth and mouth</td>
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<td></td>
<td>2.00</td>
<td>.94</td>
</tr>
<tr>
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<td>31</td>
<td>36.0</td>
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<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>31</td>
<td>36.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>17</td>
<td>19.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very often (4)</td>
<td>7</td>
<td>8.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teeth appearance affected job interview</td>
<td></td>
<td></td>
<td>1.81</td>
<td>.39</td>
</tr>
<tr>
<td>Yes (1)</td>
<td>14</td>
<td>18.9</td>
<td></td>
<td></td>
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<tr>
<td>No (2)</td>
<td>60</td>
<td>81.1</td>
<td></td>
<td></td>
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<tr>
<td>Total</td>
<td>74</td>
<td>100</td>
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Figure 1. Condition of the Mouth in Adults with Cystic Fibrosis.

Figure 2. Condition of the Teeth in Adults with Cystic Fibrosis.
Participants experienced physical manifestations of oral health issues on different levels in the twelve months prior to the survey. Of the 87 respondents, most \( n=40 \) never had difficulty chewing food \( (M=1.97) \). Only 27 participants had occasional to frequent trouble chewing food (See Table 3). Likewise, most subjects \( n=57 \) never had trouble with speech due to oral health issues. While 14 respondents reported never having dry mouth, more than half of respondents \( n=54 \) experienced dry mouth occasionally to very often. Additionally, 51 respondents never experienced problems sleeping compared to 24 subjects who had sleeping problems within the last 12 months. Only 26 participants did not experience pain related to their mouth and teeth during the past 12 months, whereas 29 participants experienced pain. Of the 87 respondents, 25 reported occasional to frequent seeing blood on their toothbrushes.
Table 3

*Frequencies and Percentages for Physical Manifestations of Oral Health Issues*

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty chewing food</td>
<td></td>
<td></td>
<td>1.97</td>
<td>1.06</td>
</tr>
<tr>
<td>Never (1)</td>
<td>40</td>
<td>46.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>19</td>
<td>22.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>17</td>
<td>19.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very often (4)</td>
<td>10</td>
<td>11.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not know</td>
<td>1</td>
<td>1.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty with speech</td>
<td></td>
<td></td>
<td>1.49</td>
<td>.81</td>
</tr>
<tr>
<td>Never (1)</td>
<td>57</td>
<td>67.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>17</td>
<td>20.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>8</td>
<td>9.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very often (4)</td>
<td>3</td>
<td>3.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not know</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>85</td>
<td>100</td>
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</tr>
<tr>
<td>Dry mouth</td>
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<td>2.73</td>
<td>1.03</td>
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<tr>
<td>Never (1)</td>
<td>14</td>
<td>16.3</td>
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<td></td>
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<tr>
<td>Rarely</td>
<td>18</td>
<td>20.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>31</td>
<td>36.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very often (4)</td>
<td>23</td>
<td>26.7</td>
<td></td>
<td></td>
</tr>
<tr>
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<td>0</td>
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<tr>
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</tr>
<tr>
<td>Sleeping problems</td>
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<td>1.78</td>
<td>1.06</td>
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<td>Never (1)</td>
<td>51</td>
<td>59.3</td>
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<td></td>
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<tr>
<td>Rarely</td>
<td>10</td>
<td>11.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>16</td>
<td>18.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very often (4)</td>
<td>8</td>
<td>9.3</td>
<td></td>
<td></td>
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<tr>
<td>Do not know</td>
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<td>1.2</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Very often (4)</td>
<td>9</td>
<td>10.6</td>
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<td></td>
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<tr>
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<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
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<td>100</td>
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<td></td>
</tr>
<tr>
<td>Blood on the toothbrush</td>
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<td></td>
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<td>.97</td>
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<td>Occasionally</td>
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<td></td>
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<tr>
<td>Very often (4)</td>
<td>8</td>
<td>9.3</td>
<td></td>
<td></td>
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<tr>
<td>Total</td>
<td>86</td>
<td>100</td>
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</tr>
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</table>
About half of participants reported having anxiety about their mouth and teeth issues. Thirty-one participants felt anxious about their mouth and teeth occasionally to very often \((M=2.10)\). Whereas 35 respondents never felt anxiety about their mouth and teeth issues (See Table 4). Of the sample, 28 respondents stated that they felt some level of embarrassment due to problems with their mouth and teeth, while 40 respondents never felt embarrassment about their mouth and teeth. Additionally, 41 respondents indicated never having avoided smiling because of their mouth and teeth issues. Twenty-four (33\%) respondents reported avoided smiling because of their mouth and teeth issues.

Table 4

*Frequencies, Percentages, Means and Standard Deviations for Anxiety about Mouth and Teeth Issues.*

<table>
<thead>
<tr>
<th>Variable</th>
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<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>20</td>
<td>23.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>18</td>
<td>20.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very often (4)</td>
<td>13</td>
<td>15.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not know</td>
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<td>0.0</td>
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<td></td>
</tr>
<tr>
<td>Total</td>
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<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt embarrassment</td>
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<td>1.11</td>
</tr>
<tr>
<td>Never (1)</td>
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<tr>
<td>Rarely</td>
<td>17</td>
<td>19.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
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<td>18.6</td>
<td></td>
<td></td>
</tr>
<tr>
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<td></td>
</tr>
<tr>
<td>Avoided smiling</td>
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<td>1.93</td>
<td>1.07</td>
</tr>
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<td></td>
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</tr>
<tr>
<td>Occasionally</td>
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<td></td>
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<tr>
<td>Very often (4)</td>
<td>11</td>
<td>12.9</td>
<td></td>
<td></td>
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<tr>
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<td>0.0</td>
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<td></td>
</tr>
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<td>Total</td>
<td>85</td>
<td>100</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Most respondents \((n=69)\) reported never taking days off work because of oral pain \((M=1.22)\). Only four respondents took days off work because of mouth pain (See Table 5). Most subjects \((n=63)\) never had difficulty doing activities due to oral health issues. Only nine respondents rated occasional to frequent difficulty doing activities due to oral health issues. Most respondents \((n=66)\) never missed participation in social activities due to oral health issues. Only 12 participants indicated they occasional to frequent missed participation in social activities because oral health issues.

Table 5

*Frequencies, Percentages, Means and Standard Deviations for General Life Activities Related to Oral Health Issues.*

<table>
<thead>
<tr>
<th>Variable</th>
<th>(n)</th>
<th>(%)</th>
<th>(M)</th>
<th>(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Took day off work because pain</td>
<td></td>
<td></td>
<td>1.22</td>
<td>.56</td>
</tr>
<tr>
<td>Never (1)</td>
<td>69</td>
<td>80.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>9</td>
<td>10.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>3</td>
<td>3.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very often (4)</td>
<td>1</td>
<td>1.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not know</td>
<td>4</td>
<td>4.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>82</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty doing usual activities</td>
<td></td>
<td></td>
<td>1.38</td>
<td>.74</td>
</tr>
<tr>
<td>Never (1)</td>
<td>63</td>
<td>74.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>12</td>
<td>14.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>7</td>
<td>8.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very often (4)</td>
<td>2</td>
<td>2.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not know</td>
<td>1</td>
<td>1.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>84</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced participation in social activities</td>
<td></td>
<td></td>
<td>1.43</td>
<td>.87</td>
</tr>
<tr>
<td>Never (1)</td>
<td>66</td>
<td>76.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>8</td>
<td>9.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>7</td>
<td>8.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very often (4)</td>
<td>5</td>
<td>5.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not know</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Internal Consistency of Oral Health and Life Satisfaction Scale

This study had 12 items that related to the overacting question, how often during the past 12 months have you felt that life in general was less satisfying because of problems with your mouth and teeth. As determined by Cronbach's alpha, these items had a high level of internal consistency (α .892). Therefore, while α coefficient is .892 and the scale exhibited validity and reliability, these items were formed as one scale. A sum of 12 items rated for each participant resulted in a score range between 12 to 48. Lower scores indicated fewer oral health issues (Yarbrough et al., 2015).

Research question one A. To what extent does oral health assessment in adults with cystic fibrosis vary by demographic categories?

Level of education of the respondents was related to statistically significant differences in respondents’ perceptions of their own oral health. Results of a one-way ANOVA indicated that there was a statistically significant relationship between level of education and the condition of the mouth, $F(1, 81) = 14.875, MSW= 62.763, p <.001$ (Table 6); there was a significant relationship between level of education and the condition of the teeth, $F(1, 82) = 8.111$, $MSW= 72.106$, $p <.05$; there was a significant relationship between level of education and the physical manifestations of oral health issues, $F(1, 83) = 7.241$, $MSW= 4761.590$, $p <.05$.

Furthermore, adults with at least a bachelor’s degree reported a better condition of the mouth ($M=3.05, SD=.85$) than those with a high school or associate degree ($M=2.22, SD=.95$). Adults with at least a bachelor’s degree reported a better condition of the teeth than those with a high school or associate degree ($M= 2.94, SD=.88$) ($M=2.27, SD= 1.07$) respectively. Participants with only a high school or associate degree were more likely to experience physical
manifestations of oral health issues \((M=25.78, SD=9.12)\), while participants who had at least bachelors’ degree were less likely to experience physical manifestations of oral health issues \((M=20.81, SD=6.93)\).

However, the results of the one-way ANOVA did not show any statistically significant difference with other demographic categories, such as marital status, race, age, gender, income, and employment status.

Table 6

*Comparison of Education and Oral Health Assessment Variables on Oral Health Status of Adults with Cystic Fibrosis*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Group A M(SD)</th>
<th>Group B M(SD)</th>
<th>F</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education Condition of mouth</td>
<td>83</td>
<td>2.22(.95)</td>
<td>3.05(.85)</td>
<td>14.875</td>
<td>1, 81</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Education Condition of teeth</td>
<td>84</td>
<td>2.27(1.07)</td>
<td>2.94(.88)</td>
<td>8.111</td>
<td>1, 82</td>
<td>.006*</td>
</tr>
<tr>
<td>Education Quality of life</td>
<td>84</td>
<td>2.22(.99)</td>
<td>1.90(.88)</td>
<td>1.970</td>
<td>1, 82</td>
<td>.164</td>
</tr>
<tr>
<td>Education Appearance of teeth affected job interview</td>
<td>73</td>
<td>1.73(.45)</td>
<td>1.83(.38)</td>
<td>.671</td>
<td>1, 71</td>
<td>.416</td>
</tr>
<tr>
<td>Education Physical manifestations of oral health issues</td>
<td>85</td>
<td>25.78(9.12)</td>
<td>20.81(6.93)</td>
<td>7.241</td>
<td>1, 83</td>
<td>.009*</td>
</tr>
</tbody>
</table>

Note. Oral health assessment includes Q1, Q2, Q3, Q4, and Q5.
Oral health issues include Q5-1, Q5-2, Q5-3, Q5-4, Q5-5, Q5-6, Q5-7, Q5-8, Q5-9, Q5-10, Q5-11, and Q5-12.
* p=<0.001.
Group A indicates high school or associate degree and Group B indicates bachelor or higher degree.
Research question two. To what extent do adults with cystic fibrosis interact with the oral health care system?

Almost all participants \( (n=85) \) reported they have health insurance. Most of respondents \( (n=66) \) stated they have dental insurance (Figure 3). Only 15 participants reported they do not have dental insurance. Forty-eight CF adults in this sample obtained their dental insurance from their employer, nine of CF adults obtained their dental insurance from the marketplace or parents, and only seven of recipients gained their insurance from Medicaid/ Medicare (See Table 7). Of the sample, 69 indicated that they did not receive Medicaid/Medicare benefits.
Table 7

*Frequencies, Percentages, Means and Standard Deviations for Health Insurance and Dental Insurance*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have health insurance</td>
<td></td>
<td></td>
<td>1.02</td>
<td>.15</td>
</tr>
<tr>
<td>Yes (1)</td>
<td>85</td>
<td>97.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (2)</td>
<td>2</td>
<td>2.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obtain health insurance from</td>
<td></td>
<td></td>
<td>.56</td>
<td>.79</td>
</tr>
<tr>
<td>Employer/Government</td>
<td>49</td>
<td>62.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marketplace/Parent</td>
<td>14</td>
<td>17.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid/Medicare</td>
<td>15</td>
<td>19.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>78</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have dental insurance</td>
<td></td>
<td></td>
<td>1.19</td>
<td>.39</td>
</tr>
<tr>
<td>Yes (1)</td>
<td>66</td>
<td>81.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (2)</td>
<td>15</td>
<td>18.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>81</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obtain dental insurance from</td>
<td></td>
<td></td>
<td>.36</td>
<td>.67</td>
</tr>
<tr>
<td>Employer</td>
<td>48</td>
<td>75.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marketplace/Parent</td>
<td>9</td>
<td>14.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid/Medicare</td>
<td>7</td>
<td>10.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>64</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receiving Medicaid benefit</td>
<td></td>
<td></td>
<td>1.80</td>
<td>.40</td>
</tr>
<tr>
<td>Yes (1)</td>
<td>17</td>
<td>19.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (2)</td>
<td>69</td>
<td>80.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Interaction with oral health system includes Q6, Q7, Q8, Q9, Q10, Q11, Q12, Q15, Q16, Q17.
The majority of respondents \( (n=55) \) with dental insurance reported ease in finding a dentist who accepts their dental insurance \( (M=1.67) \). Only 11 respondents stated that finding a dentist who accepts their dental insurance was somewhat difficult to extremely difficult (See Table 8). Most of the respondents \( (n=71) \) indicated use of a single dentist as their regular source of dental care. Most participants \( (n=60) \) visited a dental office during the past 12 months (Figure 4), while only 26 participants had not visited a dental office within the past 12 months. Of the participants who had not visited the dentist in a year or more, nine respondents cited financial or insurance problems, while 16 respondents indicated their reason they had not experienced pain. Most subjects \( (n=72) \) planned to visit a dental office within the next 12 months.

![Figure 4. Length of Time Since Last Dental Visit](image)
Table 8

*Frequencies, Percentages, Means and Standard Deviations for Interaction with the Oral Health System of CF Adults*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty finding a dentist for those with dental insurance</td>
<td></td>
<td></td>
<td>1.67</td>
<td>.90</td>
</tr>
<tr>
<td>Extremely easy (1)</td>
<td>37</td>
<td>56.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat easy</td>
<td>18</td>
<td>27.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat difficult</td>
<td>7</td>
<td>10.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely difficult (4)</td>
<td>4</td>
<td>6.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>66</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single dentist as a regular source of dental care</td>
<td></td>
<td></td>
<td>1.18</td>
<td>.39</td>
</tr>
<tr>
<td>Yes (1)</td>
<td>71</td>
<td>81.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No (2)</td>
<td>15</td>
<td>18.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of time since last dental visit</td>
<td></td>
<td></td>
<td>1.51</td>
<td>.89</td>
</tr>
<tr>
<td>Less than 12 months (1)</td>
<td>60</td>
<td>69.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 to 2 years</td>
<td>13</td>
<td>15.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 to 5 years</td>
<td>8</td>
<td>9.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 5 years (4)</td>
<td>5</td>
<td>5.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reason for infrequency dental care if greater than 12 months</td>
<td></td>
<td></td>
<td>.64</td>
<td>.49</td>
</tr>
<tr>
<td>Financial or insurance problems</td>
<td>9</td>
<td>36.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No pain</td>
<td>16</td>
<td>64.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visit dentist in the next 12 months</td>
<td></td>
<td></td>
<td>1.33</td>
<td>.74</td>
</tr>
<tr>
<td>Yes (1)</td>
<td>72</td>
<td>83.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am not sure (3)</td>
<td>14</td>
<td>16.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Interaction with oral health system includes Q6, Q7, Q8, Q9, Q10, Q11, Q12, Q15, Q16, Q17.
Research question two A. To what extent does interaction with the oral health care system vary by demographic categories in adults with cystic fibrosis?

The data indicated a statistically significant relationship between participants’ marital status and the participation in dental insurance plans, $F(1, 79) = 7.361, MSW = 11.180, p = .008$ (See Table 9). Married status was significant determiner in respondents’ having dental insurance ($M = 1.07, SD = .26$) as compared with single participants ($M = 1.30, SD = 0.46$).

Similarly, the data indicated a statistically significant relationship between participants’ marital status and their having visited dental offices, $F(1, 84) = 15.462, MSW = 14.519, p < .001$. Single adults with CF reported fewer dental visits than married adults with CF ($M = .45, SD = 0.50$) ($M = .10, SD = .30$), respectively.

The data indicated a statistically significant relationship between participants’ marital status and the participants’ plans to visit dental offices, $F(1, 83) = 8.949, MSW = 42.224, p = .004$. Individuals of married status ($M = 1.10, SD = 0.43$) were more willing to visit a dental office compared to individuals with single status ($M = 1.56, SD = 0.90$).
Table 9

*Comparison of Martial status and Interaction with the Oral Health System Variables on the Oral Health Status of Adults with CF*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Group A M(SD)</th>
<th>Group B M(SD)</th>
<th>F</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have health insurance</td>
<td>86</td>
<td>1.05(.21)</td>
<td>1.00</td>
<td>1.953</td>
<td>1.84</td>
<td>.166</td>
</tr>
<tr>
<td>Origin of health insurance</td>
<td>77</td>
<td>.84(.82)</td>
<td>.26(.63)</td>
<td>12.230</td>
<td>1, 75</td>
<td>.001*</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have dental insurance</td>
<td>81</td>
<td>1.30(.46)</td>
<td>1.07(.26)</td>
<td>7.361</td>
<td>1, 79</td>
<td>.008*</td>
</tr>
<tr>
<td>Origin of dental insurance</td>
<td>64</td>
<td>.62(.85)</td>
<td>.18(.45)</td>
<td>6.880</td>
<td>1, 62</td>
<td>.011*</td>
</tr>
<tr>
<td>Difficulty finding a dentist for those with</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>dental insurance</td>
<td>66</td>
<td>1.79(1.03)</td>
<td>1.58(.79)</td>
<td>.849</td>
<td>1, 64</td>
<td>.360</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single dentist as a regular source of dental</td>
<td>86</td>
<td>1.25(.43)</td>
<td>1.10(.29)</td>
<td>3.642</td>
<td>1, 84</td>
<td>.060</td>
</tr>
<tr>
<td>care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receiving Medicaid benefits</td>
<td>85</td>
<td>1.68(.47)</td>
<td>1.93(.26)</td>
<td>8.579</td>
<td>1, 83</td>
<td>.004*</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of time since last dental visit</td>
<td>85</td>
<td>.45(.50)</td>
<td>.10(.30)</td>
<td>15.462</td>
<td>1, 84</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reason for infrequency dental care if greater</td>
<td>24</td>
<td>.60(.50)</td>
<td>1.00</td>
<td>2.444</td>
<td>1, 22</td>
<td>.132</td>
</tr>
<tr>
<td>than 12 months since last visit</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plan to visit dental office</td>
<td>85</td>
<td>1.56(.90)</td>
<td>1.10(.43)</td>
<td>8.949</td>
<td>1, 83</td>
<td>.004*</td>
</tr>
</tbody>
</table>

*Group A indicates single status and Group B indicates married status.

* p=<0.05
In addition, results of a one-way ANOVA found a statistically significant relationship between income levels and the likelihood to obtain care at single dental office, \( F(1, 81) = 9.371, MSW = 11.015, p = .003 \) (See Table 10). Participants with middle income or higher tend significantly to have single dental office that is usual source for dental care \((M = 1.10, SD = .30)\) compared to participants with low income \((M = 1.38, SD = 0.49)\).

Results of a one-way ANOVA indicated that there was a statistically significant relationship between income levels and have visited dental office within 12 months, \( F(1, 80) = 29.119, MSW = 12.133, p < .001 \). Cystic Fibrosis adults with middle income or higher, reported greater frequency of dental visits than CF adults with low income \((M = .14, SD = 0.34)\); \((M = .65, SD = .48)\), respectively.

Results of a one-way ANOVA also indicated that there was a statistically significant relationship between income levels and participants’ plans to visit dental offices in the next 12 months, \( F(1, 81) = 11.412, MSW = 40.805, p = .001 \). Adults with middle income or higher \((M = 1.17, SD = 0.56)\) were planned to visit a dental office as compared to CF participants with low income \((M = 1.75, SD = 0.98)\).
Table 10

*Comparison of Income and Interaction with the Oral Health System Variables on the Oral Health Status of Adults with CF*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Group A M(SD)</th>
<th>Group B M(SD)</th>
<th>F</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have health insurance</td>
<td>83</td>
<td>1.04(.20)</td>
<td>1.02(.13)</td>
<td>.435</td>
<td>1, 81</td>
<td>.511</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Origin of health insurance</td>
<td>74</td>
<td>1.43(.74)</td>
<td>.23(.50)</td>
<td>64.072</td>
<td>1, 72</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have dental insurance</td>
<td>78</td>
<td>1.25(.44)</td>
<td>1.17(.38)</td>
<td>.566</td>
<td>1, 76</td>
<td>.454</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Origin of dental insurance</td>
<td>61</td>
<td>1.20(.86)</td>
<td>.11(.31)</td>
<td>53.499</td>
<td>1, 59</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty finding a dentist for those with dental insurance</td>
<td>63</td>
<td>1.93(1.10)</td>
<td>1.58(.82)</td>
<td>1.757</td>
<td>1, 61</td>
<td>.190</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single dentist as a regular source of dental care</td>
<td>83</td>
<td>1.38(.49)</td>
<td>1.10(.30)</td>
<td>9.371</td>
<td>1, 81</td>
<td>.003*</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receiving Medicaid benefits</td>
<td>82</td>
<td>1.43(.50)</td>
<td>1.93(.25)</td>
<td>34.918</td>
<td>1, 80</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of time since last dental visit</td>
<td>82</td>
<td>.65(.48)</td>
<td>.14(.34)</td>
<td>29.119</td>
<td>1, 80</td>
<td>&lt;.001*</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reason for infrequency dental care if greater than 12 months since last visit</td>
<td>23</td>
<td>.57(.51)</td>
<td>.78(.44)</td>
<td>.983</td>
<td>1, 21</td>
<td>.333</td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plan to visit dental office</td>
<td>83</td>
<td>1.75(.98)</td>
<td>1.17(.56)</td>
<td>11.412</td>
<td>1, 81</td>
<td>.001*</td>
</tr>
</tbody>
</table>

Group A indicates poor status and Group B indicates non-poor status.

* p=<.001
Research question three. To what extent are adults with cystic fibrosis aware of good oral health?

Oral health awareness in adults with CF was measured in respondents with a “true or false” question. Of the 87 respondents with CF, most respondents ($n=68$) reported that some medical conditions, like diabetes, affect the health of their mouths ($M=1.01$). Only 18 respondents indicated they did not know if medial conditions like diabetes affected the health of their mouths (See Table 11). Likewise, most subjects ($n=79$) did not believe that if they did not have any pain in their mouths, then their mouths were disease free. Only five respondents did believe that if they did not have any pain in their mouths, then their mouths were disease free, while three additional respondents did not know. When asked if sugary foods and drinks cause tooth decay, more than 98% responded in the affirmative. Almost all participants ($n=86$) agreed that some medicines can affect the health of their mouths. Most ($n=66$) respondents also agreed that blood on their toothbrushes was a sign of gum disease, while seven respondents did not agree, and 14 respondents did not know. The majority of respondents ($n=82$) did not agree with the statement “I do not need to brush my teeth at least twice a day” while four respondents did agree. When asked to evaluate the statement, “I do not need to floss my teeth”, 72 respondents answered “False”, 11 respondents answered “True”, and only four respondents answered, “Do not know.”
Table 11

*Frequencies, Percentages, Means and Standard Deviations for True and False Statements*

<table>
<thead>
<tr>
<th>Variable</th>
<th>$n$</th>
<th>%</th>
<th>$M$</th>
<th>$SD$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some medical conditions like diabetes affect oral health</td>
<td></td>
<td></td>
<td>1.01</td>
<td>.12</td>
</tr>
<tr>
<td>True (1)</td>
<td>68</td>
<td>78.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>False (2)</td>
<td>1</td>
<td>1.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not Know</td>
<td>18</td>
<td>20.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If I am not having any pain in my mouth, then my mouth is disease free</td>
<td></td>
<td></td>
<td>1.94</td>
<td>.23</td>
</tr>
<tr>
<td>True (1)</td>
<td>5</td>
<td>5.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>False (2)</td>
<td>79</td>
<td>90.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not Know</td>
<td>3</td>
<td>3.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sugary foods and drinks cause tooth decay</td>
<td></td>
<td></td>
<td>1.01</td>
<td>.10</td>
</tr>
<tr>
<td>True (1)</td>
<td>86</td>
<td>98.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>False (2)</td>
<td>1</td>
<td>1.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not Know</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some medicines can affect oral health</td>
<td></td>
<td></td>
<td>1.00</td>
<td>.00</td>
</tr>
<tr>
<td>True (1)</td>
<td>86</td>
<td>98.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>False (2)</td>
<td>1</td>
<td>1.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not Know</td>
<td>0</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood on the toothbrush is a sign of gum disease</td>
<td></td>
<td></td>
<td>1.10</td>
<td>.29</td>
</tr>
<tr>
<td>True (1)</td>
<td>66</td>
<td>75.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>False (2)</td>
<td>7</td>
<td>8.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not Know</td>
<td>14</td>
<td>16.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not need to brush my teeth at least twice a day</td>
<td></td>
<td></td>
<td>1.95</td>
<td>.21</td>
</tr>
<tr>
<td>True (1)</td>
<td>4</td>
<td>4.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>False (2)</td>
<td>82</td>
<td>94.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not Know</td>
<td>1</td>
<td>1.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not need to floss my teeth</td>
<td></td>
<td></td>
<td>1.87</td>
<td>.34</td>
</tr>
<tr>
<td>True (1)</td>
<td>11</td>
<td>12.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>False (2)</td>
<td>72</td>
<td>82.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not Know</td>
<td>4</td>
<td>4.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Oral health awareness includes Q13 and Q14.
Perceptions of oral health in adults with CF were measured through questions scaled between “strongly disagree” to “strongly agree”. Of the 87 respondents with CF, most respondents ($n=80$) reported to “somewhat agree” or “strongly agree” that they valued keeping their mouths healthy ($M=3.60$). Only seven respondents reported to not value keeping their mouths healthy, have reported “somewhat disagree” and “strongly disagree” with the question (See Table 12). Likewise, the majority of respondents ($n=80$) indicated to “somewhat agree” and “strongly agree” that regular visits to the dentist would help keep their mouths healthy. Over half of the respondents ($n=46$) accept as they grow up, they may lose some of their teeth. Only 39 respondents did not accept as they grow up, they may lose some of their teeth. When asked if it would be easier to get ahead in life if they had straight/bright teeth, 68 responded affirmatively. Most respondents ($n=71$) reported that they need to visit the dentist twice a year, indicating the respondents are cognizant of their oral health.
Table 12

_Frequencies, Percentages, Means and Standard Deviations for Perception of the Mouth Health_

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>I value keeping my mouth healthy.</td>
<td>87</td>
<td>100</td>
<td>3.60</td>
<td>.79</td>
</tr>
<tr>
<td>Strongly Disagree (1)</td>
<td>5</td>
<td>5.7</td>
<td>3.60</td>
<td>.79</td>
</tr>
<tr>
<td>Somewhat Disagree</td>
<td>2</td>
<td>2.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat Agree</td>
<td>16</td>
<td>18.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Agree (4)</td>
<td>64</td>
<td>73.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular visits to the dentist will help keep me healthy.</td>
<td>87</td>
<td>100</td>
<td>3.60</td>
<td>.75</td>
</tr>
<tr>
<td>Strongly Disagree (1)</td>
<td>4</td>
<td>4.6</td>
<td>3.60</td>
<td>.75</td>
</tr>
<tr>
<td>Somewhat Disagree</td>
<td>2</td>
<td>2.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat Agree</td>
<td>18</td>
<td>20.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Agree (4)</td>
<td>62</td>
<td>71.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
<td>1.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>As I grow old, I accept that I will lose some of my teeth</td>
<td>87</td>
<td>100</td>
<td>2.58</td>
<td>1.06</td>
</tr>
<tr>
<td>Strongly Disagree (1)</td>
<td>17</td>
<td>19.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat Disagree</td>
<td>22</td>
<td>25.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat Agree</td>
<td>26</td>
<td>29.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Agree (4)</td>
<td>20</td>
<td>23.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
<td>2.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I need to see the dentist twice a year.</td>
<td>87</td>
<td>100</td>
<td>3.43</td>
<td>.81</td>
</tr>
<tr>
<td>Strongly Disagree (1)</td>
<td>3</td>
<td>3.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat Disagree</td>
<td>8</td>
<td>9.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat Agree</td>
<td>22</td>
<td>25.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Agree (4)</td>
<td>49</td>
<td>56.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>5</td>
<td>5.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is easier to get ahead in life if I have straight bright teeth.</td>
<td>87</td>
<td>100</td>
<td>3.08</td>
<td>.79</td>
</tr>
<tr>
<td>Strongly Disagree (1)</td>
<td>3</td>
<td>3.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat Disagree</td>
<td>14</td>
<td>16.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat Agree</td>
<td>41</td>
<td>47.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strongly Agree (4)</td>
<td>27</td>
<td>31.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>2</td>
<td>2.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td>100</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Oral health awareness includes Q13 and Q14.
**Relationship between question 13 variables**

Question 13 (true and false statements) was summarized as one scale based on the survey which was adapted from the American Dental Association’s Survey (Yarbrough et al., 2015). This question was calculated into one scale as sum of the number of items answered correctly for each participant, excluding the “Do not know” answer. The score of 7 indicated respondents answered all seven questions correctly.

**Internal Consistency of Oral Health Awareness and Perception of the Healthy Mouth Scale**

The study had 4 items which identified how CF adults perceive the health of their mouths. As determined by Cronbach's alpha, these items had an acceptable level of internal consistency ($\alpha = .62$). Therefore, while the $\alpha$ coefficient is .62, these items were formed as a scale (Yarbrough et al., 2015). Excluding “Do not know” answer, the score of 4 indicated respondents answered all five questions with a good perception about the oral health awareness.

**Research question three A. To what extent are demographic categories related to level of awareness in adults with cystic fibrosis?**

Results of a one-way ANOVA indicated that there was a statistically significant relationship between age and oral health awareness variables (Question 13), $F(1, 83) = 4.566$, $MSW= 95.723$, $p = .036$ (See Table 13). Adults with CF aged $\geq 33$ years old or older had a higher total score on this question ($M = 6.49$, $SD = .74$) than adults with CF aged $<33$ years old or younger ($M = 5.98$, $SD = 1.25$).

However, there was no statistically significant relationship between age and oral health awareness variables (Question 14), $F(1,83) = 2.625$, $MSW= 53.143$, $p = .109$. 
Table 13

*Comparison of Age and Oral Health Awareness Variables on the Oral Health Status of Adults with CF*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Group A M(SD)</th>
<th>Group B M(SD)</th>
<th>F</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td>4.566</td>
<td>1, 83</td>
<td>.036*</td>
</tr>
<tr>
<td>Oral health-Question 13</td>
<td>85</td>
<td>5.98(1.25)</td>
<td>6.49(.74)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td>2.625</td>
<td>1, 83</td>
<td>.109</td>
</tr>
<tr>
<td>Oral health-Question 14</td>
<td>85</td>
<td>3.00(.88)</td>
<td>3.28(.66)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Oral health awareness includes Q13 and Q14.
Group A indicates CF adults aged <33 and Group B indicates CF adults aged ≥ 33.

* p=<0.05

In addition, oral health awareness variable marginally differed by gender (Question 13), $F(1, 82) = 2.899$, $MSW = 94.318$, $p = .061$ (See Table 14). Female respondents had a higher total score on this question ($M = 6.32$, $SD = .97$) than male respondents ($M = 5.67$, $SD = 1.37$).

Also, genders differed significant difference in the oral health awareness variable (Question 14), $F(1, 82) = 8.303$, $MSW = 45.591$, $p = .001$. Female respondents expressed more agreement with statements about their oral health ($M = 3.27$, $SD = .56$) than male respondents ($M = 2.50$, $SD = 1.20$).
### Table 14

*Comparison of Gender and Oral Health Awareness Variables on the Oral Health Status of Adults with CF*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Group A (M(SD))</th>
<th>Group B (M(SD))</th>
<th>(F)</th>
<th>df</th>
<th>(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>85</td>
<td>5.67(1.37)</td>
<td>6.32(.97)</td>
<td>2.899</td>
<td>1, 82</td>
<td>.061</td>
</tr>
<tr>
<td>Oral health-Question 13</td>
<td>7 items</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>85</td>
<td>2.50(1.20)</td>
<td>3.27(.56)</td>
<td>8.303</td>
<td>1, 82</td>
<td>.001*</td>
</tr>
<tr>
<td>Oral health-Question 14</td>
<td>4 items</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Oral health awareness includes Q13 and Q14. Group A indicates male and group B indicates female. * \(p<0.001\).

One-way ANOVA showed a statistically significant relationship between employment status and oral health awareness variables (Question 13), \(F(1, 83) = 5.800, MSW= 94.392, p = .018\) (See Table 15). Cystic fibrosis adults of employed status had a lower total score on this question (\(M = 5.96, SD = 1.26\)) than CF adults of unemployed status (\(M = 6.53, SD = .66\)).

There was a slightly statistically significant relationship between employment status and oral health awareness variables (Question 14), \(F(1, 83) = 3.803, MSW= 52.422, p = .055\). Cystic fibrosis adults of employed status stated more agreement about their oral health (\(M = 3.25, SD = .84\)) than CF adults with no job or retired (\(M = 2.91, SD = .71\)).
Table 15

*Comparison of Employment status and Oral Health Awareness Variables on the Oral Health Status of Adults with CF*

<table>
<thead>
<tr>
<th>Variable</th>
<th>$n$</th>
<th>Group A $M(SD)$</th>
<th>Group B $M(SD)$</th>
<th>$F$</th>
<th>df</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
<td>5.80</td>
<td>1, 83</td>
<td>.018*</td>
</tr>
<tr>
<td>Oral health-Question 13</td>
<td>85</td>
<td>5.96(1.26)</td>
<td>6.53(.66)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
<td>3.80</td>
<td>1, 83</td>
<td>.055</td>
</tr>
<tr>
<td>Oral health-Question 14</td>
<td>85</td>
<td>3.25(.84)</td>
<td>2.91(.71)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Oral health awareness includes Q13 and Q14. Group A indicates employed and group B indicates non-employed. *$p<.05$.

One-way ANOVA showed no statistically significant relationship between education level and oral health awareness variables (Question 13), $F(1, 83) = .005, MSW= 100.982, p =.018$ (See Table 16). However, there was a statistically significant difference between education level and oral health awareness variables (Question 14), $F(1, 83) = 5.728, MSW= 51.284, p =.942$. Cystic fibrosis adults with high school or associate degrees were less agreeable with the statements about their oral health ($M = 2.78, SD = .73$) than CF adults with at least a bachelors level education ($M = 3.24, SD = .80$).
Table 16

Comparison of Education and Oral Health Awareness Variables on the Oral Health Status of Adults with CF

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Group A M(SD)</th>
<th>Group B M(SD)</th>
<th>F</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral health awareness</td>
<td>85</td>
<td>6.17(.98)</td>
<td>6.19(1.14)</td>
<td>.005</td>
<td>1, 83</td>
<td>.942</td>
</tr>
<tr>
<td>7 items</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral health awareness</td>
<td>85</td>
<td>2.78(.73)</td>
<td>3.24(.80)</td>
<td>5.728</td>
<td>1, 83</td>
<td>.019*</td>
</tr>
<tr>
<td>4 items</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Oral health awareness includes Q13 and Q14.
Group A indicates high school or associate degree and group B indicates bachelor or graduate education.
* p=<0.05.
CHAPTER V

DISCUSSION

To the best of our knowledge, this is the first study of oral health status, interaction with the oral health system, and oral health awareness in adults with CF. A recent systematic review of dental caries in individuals with CF reinforced the paucity of those studies (Chi, 2013). Research is needed to identify dental needs of adults with CF.

The oral-health assessment data obtained in this study are consistent with the findings of Dabrowska et al. (2006), who found the incidence of oral health problems to be very high in patients with cystic fibrosis between ages 13 and 24 years as compared to younger patients with cystic fibrosis. In addition, Storhaug (1985) and Storhaug and Holst (1987) found similar results for habits and problems related to disabled children’s dental health. These findings indicate that the high caloric intake and poor oral hygiene are related to oral health problems in the cystic fibrosis population. (Dabrowska et al., 2006; Jonathan et al., 2016; Smyth et al., 2014; Storhaug, 1985; Storhaug & Holst, 1987; Woestenenk et al., 2012).

Dry mouth is one indication between poor to good oral health in adults with CF. Dry mouth has been documented as resulting from the cystic fibrosis genetic disorder. Individuals with cystic fibrosis experience a lower rate of saliva production than do individuals without CF due to the impact of the CFTR gene (Blomfield et al., 1973; Jajels & Sweeney, 1976). Xerostomia has also been linked to daily oral medications for cystic fibrosis (Flume et al., 2007; Halfhide et al., 2005; Kargul et al., 1998; Milano et al., 2006).

Another factor for the identification of poor to good oral health status in CF adults is the presence of blood on toothbrushes following brushing. Periodontal health is associated with salivary components, saliva concentration, patient demographics, and social class (Narang et al.,
This study’s findings are similar to others that those with cystic fibrosis experience higher numbers of sextants with calculus deposits and gingival bleeding, as compared to those without this condition (Jonathan et al. 2016; Narang et al., 2003).

Anxiety is well-documented in individuals with CF because of the disease’s typical development, medications, and long-term impact (CFF, 2016). It is not surprising that adults with CF felt occasional to very often anxious and embarrassed and avoided smiling due to concerns with their mouth and teeth. Oral medications may have contributed to oral-health issues such as extrinsic stains (Jajels & Sweeney, 1976; Swaalow et al., 1967) and enamel defects (Ferrazzano et al., 2012; Narang et al., 2003).

Level of education and oral-health status was not obtained in this study as a biological phenomenon; however, education did impact self-reported oral-health issues. Oral health issues increased among those with non-college education as a result of being exposure to several unfavorable factors.

Over half of the participants stated that they had dental insurance, visited a dental office within the last 12 months, and planned to visit a dental office within the next 12 months. This suggests that CF adults interacted with the oral-health system because of their awareness of the impact of oral infections on their overall health. It is important to provide persons with CF an introduction to general medical and oral/dental care, and to encourage regular appointments for preventive procedures (Berlinski, Chambers, Willis, Homa, & Com, 2014). Findings from this study were not consistent with those of Nelson et al. (2011), who reported that children with disabilities (including CF) were not being served under the current system of dental coverage. This study’s findings are also not consistent with the study based on Iowa’s Medicaid program.
The researchers in that study focused on comparing oral-health interactions among children with
cystic fibrosis and those without cystic fibrosis (Sarvas et al., 2015).

Socioeconomic factors, such as income have been associated with interaction with the
oral health system (Reid et al., 2004; Sabbah et al., 2009; Smaje, 1996). Generally, adults with
private dental care had dental insurance and visited dental clinics (Bloom et al., 2012). Results
from this study found that middle- and -high income adults tend to interact regularly with the
oral health system.

Marital status has been linked to better health outcomes, which suggests that married
individuals interact more often with the oral health system than unmarried individuals.
(McDonald & Gaboda, 2013; Okunseri, Bajorunaite, Mehta, Hodgson, & Iacopino, 2009).
Married individuals in our sample were more likely to have dental insurance, visited the dentist
within the last 12 months, and were willing to visit the dentist in the next 12 months when
compared to non-married respondents.

Oral-health awareness can decrease the societal burden of related problems (Downer,
1991). Even though adults with CF seemed to have knowledge of oral health and of its impact on
overall health, some of them reported some oral-health concerns. Perhaps the difficulty and time-
consuming nature of treatment contributes to self-management among adults with CF (George et
al., 2010) and therefore, affecting quality of life. (Abbott et al., 2013; George et al., 2010).

It is known that age, gender, employment status, and education affect perceptions of oral-
health awareness (McDonald & Gaboda, 2013). This study also found age, gender, employment
status and education levels were partially reinforced. Participants aged at least 33 years old and
unemployed or retired performed better with regard to true and false statements. Additionally,
females and those with a college education expressed more agreement with statements about
their oral health than did other groups. More research is needed to identify how oral health awareness interacts with employment status and education level in adults with CF.

**Risk and Potential Benefits of this Study**

The risk to adults with cystic fibrosis was minimal. There were no known risks to the subjects who participated in the survey. The survey questions did not contain any sensitive information related to the participants or their names. There was no direct benefit from participation in this study; however, results could provide a better understanding of oral care needs of those with cystic fibrosis. Additionally, findings might identify barriers to dental care utilization among the cystic fibrosis population for the development of a strategic plan to reduce barriers. Moreover, this study might guide researchers and cystic fibrosis centers to establish educational programs to improve oral health status of individuals with cystic fibrosis.

**Limitations**

The Hawthorne effect was a threat to internal validity as this online study relies on self-reporting. Selection bias could also be a threat to external validity as the study was launched on social media.

The design of the study made it impossible to identify causal effects. Oral health assessment was based on the adult’s self-assessment of the condition of his or her mouth and teeth. No clinical measurements were obtained; therefore, a participant’s oral health assessment might differ from the evaluation of oral health status if assessed by a dental health professional.

Obtaining a representative sample in CF studies is difficult because the disease is uncommon and frequent hospitalization (Chi, 2013); however, using social media to disseminate the survey led to greater randomization of responses. Higher percentage of Caucasian adults with CF might be perceived as a limitation; however, the prevalence of disease is more prevalent in
Caucasians (CFF, 2016). This study may also have maturation effects, which might affect recall leading to inaccurate responses.

**Future Research**

To have a more accurate understanding of oral disease among the CF population, a clinical study with two randomized groups is suggested; one with CF and one without CF matched by demographics. Each participant would receive a clinical examination by two calibrated examiners. Examiners would be calibrated, and inter- and intra-rater reliability would be assessed to improve accuracy of oral conditions in those with cystic fibrosis.
CHAPTER VI

CONCLUSION

Oral health is essential to general health and quality of life (WHO, 2012). Good oral hygiene results in healthy teeth, gums and tongue (WHO, 2012). The literature has shown that individuals with CF might be at a higher risk for oral diseases because the impaction of this disease (Dabrowska et al., 2006; Storhaug, 1985; Storhaug & Holst, 1987).

The objectives of this study were to understand how adults with CF would evaluate their oral health status, interaction with the oral health system, and oral health awareness. Outcomes from the study will be useful for cystic fibrosis foundations, dental offices, dental schools and will add to the literature to assist with the improvement of oral in individuals with CF.

Adults with CF, a high school or associate degree, were more likely to report fair to poor condition of their mouth and teeth, and experience oral health problems, particularly dry mouth or xerostomia, pain, and gingival bleeding. Married status and middle- to high- incomes were associated with accessing the oral health system. Age, gender, employment status, and education significantly influenced oral health awareness.
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APPENDICES

APPENDIX A

Q1. In what country or region do you currently reside?

[Several Options, but all respondents chose “United States”]

Q2. In what year were you born?

[Response range: 1906-1997]

Q3. What is your zip code?

[Keyed response]

Q4. How would you describe the condition of your mouth and teeth?

[Poor, Fair, Good, Very Good, Don’t Know]

Q5. How often during the past 12 months have you felt that life in general was less satisfying because of problems with your mouth and teeth?

[Never, Rarely, Occasionally, Very Often, Don’t Know]

Q6. Have you ever felt that the appearance of your mouth and teeth affected your ability to interview for a job?

[Yes, No, Don’t Know]

Q7. How often have you experienced each of the following problems related to your mouth and teeth during the past 12 months?

• Difficulty when biting or chewing foods

[Never, Rarely, Occasionally, Very Often, Don’t Know]

• Difficulty with speech or trouble

[Never, Rarely, Occasionally, Very Often, Don’t Know]

pronouncing words

[Never, Rarely, Occasionally, Very Often, Don’t Know]

• Dry mouth
[Never, Rarely, Occasionally, Very Often, Don’t Know]

- Felt anxiety

[Never, Rarely, Occasionally, Very Often, Don’t Know]

- Felt embarrassment

[Never, Rarely, Occasionally, Very Often, Don’t Know]

- Avoided smiling

[Never, Rarely, Occasionally, Very Often, Don’t Know]

- Took days off work because of pain or discomfort

[Never, Rarely, Occasionally, Very Often, Don’t Know]

- Difficulty doing usual activities

[Never, Rarely, Occasionally, Very Often, Don’t Know]

- Reduced participation in social activities

[Never, Rarely, Occasionally, Very Often, Don’t Know]

- Problems sleeping

[Never, Rarely, Occasionally, Very Often, Don’t Know]

- Experienced pain

[Never, Rarely, Occasionally, Very Often, Don’t Know]

Q8. Are the following statements true or false? If you are not sure, please make your best guess.

- Some medical conditions like diabetes affect the health of your mouth

[True, False]

- People who smoke are more likely to have cancer in their mouth

[True, False]

- Children do not need to see a dentist until they start school

[True, False]
• Because they do not stay in your child’s mouth very long, baby teeth are not that important
[True, False]

• Some medicines can affect the health of your mouth
[True, False]

• Blood on your toothbrush is a sign of gum disease
[True, False]

• If I am not having any pain in my mouth, then my mouth is disease free
[True, False]

• Sugary foods and drinks cause tooth decay
[True, False]

Q9. How strongly do you agree or disagree with the following statements about how you perceive the health of your mouth?

• I value keeping my mouth healthy
[Strongly Disagree, Somewhat Disagree, Somewhat Agree, Strongly Agree, Don’t Know]

• Regular visits to the dentist will help keep me healthy
[Strongly Disagree, Somewhat Disagree, Somewhat Agree, Strongly Agree, Don’t Know]

• As I grow old I accept that I will lose some of my teeth
[Strongly Disagree, Somewhat Disagree, Somewhat Agree, Strongly Agree, Don’t Know]

• I need to see the dentist twice a year
[Strongly Disagree, Somewhat Disagree, Somewhat Agree, Strongly Agree, Don’t Know]

• It is easier to get ahead in life if I have straight bright teeth

Q10. Do you currently have health insurance for 2015?
[Yes, No, Don’t Know]

Q11. Do you currently have dental insurance for 2015?
Q12. How did you obtain your own individual health insurance for 2015?  
Please select all that apply.

• Employer (mine or my spouse/partner’s)
• Through the new health insurance marketplace
• Directly from the insurance company, not through the marketplace
• Medicaid
• Medicare
• Through a government program other than Medicaid/Medicare (e.g., VA, TRICARE, SSI)
• Other
• Don’t know
• N/A – I do not have health insurance for 2015

Q13. How did you obtain your own individual dental insurance for 2015?  
Please select all that apply.

• Employer (mine or my spouse/partner’s)
• Through the new health insurance marketplace
• Directly from the insurance company, not through the marketplace
• Medicaid
• Medicare
• Through a government program other than Medicaid/Medicare (e.g., VA, TRICARE, SSI)
• Other
• Don’t know
• N/A - I do not have health insurance for 2015

Q14. Ask if respondent does have dental insurance: How easy or difficult is it for you to find a dentist that accepts your dental insurance?

[Very Difficult, Somewhat Difficult, Somewhat Easy, Very Easy]

Q15. Do you have a single dentist or dental office that is your usual source of dental care?

[Yes, No]

Q16. How long since you last had a dental visit?

• Less than 12 months
• 1 to 2 years
• 3 to 5 years
• More than 5 years
• N/A – I’ve never been to a dentist

Q17. Do you plan to visit the dentist in the next 12 months?

[Yes, No, I am not sure]

Q18. Ask if last dental visit was more than 12 months: Why did you not visit the dentist more frequently? Please select all that apply.

• My mouth is healthy so I do not need to visit the dentist
• I do not know where to go to receive dental services
• I cannot afford to go to the dentist
• It is too hard to find a dentist that accepts my dental plan or Medicaid
• I cannot find the time to get to a dentist (e.g., cannot get the time off from work, dentist does not have convenient office hours)
• Many services are not covered by my dental plan or Medicaid, so I end up having to pay with my own money
• I cannot travel to a dentist easily (e.g., do not have transportation, located too far away)

• I do not any of my original teeth (i.e. I have no teeth, or I have dentures)

• I am afraid of going to the dentist

• Other

• No reason

Q19. Including yourself, how many people age 18 or older live in your household?

[Keyed response]

Q20. How many people under the age of 18 live in your household?

[Keyed response]

Q21. Are you currently receiving any Medicaid benefits?

[Yes, No, Don’t Know]

Q22. Are you male or female?

[Male, Female]

Q23. Which one of the following best describes your employment status?

• Employed full time

• Employed part time

• Self-employed

• Not employed, but looking for work

• Not employed and not looking for work

• Retired

• Not employed, unable to work due to a disability or illness
• Student
• Stay-at-home spouse or partner
• Unknown

Q24. Which of the following income categories best describes your total 2014 household income before/after taxes?

• Less than $15,000
• $15,000 to $24,999
• $25,000 to $34,999
• $35,000 to $49,999
• $50,000 to $74,999
• $75,000 to $99,999
• $100,000 to $124,999
• $125,000 to $149,999
• $150,000 to $199,999
• $200,000 to $249,999
• $250,000 or more

Q25. In what state, province or territory do you currently reside?

• Alabama • Alaska • Arizona • Arkansas • California • Colorado • Connecticut • Delaware
• District of Columbia • Florida • Georgia • Hawaii • Idaho • Illinois • Indiana • Iowa
• Kansas • Kentucky • Louisiana • Maine • Maryland • Massachusetts • Michigan
• Minnesota • Mississippi • Missouri • Montana • Nebraska • Nevada • New Hampshire
• New Jersey • New Mexico • New York • North Carolina • North Dakota • Ohio
• Oklahoma • Oregon • Pennsylvania • Rhode Island • South Carolina • South Dakota
• Tennessee • Texas • Utah • Vermont • Virginia • Washington • West Virginia • Wisconsin
• Wyoming
Q26. How many hours per week do you typically spend on the Internet or World Wide Web?

[Keyed response]

Q27. What is your marital status?

• Never married
• Married or civil union
• Divorced
• Separated
• Widow/Widower
• Living with partner
• Unknown
• Decline to answer

Q28. What is the highest level of education you have completed or the highest degree you have received?

• Less than high school
• Completed some high school
• Completed high school
• Completed some college
• Completed college
• Completed some graduate school
• Completed graduate school
• Associate Degree
• Job-specific training program(s) after high school
• Some college, but no degree
• Some college, but no 4 year degree
• College (such as B.A., B.S.)
• Some graduate school, but no degree
• Graduate degree (such as M.B.A., M.S., M.D., Ph.D.)
• M.A., M.S., M.F.A.
• M.B.A.
• Ph.D., Psy.D., or other academic doctorate
• J.D.
• M.D.
• Other graduate or professional degree

Q29. What is your race/ethnicity?
• White
• Black
• Asian or Pacific Islander
• Native American or Alaskan Native
• Mixed Race
• Some other race
• Hispanic
• African American
• First Nation/Native Canadian
• South Asian
• Chinese
• Korean
• Japanese
• Other Southeast Asian
• Filipino
• Arab/West Asian
• Decline to Answer
• Unknown
APPENDIX B

INSTRUMENT

Q. Do you have cystic fibrosis?
[Yes, No] Answer no will lead participant to be out of the survey.

Q. Are you 18 years-old or older and English-speaking?
[Yes, No] Answer no will lead participant to be out of the survey.

Q1. How would you describe the condition of your mouth?
[Poor, Fair, Good, Very Good, Don’t Know]

Q2. How would you describe the condition of your teeth?
[Poor, Fair, Good, Very Good, Don’t Know]

Q3. How often during the past 12 months have you felt that life in general was less satisfying because of problems with your mouth and teeth?
[Never, Rarely, Occasionally, Very Often, Don’t Know]

Q4. Have you ever felt that the appearance of your mouth and teeth affected your ability to interview for a job?
[Yes, No, Don’t Know]

Q5. How often have you experienced each of the following problems related to your mouth and teeth during the past 12 months?

• Difficulty when biting or chewing foods
  [Never, Rarely, Occasionally, Very Often, Don’t Know]

• Difficulty with speech or trouble pronouncing words
  [Never, Rarely, Occasionally, Very Often, Don’t Know]

• Dry mouth
• Felt anxiety
• Felt embarrassment
• Avoided smiling
• Took days off work because of pain or discomfort
• Difficulty doing usual activities
• Reduced participation in social activities
• Problems sleeping
• Experienced pain
• Blood on your toothbrush

Q6. Do you currently have HEALTH insurance for 2018?
[Yes, No, Don’t Know]

Q7. How did you obtain your own individual HEALTH insurance for 2018?
Please select all that apply.
• Employer (mine or my spouse/partner’s)
• Through the new health insurance marketplace
• Directly from the insurance company, not through the marketplace
• Medicaid
• Medicare
• Through a government program other than Medicaid/Medicare (e.g., VA, TRICARE, SSI)
• Other
• Don’t know
• N/A – I do not have health insurance for 2018

Q8. Do you currently have DENTAL insurance for 2018?
[Yes, No, Don’t Know]

Q9. How did you obtain your own individual DENTAL insurance for 2018?
Please select all that apply.
• Employer (mine or my spouse/partner’s)
• Through the new health insurance marketplace
• Directly from the insurance company, not through the marketplace
• Medicaid
• Medicare
• Through a government program other than Medicaid/Medicare (e.g., VA, TRICARE, SSI)
• Other
• Don’t know
• N/A - I do not have health insurance for 2018

Q10. (If respondent does have dental insurance):
How easy or difficult is it for you to find a dentist that accepts your dental insurance?
[Very Difficult, Somewhat Difficult, Somewhat Easy, Very Easy]
Q11. Do you have a single dentist or dental office that is your usual source of dental care?
[Yes, No]

Q12. Are you currently receiving any Medicaid benefits?
[Yes, No, Don’t Know]

Q13. Are the following statements true or false? If you are not sure, please make your best guess.

• Some medical conditions like diabetes affect the health of your mouth
  [True, False, Do not Know]

• If I am not having any pain in my mouth, then my mouth is disease free
  [True, False, Do not Know]

• Sugary foods and drinks cause tooth decay
  [True, False, Do not Know]

• Some medicines can affect the health of your mouth
  [True, False, Do not Know]

• I do not need to brush my teeth at least twice a day
  [True, False, Do not Know]

• I do not need to floss my teeth
  [True, False, Do not Know]

Q14. How strongly do you agree or disagree with the following statements about how you perceive the health of your mouth?

• I value keeping my mouth healthy
  [Strongly Disagree, Somewhat Disagree, Somewhat Agree, Strongly Agree, Don’t Know]

• Regular visits to the dentist will help keep me healthy
  [Strongly Disagree, Somewhat Disagree, Somewhat Agree, Strongly Agree, Don’t Know]

• As I grow old, I accept that I will lose some of my teeth
[Strongly Disagree, Somewhat Disagree, Somewhat Agree, Strongly Agree, Don’t Know]
• I need to see the dentist twice a year

[Strongly Disagree, Somewhat Disagree, Somewhat Agree, Strongly Agree, Don’t Know]
• It is easier to get ahead in life if I have straight bright teeth

[Strongly Disagree, Somewhat Disagree, Somewhat Agree, Strongly Agree, Don’t Know]

Q15. How long since you last had a dental visit?
• Less than 12 months
• 1 to 2 years
• 3 to 5 years
• More than 5 years
• N/A – I’ve never been to a dentist

Q16. If last dental visit was more than 12 months: Why did you not visit the dentist more frequently? Please select all that apply.
• My mouth is healthy, so I do not need to visit the dentist
• I do not know where to go to receive dental services
• I cannot afford to go to the dentist
• It is too hard to find a dentist that accepts my dental plan or Medicaid
• I cannot find the time to get to a dentist (e.g., cannot get the time off from work, dentist does not have convenient office hours)
• Many services are not covered by my dental plan or Medicaid, so I end up having to pay with my own money
• I cannot travel to a dentist easily (e.g., do not have transportation, located too far away)
• I do not any of my original teeth (i.e. I have no teeth, or I have dentures)
• I am afraid of going to the dentist
• Other
• No reason
Q17. Do you plan to visit the dentist in the next 12 months?
[Yes, No, I am not sure]

Q18. Including yourself, how many people AGE 18 OR OLDER live in your household?
[Keyed response]

Q19. How many people UNDER THE AGE OF 18 live in your household?
[Keyed response]

Q20. What is your marital status?
• Never married  • Married or civil union
• Divorced  • Separated
• Widow/Widower  • Living with partner
• Unknown  • Decline to answer

Q21. What is the highest level of education you have completed or the highest degree you have received?
• Less than high school  • Completed some high school
• Completed high school  • Completed some college
• Completed college  • Completed some graduate school
• Completed graduate school  • Associate Degree
• Job-specific training program(s) after high school

Q22. What is your race/ethnicity?
• White
• Black
• Asian or Pacific Islander
• Native American
or Alaskan Native
• Mixed Race
• Some other race
• Hispanic
• African American
• First Nation/Native Canadian
• South Asian
• Chinese
• Korean
• Japanese
• Other Southeast Asian
• Filipino
• Arab/West Asian
• Decline to Answer

Q23. How old are you?
18-22
23-27
28-32
33-37
38-42
43-47
48-52
53-57
Other

Q24. What is your gender?
[Male, Female, other, Do not wish to respond]
Q25. Which one of the following best describes your employment status?

- Employed full time
- Employed part time
- Self-employed
- Not employed, but looking for work
- Not employed and not looking for work
- Retired
- Not employed, unable to work due to a disability or illness
- Student
- Stay-at-home spouse or partner
- Unknown

Q26. Which of the following income categories best describes your total 2017 household income after taxes?

- Less than $15,000
- $15,000 to $24,999
- $25,000 to $34,999
- $35,000 to $49,999
- $50,000 to $74,999
- $75,000 to $99,999
- $100,000 to $124,999
- $125,000 to $149,999
- $150,000 to $199,999
- $200,000 to $249,999
- $250,000 or more

Q27. In what state do you currently reside?

[Keyed response]
<table>
<thead>
<tr>
<th>Content</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral Health Assessment</td>
<td>Q1 – Q2 - Q3 – Q4 – Q5</td>
</tr>
<tr>
<td>Interaction with Oral Health System</td>
<td>Q6 – Q7 – Q8 – Q9 – Q10 – Q11 – Q12 – Q15 – Q16 – Q17</td>
</tr>
<tr>
<td>Oral Health Awareness</td>
<td>Q13 – Q14</td>
</tr>
</tbody>
</table>
APPENDIX D

SURVEY INVITATION

Dear Participants,

My name is Ahmed Almuntashiri and I am currently a student in the Master of Science program in the dental hygiene program at Old Dominion University. I am conducting a research study on the oral health of individuals with the genetic disorder known as cystic fibrosis as a requirement for completing a Master of Science in Dental Hygiene. You are invited to participate in a research study entitled “Self-Reported Oral Health Status and Attitudes Toward Oral Health of Adults with Cystic Fibrosis in Virginia.” The purpose of my research is to develop a profile of oral health status, interaction with the oral health care system, and oral health awareness in individuals with cystic fibrosis.

Your opinions are very important, and your responses will remain confidential and anonymous. This study has no known risks to participation, and the survey has only 27 questions. Your participation in the survey is completely voluntary and you may refuse to participate at any time if you wish by closing your browser.

To be eligible for participation, each participant must be 18 years of age or older, and English speaking. If you agree to participate in this study, complete the questionnaire in the link below. This study should take around 15 minutes or less to be completed. Should you have any questions about this research study, you can contact me at this email aalmu011@odu.edu or my supervisor for this study Dr. Susan Daniel, at this email SJDANIEL@odu.edu.
APPENDIX E

INSTITUTIONAL REVIEW BOARD

OFFICE OF THE VICE PRESIDENT FOR RESEARCH

Physical Address
4111 Moan’s Way, Suite 201
N. Norfolk, Virginia 23508
Mailing Address
Office of Research
1 Old Dominion University
N. Norfolk, Virginia 23529
Phone: (757) 683-5402
Fax: (757) 683-8962

DATE: April 9, 2018

TO: Susan Danelo, PhD
FROM: Old Dominion University Health Sciences Human Subjects Review Committee

PROJECT TITLE: [Y2012006-2] Assessment and Attitudes Toward Oral Health for Adults with Cystic Fibrosis in Virginia
REFERENCE #: 
SUBMISSION TYPE: Response/Follow-Up

ACTION: DETERMINATION OF EXEMPT STATUS

DECISION DATE:

REVIEW CATEGORY: Exemption category # 6.2

Thank you for your submission of Response/Follow-Up materials for this project. The Old Dominion University Health Sciences Human Subjects Review Committee has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact Harry Zhang at 757-683-6870 or a.zhang@odu.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Old Dominion University Health Sciences Human Subjects Review Committee’s records.
## APPENDIX F
### STATISTICAL ANALYSIS

<table>
<thead>
<tr>
<th>Research questions</th>
<th>Independent variable</th>
<th>Dependent Variable</th>
<th>Statistical analysis</th>
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<tr>
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<td>Demographic checklist</td>
<td>Oral health assessment</td>
<td>ANOVA</td>
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<tr>
<td>Research question 2a</td>
<td>Demographic checklist</td>
<td>Interaction with the oral health system</td>
<td>ANOVA</td>
</tr>
<tr>
<td>Research question 3a</td>
<td>Demographic checklist</td>
<td>Oral health awareness</td>
<td>ANOVA</td>
</tr>
</tbody>
</table>
VITA

Ahmed Ali Almuntashiri
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EDUCATION:
Bachelor of Science in Dental Hygiene
Al Baha University
Al Baha, Saudi Arabia
June 2013

Old Dominion University
Norfolk, Virginia
Master of Science in Dental Hygiene
August 2018

ACADEMIC APPOINTMENTS:
May 18 to June 15, 2017 Teaching Assistant – Old Dominion University, Health Science College, Department of Dental Hygiene, Anxiety and Pain Control Course.

Responsibilities included clinician in clinic; grade weekly quizzes; and lecturer.