

Oral Health-Related Quality of Life in Pediatric Cancer Survivors.

BY

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THESIS

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LIST OF ABBREVIATIONS

ALL	Acute Lymphoblastic Anemia
AAPD	American Academy of Pediatric Dentistry
CC	Childhood Cancer
CCSS	Childhood Cancer Survivor Study
CDC	Centers for Disease Control
COHIP	Child Oral Health Impact Profile
C-OIDP	Child Oral Impacts on Daily Performances Index
CPQ	Child Perceptions Questionnaire
C-OIDP	Child Oral Impacts on Daily Performances Index
ECOHIS	Early Child Oral Health Impact Scale
HCT	Human Cell Transplant
GA	General Anesthesia
Gy	Gray unit of ionizing radiation
IRB	Institutional Review Board
MOHRQoL	Michigan Oral Health-Related Quality of Life scale
OHRQoL	Oral Health-related Quality of Life
POQL	Pediatric Oral Health-Related Quality of Life Measure
QoL	Quality of Life
SOHO-5	Scale of Oral Health Outcomes for 5-year-old children
UIC	University of Illinois at Chicago
USA	United States of America

Summary

As survival rates of children with cancer improved considerably during the past decades, the long-term effects of antineoplastic therapy gained an increasing importance. Survivors of childhood cancer remain at risk for radiation and chemotherapy associated dental complications. Childhood cancer survivors may have experienced a high number of invasive medical and dental procedures, which may affect their oral health-related quality of life (OHRQoL).

This study was a cross-sectional assessment of the OHRQoL in pediatric cancer survivors and a healthy control. Structured telephone interviews of child cancer survivors and their parents, with a control group of University of Illinois at Chicago Hospital outpatient children were completed using two surveys.

The purpose of the study was to compare the OHRQoL of pediatric cancer survivors with healthy controls and to assess the OHRQoL of pediatric cancer survivors.

1. INTRODUCTION

1.1 **Background Information**

A diagnosis of cancer is a life altering event for children and adolescents as well as their families. Although it is promising that the overall 5 - year survival rates for childhood cancer have improved due to improved diagnosis and treatment, yet cancer is still the second leading cause of death in children aged 5 to 14 years (Murphy et al., 2013, Howlader et al., 2013).

Cancer is characterized by uncontrolled growth of cells that lack the normal growth controls seen in healthy cells. This uncontrolled growth allows the cancer cells to invade adjacent structures and then destroy surrounding tissues and organs. (Fraumeni, 1982, McCance, 1998).

1.2 **Current Research on Oral Health in Cancer Survivors**

Children diagnosed with childhood cancer often undergo therapies including radiation, transplantation, immunotherapy and/or chemotherapy. These therapies, along with medications provided to children during cancer therapy, have been known to cause oral complications such as caries, and dental developmental abnormalities including agenesis, dental hypoplasia, root stunting, and enamel defects. Survivors also have a higher prevalence of xerostomia, and cariogenic microflora, which have been linked to risk of periodontal disease (Purdell-Lewis, 1988, Dreizen, 1988, Cowman, 1993, Makkonen, 1986, Nasman, 1994, Brown, 1992, Jones, 1992, Dahlloof, 1997).

While the oral condition of patients with cancer have been studied, and addressed in the literature, yet no studies have examined Oral Health-related Quality of Life in the Pediatric cancer survivors population. It is our belief that cancer and its oral complications may have an impact on OHRQoL of the pediatric cancer survivor.

1.3 **Purpose of the Study**

The purposes of this study were:

1. To assess the impact of oral health in the quality of life of childhood cancer survivors.
2. To compare the OHRQoL of pediatric cancer survivors with healthy outpatients.

1.4 **Hypothesis of the Study**

The null hypothesis of the study is:

- There is no difference in OHRQoL scores between cancer survivors and healthy controls.

2. REVIEW OF LITERATURE

2.1 Childhood Cancer

A structured review of the literature on the topic of Childhood Cancer Survivor and oral health was undertaken using the search engines PubMed, Cochrane database, and Medline Plus. A PubMed search was completed using MeSH terms “Childhood Cancer Survivor” and: “Childhood Cancer”; “Oral Health”; “Dental Caries”; “Dental Health Surveys”; as well as general searches of “Childhood Cancer review”; “oral health-related quality of life”; and “COHIP”. PubMed features ‘Related Searches’ and ‘Related Citations’ were used to find additional articles. Eighty-nine articles were selected by the contents of the abstract and full review.

In the United States, it was estimated that 15,270 children and adolescents ages 0 to 19 years would be diagnosed with cancer and 1,790 would die of the disease in 2017 (Siegel et al., 2017). Data published by the National Cancer Institute’s Surveillance, Epidemiology and End Results Program in 2014 demonstrated the incidence, mortality, and survival rates of childhood cancers. Among children ages 0 to 14 years, it was estimated that 10,270 would be diagnosed with cancer and 1,190 would die of the disease in 2017 (Howlader et al., 2017).

In the United States, approximately 419,000 survivors of childhood and adolescent cancer diagnosed at ages 0 to 19 years were alive according to the latest data published (Howlader et al., 2017). The number of survivors will continue to increase, given that the incidence of childhood cancer has been rising slightly in recent decades and that survival rates overall are improving.

Acute lymphoblastic leukemia (ALL) is the most common type of cancer diagnosed in children ages 0 to 14 years in the United States, followed by brain and other central nervous system tumors, lymphomas, soft tissue sarcomas, neuroblastoma, and kidney tumors (Siegel et al., 2017). Lymphomas are the most common types of cancer diagnosed in 15- to 19-year-olds adolescents, followed by brain and other central nervous system tumors, leukemia, gonadal germ cell tumors, thyroid cancer, and melanoma (Siegel et al., 2017).

Due to the improvement in treatments modalities introduced beginning in the 1960s and 1970s, the 5-year survival rate for children diagnosed with ALL before age 20 years raised from less than 10% in the 1960s to about 88% in 2007–2013. Furthermore, the 5-year survival rate for children diagnosed with non-Hodgkin lymphoma before age 20 years has increased dramatically, from less than 50% in the late 1970s to about 89% in 2007–2013.

ALL is more common in industrialized countries than in developing countries. Higher incidence rates of ALL have been noted at ages 2 to 4 years. In the United States, ALL is more common in boys than in girls and Hispanic and white children than in black children (Ward et al., 2014).

The exact causes of most childhood cancers are not known. About 5% of all cancers in children are caused by an inherited genetic mutation. For example, an inherited mutation in a gene *RBI* causes 25% to 30% of cases of retinoblastoma (Moore, 2009). However, only 4% of all cancers in children ages 0 to 14 years are retinoblastoma. An increase in the risk of childhood cancer has been documented in many syndromes that are associated with inherited mutations. Examples are Li-Fraumeni syndrome, Beckwith- Wiedemann syndrome, Fanconi anemia syndrome, von Hippel-Lindau syndrome (Moore, 2009). Children who have Down syndrome,

also known as trisomy 21, are 10 to 20 times more likely to develop leukemia than children without Down syndrome.

Development of leukemia has been associated with the exposure to ionizing radiation. This was seen in children and adolescents who were exposed to radiation from the World War II atomic bomb blasts as they had an elevated risk of leukemia (Hsu et al., 2013). Furthermore, children whose mothers had radiographs during pregnancy and children who were exposed after birth to diagnostic medical radiation from computed tomography scans also have an increased risk of developing cancers (Linnet et al., 2009).

Parental exposure to cancer-causing chemicals, childhood exposure to common infectious agents, prenatal exposure to pesticides and living near a nuclear power plant, are possible environmental risk factors that have produced mixed results in different studies. While some studies have found possible associations between these factors and risk of developing cancers in children, other studies have found no such associations (Belson, 2007, Kinlen, 2011, Ma X, 2009).

Clinical signs and symptoms of cancer include anorexia, irritability, lethargy, anemia, bleeding, petechia, fever, lymphadenopathy, splenomegaly and hepatomegaly. Oral side effects that may manifest with the disease include lymphadenopathy, sore throat, laryngeal pain, gingival bleeding, and oral ulceration (Best, 1990, Berkowitz, 1988, Fayle, 1991, Pinkham, 2005).

Depending on the cancer type, different advanced treatment approaches are utilized, including surgery, radiotherapy, chemotherapy and hematopoietic cell transplantation (HCT). These treatments approaches target the rapidly dividing cells that can lead to destruction of the tissues. Common side effects to these approaches include nausea, hair loss, and anorexia. A child

diagnosed with ALL will be treated in multimodal therapies, completed in phases. The phases of cancer treatment are induction, consolidation/intensification, and maintenance phases. The aim of the induction phase is to kill all the leukemic cells in the blood and bone marrow. Eradication of any potential leukemic cells that may regenerate is the goal for the consolidation and maintenance phases (Little et al., 2008). Allogeneic bone marrow transplantation is recommended for some children whose leukemia has high-risk characteristics at diagnosis and for children who develop recurrence after remission. It may also be used if the leukemia does not go into remission after successive courses of induction chemotherapy (Margolin et al., 2010).

2.2 Childhood Cancer Survivor

The overall 5-year survival rates for childhood cancers have steadily increased since the 1970s and are currently over 80% (Howlader et al., 2017). Despite the advanced approaches to treat cancer, cancer survivors are at risk for numerous physical and psychological late effects with different effects on their health-related quality of life because of their cancer and the therapy (McDougall and Tsonis, 2009). To better understand these late effects, to increase survival, and to minimize harmful health effects, the Childhood Cancer Survivor Study (CCSS) was started in 1994. It is funded by the National Cancer Institute and other organizations and it is a large, geographically and socioeconomically diverse, retrospectively established cohort study that follows health and disease outcomes in individuals from 26 North American pediatric cancer hospitals who were diagnosed with cancer during childhood or adolescence and who survived at least five-years. (Robinson et al., 2002, Robinson et al., 2009). The distribution of cancer types among the CCSS cohort reflects the general representation of these cancers among children. As expected, the most common primary diagnosis is leukemia (34%), followed by Hodgkin disease

(14%) and CNS tumors (13%), with a lesser representation of kidney, soft tissue and bone tumors, non-Hodgkin lymphoma, and neuroblastoma.

According to the CCSS investigations, late effects have been documented and summarized. These effects are increased number and severity of chronic health conditions (Oeffinger, 2006, Hudson, 2013), hospitalizations (Zhang, 2014, Kurt, 2012), psychological distress, neurocognitive dysfunction (Zeltzer et al., 1997, 2008) and reduced productivity due to health problems. Adult survivors of childhood cancers also report poorer overall health and physical health-related quality of life (HRQOL) (Dowling, 2010). It has been estimated that approximately 60% of survivors experience one or more late physical effects, which can include cardiopulmonary, renal, endocrine, or pulmonary dysfunction, neurocognitive impairments, the development of secondary cancers, and infertility (Stevens, 1988). Survivors of childhood brain tumors are at increased risk of late neurological and neurosensory morbidities. These morbidities include hearing impairments, blindness, cataracts, and double vision, neurological dysfunction specifically coordination and motor problems, and seizure disorder. Combinations of the primary tumor and treatment with surgery, radiation and chemotherapy contribute to these morbidities (Anderson, 2001).

With regard to psychological effects, brain tumor survivors are at greater risk for psychological distress, fatigue, cognitive problems, and diminished life satisfaction. Moreover, survivors of leukemia, neuroblastoma, bone tumor and sarcoma, Wilms tumor, and lymphoma are at-risk for depression, anxiety, impaired physical or general health, or somatic distress as compared with other diagnostic groups or sibling controls (Zeltzer et al., 1997, 2008).

Many studies have assessed and evaluated academic achievement among survivors of specific types of childhood cancer based on investigations using the CCSS cohort (Nagarajan et.,

2003, Mitby et al., 2003, Mulrooney., 2008, Punyko et al., 2007). According to Mitby et al. (2003), when comparing the brain tumor survivors to their siblings, brain tumor survivors who were diagnosed as preschoolers had 18-fold higher odds of a special education history than did those in the sibling group. Nagarajan et al (2003) found deficits in education among bone tumor survivors when compared with their siblings. Punyko et al (2007) evaluated educational outcomes among rhabdomyosarcoma survivors compared to siblings, and reported that the survivors of childhood rhabdomyosarcoma were more likely than siblings to have failed to complete high school. Similar results were found in the Canadian Cohort of Childhood Cancer Survivors. In this cohort study, cancer survivors age 17 years or younger were matched by age and sex with a group of control participants and evaluated for social outcomes. More survivors than controls repeated a grade in school, attended learning disability or special education programs, had no close friends, and did not use friends as confidants. Specifically, survivors of brain tumors, followed by leukemia and neuroblastoma, were most likely to have educational problems and no close friends (Barrera, 2005).

2.3 **Childhood Cancer and Oral Health**

Research from the past three decades suggests patients with childhood cancer have an altered oral health condition, which negatively affect their oral health. According to the American Academy of Pediatric Dentistry (AAPD) and National Cancer Institute: 2013, the oral cavity is highly susceptible to the effects of chemotherapy and radiation and is the most frequently documented source of sepsis in the immunosuppressed cancer patient. The prevalence and management of oral complications in cancer patients are well-established (Belfield, 2004, da Fonseca, 2004, Fayle, 1991, Scully, 1996, Sonis, 1998). Common oral complications include oral mucositis, oral infections, salivary gland dysfunction and taste dysfunction. These complications

can lead to secondary complications such as nutritional disorder, xerostomia or hemorrhage. (National Cancer Institute: 2013, Hong CH et al., 2009, da Fonseca, 2011).

The immunocompromised status of a cancer patient can lead to oral mucosal infections (*candidiasis*, herpes simplex, varicella/zoster, cytomegalovirus) (Belfield, 2004, Brennan, 2008). Studies have shown an increased proliferation and colonization of gram-negative bacteria including *Escheria coli*, *Pseudomonas aeruginosa*, *Klebsiella* and *Enterobacter* species in the oral cavity of patients with ALL when compared to their healthy counterparts (Napenas, 2007, Sixou, 1996). Medication side effects and cancer therapy, such as radiation, as well as a change in oral hygiene practices, alter the oral environment, creating an increased risk for opportunistic oral infections. Pediatric patients with cancer are at a higher risk for fungal infections, due to the use of broad- spectrum antibiotics, steroids, poor oral hygiene and poor nutrition (Belfield, 2004). Childers et al. (1993) reported that *Candida* was four times more likely to occur in children with solid tumors than children with leukemia.

Childhood cancer survivors remain at risk from late dental complications after receiving treatment with either radiation, chemotherapy or stem cell transplant. These effects can be summarized according to the treatment received.

First, radiation therapy to the head and neck region is the mode of treatment in certain forms of cancer. Radiation interferes with dental development by directly inhibiting mitotic activity of odontoblasts. The availability of rapidly dividing presecretory odontoblasts in young children makes them particularly susceptible to the effects of radiation. Enamel formation is, on the other hand, indirectly affected by radiation which induces formation of osteodentin, replacing normal dentin. Osteodentin inhibits nucleation of enamel crystals and this leads to deficient enamel mineralization (Collett WK, 1965, Arsenault, 1989, Kaste, 1994). According to Kaste

(1994), tooth development is arrested by 30 Gray (Gy), and mature ameloblasts are damaged by 10 Gy, of direct irradiation. However, Fromm (1986) reported late dental effects in patients treated with radiation doses as low as four Gy. Several variables play a role in the dose related oral changes, including patient age, total radiation dose, daily radiation fraction size, exposed tissue volume, interaction with specific chemotherapeutic agents, pre-existing dental health, and presence of chronic graft-versus-host disease in HCT survivors. The risk of dental abnormalities after radiotherapy is influenced by both younger age at irradiation (McGinnis, 1985, Sonis, 1990, Kaste, 1997) and by higher doses of radiation (Jaffe, 1984, Kaste, 2009)

Dental root stunting, microdontia, hypodontia, enlarged pulp chambers, and over-retention of primary teeth are some of the dental abnormalities seen in children treated with radiation therapy for ALL (Kaste, 1997). Scully, et al. (1996) similarly reported long-term complications of radiation to the oral cavity in children, including enamel hypoplasia, microdontia, delay or failure of tooth development and eruption, altered root formation, and maldevelopment in the craniofacial skeleton. In addition to the changes of oral structures, radiation therapy damages salivary glands, salivary flow rate, pH and production of saliva (Whitmyer, 1997). Post-radiation salivary gland damage reduces salivary secretion, makes saliva more acidic, and promotes highly cariogenic oral microflora such as streptococci mutans and lactobacilli (Whitmyer, 1997). Xerostomia, along with mucosal ulcers, creates dental pain and discomfort, which can lead to changes in eating habits. Consumption of foods with high sucrose content and ease of eating are preferred by the patient, and as a result, predisposes the patient to caries (Sonis, 1988, Scully, 1996).

Although the dental effects of chemotherapy have been well studied in childhood cancer survivors, yet it can be difficult to distinguish whether these effects are caused by chemotherapy

alone or combination of chemotherapy and radiation. Vincristine and alkylating agents have been associated with dental abnormalities among survivors of childhood cancer. Prominent incremental lines on the dentin of extracted teeth among survivors of various childhood cancers corresponding to cycles of intravenous chemotherapy including vincristine were reported in two studies (Maguire, 1987, Macleod, 1987). This could be related to the inhibitory effect of vincristine on the secretion of collagenous dentine matrix by odontoblasts (Moskalewski, 1975, Stene, 1980). A dose-dependent risk of having at least one dental abnormality among survivors treated with alkylating agents when compared to those who received no alkylating agents was reported by Kaste et al. (2009). Dental caries (Pajari, 1988, Purdell-Lewis, 1988, Fromm, 1986, Kaste, 2009, Dens, 1995, Kaste, 1998, Kupeli, 2006, Avsar, 2007) a higher DMFT score (Fleming, 1993, Dens, 1995, Alberth, 2004, Hutton, 2010), or a higher decayed, missing, filled surface (DMFS) score (Pajari, 1988, Dens, 1995, Alberth, 2004) are the most commonly reported dental late effects following chemotherapy in childhood cancer survivors. It has been hypothesized that changes in the oral cavity, eating habits, and hygiene practices promotes a cariogenic environment for the pediatric cancer survivor. Avsar, (2007) reported after mean follow up of two years and half, 96 survivors of childhood cancer treated with chemotherapy and no radiation to the teeth had lower salivary flowrate and higher cariogenic bacteria such as mutans streptococci and lactobacillus compared to healthy controls. Among cancer survivors, the prevalence of caries and DMFT scores were reported higher than the healthy controls. Pajari, (1995) studied the caries incidence of children with ALL related to the therapy used and compared them to healthy controls. Overall, a higher proportion of filled anterior permanent tooth surfaces were found at the age of 12 years among those treated with chemotherapy alone, chemotherapy and cranial radiation, and chemotherapy and total body radiation when compared

to controls. Similarly, another study found that DMFT scores of children undergoing chemotherapy and radiation therapy was significantly higher when compared to children undergoing chemotherapy alone (Nasim et al., 2007).

Disturbances to both odontogenesis and amelogenesis, due to chemotherapy treatments lead to dental developmental abnormalities. Dental agenesis, dental hypoplasia, root stunting, and enamel hypoplasia after chemotherapy have been reported in several studies. Maciel JCC, (2009) studied the oral health and dental anomalies in children and adolescents treated for ALL with chemotherapy. Higher prevalence of hypodontia, microdontia, enamel discoloration and root stunting among the survivors when compared to healthy controls in ALL and neuroblastoma survivors treated with chemotherapy (Alpaslan, 1999, Maciel, 2009, Kaste, 1998). Moreover, Avsar et al (2007) investigated the association between chemotherapy and dental abnormalities among childhood cancer survivors with various diagnoses. In this study, higher rates of arrested root development with short V-shaped root formation and white/cream enamel opacity were found in cancer survivors compared to healthy controls matched on age, sex, and socioeconomic status.

Several studies concluded that there is a direct relationship between the age of cancer survivors at chemotherapy treatment and concomitant radiation treatment on the incidence of dental developmental abnormalities (Cubukcu, 2012, Maciel, 2009, Minicucci, 2003, Pedersen, 2012). Minicucci et al. (2003) found an increased prevalence of dental abnormalities, including delayed development, microdontia, malformed roots, and enamel hypoplasia with younger age at treatment (1–6 years of age vs. 7–12 years). Maciel et al. (2009) reported a higher mean number of teeth with dental abnormalities found among survivors of ALL treated with chemotherapy,

radiotherapy and HCT when compared to those treated with chemotherapy and radiotherapy or chemotherapy.

Common late dental effects of HCT were also reported in the literature. Regarding dental caries, two studies reported no effect of HCT on mean of DMFT or DMFS scores among HCT survivors who were conditioned with 10 Gy TBI and cyclophosphamide and controls (Nasman, 1994, Dahllof, 1997). The authors concluded that these findings could be attributed to the use of fluoride prophylaxis, chlorhexidine rinse and parental training in dental care. On the other hand, higher DMFT scores among survivors treated with HCT compared to those treated with chemotherapy alone were reported by other studies (Hutton, 2010, Maciel, 2009, Uderzo, 1997). Regarding dental developmental abnormalities after the HCT treatment, several studies found increased risk later in life. This was especially for children conditioned with TBI and high-dose chemotherapy before HCT (Dahllof et al., 1997, Nasman et al., 1994, Nasman et al., 1997, Uderzo et al., 1997, Vaughan et al., 2005, Vesterbacka et al., 2012).

2.4 **Studies on Oral Health- related Quality of Life**

Oral Health Related Quality of Life (OHRQoL) is an extension of HRQoL that specifically reflects the patient's perception of the impact of their current oral health status on their current quality of life. The OHRQoL has been defined as a multidimensional concept which includes a subjective evaluation of the individual's oral health, functional well-being, expectations and satisfaction with care, and sense of self (Sischo & Broder, 2011). Oral Health Related Quality of Life in children and adolescents can be assessed with two different approaches. Either children can directly report their own perceptions, or parents can report and rate their child. In the last decade, many OHRQoL questionnaires have been developed for children and adolescents. They include the Child Perceptions Questionnaire (CPQ) (Jokovic et

al., 2002, Jokovic et al., 2004, Jokovic et al., 2006), the Child Oral Impacts on Daily Performances Index (C-OIDP) (Gherunpong, 2004), the Child Oral Health Impact Profile (COHIP) (Broder & Wilson-Genderson, 2007), the Early Child Oral Health Impact Scale (ECOHIS) (Pahel, 2004) , the Scale of Oral Health Outcomes for 5-year-old children (SOHO-5) (Tsakos, 2012), the Michigan Oral Health-Related Quality of Life scale (MOHRQoL) (Filstrup, 2003) and the Pediatric Oral Health-Related Quality of Life Measure (POQL) (Huntington, 2011).

The Child Oral Health Impact Profile (COHIP) is the first children's OHRQoL instrument to incorporate both positive and negative health impacts, therefore has the potential to measure more than the absence of a condition but can measure positive attributes or enhanced well-being as a result of care. (Sischo and Broder, 2011). It displayed good validity and reliability in children and adolescents ages 8-15 years (Broder and Wilson-Genderson, 2007). The COHIP questionnaire contains items to assess both positive and negative aspects of OHRQoL, following the World Health Organization concept that health is more than the absence of disease (Broder et al., 2007). The COHIP questionnaire is available in a long version with 34 items and a short version which contains 19 items. The short version of COHIP has been tested and its reliability and validity are consistent with those reported in the literature for the long version COHIP (Broder et al., 2012). The COHIP measures OHRQoL in five domains: Oral Health, Functional Well- Being, Social-Emotional Well-Being, School Environment and Self Image. Oral health quality of life has been studied in other conditions such as sickle cell disease (Ralstrom, 2014), orofacial defects (Ward, 2013), orthodontics, craniofacial, and pediatric medicine (Broader et al., 2007) and cystic fibrosis (Patrick et al., 2016).

While the oral condition of patients with cancer have been studied, no studies have examined OHRQoL in childhood cancer survivors population.

3. MATERIALS AND METHODS

3.1 **Study approval**

This study was approved by the Institutional Review Boards (IRB) of the University of Illinois at Chicago (UIC) IRB (approval #2017-0694), Chicago, IL (Appendix A).

3.2 **Study Criteria**

The following were the **inclusion criteria** for eligibility to participate in this study:

For cases:

1. Patients at least one year cancer free.
2. Patients between 8 and 15 years of age.
3. Patients at the Pediatric Cancer Clinic at the University of Illinois Hospital
4. Patients and legal guardians who are able to speak and read English or Spanish.

For controls:

1. Healthy controls between 8 and 15 years of age.
2. Patients at University of Illinois Hospital outpatient clinic.
3. Patients and legal guardians who are able to speak and read English or Spanish.

The exclusion criteria were:

For cases:

1. Patients and/or legal guardians who have a diagnosis of intellectual disability or any other cognitive problems.

For controls:

1. Patients who have a diagnosis of cancer or any medical condition.
2. Patients and/or legal guardians who have a diagnosis of intellectual disability or any other cognitive problems

3.3 **Recruitment Process**

The research method was structured telephone interviews of child cancer survivors and their parents, with a control group of outpatient children from the UIC hospital system. The project was a collaborative effort between the Pediatric Cancer Clinic and the Pediatric Outpatient Clinic at the University of Illinois Hospital. After determining eligibility, patients and legal guardians were contacted by two doctors at the UIC hospital to obtain permission to be contacted by the principal investigator for the study by phone call interview (see the medical doctor telephone script English & Spanish version, Appendices B & C). Once the legal guardians agreed, the child name, contact phone number and preferred language were added to an eligibility criteria checklist (Eligibility criteria checklist, Appendix D) and the list was sent to the principal investigator via encrypted email. A one-page information sheet was mailed to a parent/guardian of all patients included in the study, explaining the purpose of the study (Subject information sheet English & Spanish version, Appendices E & F). A maximum of three telephone attempts were completed by the PI and Spanish speaking co- investigator on three separate days and at different times of the day to obtain the interview. Once the parents/guardians were reached by telephone, the study details were provided and verbal consent to participate was obtained by the PI or the Spanish speaking co- investigator (PI telephone script, English and Spanish, Appendices G & H). Parents/guardians were given the option of completing the interview at that time or scheduling a more convenient day and time for them and their child for the phone interview, which required approximately 15-20 minutes to be completed. The consent and assent were discussed with the patient and legal guardian. Study subjects were informed that participation was strictly voluntary, with no compensation. Filled questionnaires were identified with an identification number which was not linked to any

personal information, thus remaining anonymous (Telephone script assent English and Spanish, Appendix I & J). The parents/ legal guardians were asked to answer the parent survey (English and Spanish, Appendix K & L) and the children were asked to answer the Child Oral Health-Related Quality of Life Impact Profile (COHIP) survey (English and Spanish, Appendix M & N). No protected health information was collected from the interview.

3.4 Parent Survey Instrument

The Parent Survey (Appendix K) contained questions about demographics, specifically the patient's gender, age, current health status, dental utilization, ethnicity and estimated annual household income, type of cancer and type of treatment.

3.5 Child Oral Health Impact Profile Survey Instrument

The second survey, the Child Oral Health-related Quality of Life Impact Profile (COHIP), was completed by the patient. The COHIP (Appendix L) was designed to assess self-reported OHRQoL in children ages 8-15 years. The instrument contains 19 questions related to oral health and quality of life, focused on five areas: oral health, functional well-being, social- emotional well-being, school environment and self-image. The format of the COHIP elicits responses with five choices. Scoring of the negatively worded items were recoded and structured so that a score of zero was the most negative, while four was the most positive. Nineteen items were used in the overall COHIP score calculation. Overall COHIP scores range from 0-76, with high COHIP scores indicating a better OHRQoL.

3.6 Data Analysis

Data gathered through all study forms were transferred into Microsoft Excel Spreadsheet (Microsoft Inc., Redmond, WA, USA). The data file was stored on a password-protected computer. The Excel data file was then transferred to the IBM SPSS Statistics 22.0 software

(IBM Corp., Amok, NY, USA). Statistical analysis included descriptive statistics, frequencies, Chi-Square, independent T- test, regression model and Analysis of Variance (ANOVA). Our goal was to achieve a power of 80% to detect a significant difference using an independent T-test and an alpha of 0.05 for the total scores and domain scores for analyses of the COHIP.

4. RESULTS

4.1 Data Collection

This study was a cross-sectional assessment of the OHRQoL in pediatric cancer survivors and a control group of UIC outpatient children. Patient recruitment, verbal parental consent, patient assent and questionnaire administration were completed by the PI and a Spanish speaking UIC dental student.

For the cancer survivors group recruitment, 63 eligible children were identified as seen in the last three years and otherwise eligible for the study. Fifty-six were able to be reached. They all agreed to be contacted by the PI. Only 42 could be reached by the PI and the Spanish speaking co-investigator. One parent refused to participate in the study after being contacted by the PI.

For the healthy controls recruitment, a physician identified potential subjects from the last 300 patient visits. All parents who were reached by the physician agreed to participate in the study. The physician provided the PI with a list of the 56 parents who agreed to be contacted. Out of the 56 subjects only 41 could be reached by the PI and the Spanish speaking co-investigator. Forty-one pairs of subjects and parents were completed for each group. All surveys were completed in paper form.

4.2 Parent Survey

The Parent Survey (Appendix K) provided demographic information (Table I), characteristics of cancer survivors (Table II), and an assessment of general and oral health status (Table III). The average age of the subjects was 12 years old for the cancer survivor group and 11 years old for the healthy control group. The proportion of male and female participants was

about half in both groups. Reported race information for cancer survivors group in descending order was Caucasian (44%), Hispanic (34%). African American (22%). Reported race information for healthy control group in descending order was African American (39%), Caucasian (34%), Hispanic (27%). The healthy controls were more likely to speak Spanish and had lower incomes than the cancer survivors ($p < .000$).

Table I
Demographic characteristics of childhood cancer survivors and healthy controls

	Cancer survivor N (%)	Healthy control N (%)	Total N (%)	Significance
Patient Gender				P> 0.1
Male	15 (37%)	23 (56%)	38 (46%)	
Female	26 (63%)	18 (44%)	44 (54%)	
	41 (100%)	41 (100%)	82 (100%)	
Patient race				P> 0.1
1. African American / African / Caribbean / Black	9 (22%)	16 (39%)	25 (30%)	
2. Caucasian / White/ Middle east	18 (44%)	14 (34%)	32 (39%)	
3. Hispanic / Latino	14 (34%)	11 (27%)	25 (30%)	
	41 (100%)	41 (100%)	82 (100%)	
Language				P<.000
1. English	29 (71%)	41 (100%)	70 (85%)	
2. Spanish	12 (29%)	0 (0%)	12 (15%)	
Patient age				P> 0.1
8 years	9 (22%)	8 (20%)	17 (20%)	
9 years	6 (15%)	9 (22%)	16 (19%)	
10 years	6 (15%)	4 (10%)	10 (12%)	
11 years	1 (2%)	5 (12%)	6 (7%)	
12 years	1 (2%)	5 (12%)	6 (7%)	
13 years	2 (5%)	4 (10%)	6 (7%)	
14 years	7 (17%)	1 (2%)	19 (23%)	
15 years	2 (5%)	5 (12%)	7 (8%)	
Annual Household income				P< .000
Less than \$50,000	20 (49%)	39 (95%)	59 (72%)	
\$50,000-99,000	15 (37%)	2 (5%)	17 (21%)	
\$100,000-149,999	6 (15%)	0 (0%)	6 (7%)	
Type of health insurance				P= .06
1. Private health insurance	5 (12%)	0 (0%)	5 (6 %)	
2. Medicare /Medicaid	36 (88%)	41 (100%)	77 (94%)	

Table II shows most of the cancer survivors were diagnosed with leukemia and treated with chemotherapy. Most of the cancer survivors were five-year cancer free.

Table II
Demographic characteristics of childhood cancer survivors

	Cancer survivor N (%)
Diagnosis	
1. Leukemia	16 (39 %)
2. Brain and central nervous system (CNS) tumors	0 (0%)
3. Neuroblastoma	4 (10%)
4. Non- Hodgkin lymphoma (NHL)	0 (0%)
5. Others	21 (51%)
Type of cancer treatment	
1. Chemotherapy	34 (83%)
2. Hormonal therapy	0 (0%)
3. Stem cell/ Bone marrow transplant	0 (0%)
4. Surgery	4 (10%)
5. Radiotherapy	0 (0%)
6. Unsure	0 (0%)
7. None of the above	0 (0%)
8. Chemotherapy and surgery	2 (5%)
Cancer free (years)	
Less than 1 year	
1 year	5 (12%)
2 years	8 (19%)
3 years	7 (17%)
4 years	5 (12%)
5 years and above	16 (39%)

Table III shows excellent oral health was reported by half of the cancer survivors' caregivers, and less excellent oral health by the healthy controls.; and nearly more than half of cancer survivors had a dental visit within six months. The presence of caries was higher in the health controls than the Pediatric cancer survivors ($p < .05$).

Table III
Parental view of child's general and oral health

	Cancer survivor N (%)	Healthy control N (%)	Total N (%)
Child's General Health (in last 4 weeks)			
1. Excellent	33 (80%)	28 (68%)	61 (74%)
2. Less than excellent	8 (20 %)	13 (32%)	21 (26%)
Child's Oral Health			
1. Excellent	23 (56%)	15 (37%)	38 (46%)
2. Less than excellent	18 (44%)	26 (63%)	44 (54%)
Time since child's last dental visit			
1. 6 months ago or less	20 (49%)	22 (54%)	42 (51%)
2. Between 6 months and 12 months ago.	21 (54%)	18 (44%)	39 (48%)
3. On an emergency basis only	0 (0%)	1 (2%)	1 (1 %)
4. My child has never seen the dentist	0 (0%)	0 (0%)	0 (0%)
Presence of caries *			
Yes	8 (20%)	18 (44%)	26 (32%)
No	33 (80%)	23 (56%)	56 (68%)
Frequency of child's brushing			
Daily	40 (97%)	40 (97%)	80 (97%)
Not everyday	1 (2%)	1 (2%)	2 (2%)
Weekly	0 (0 %)	0 (0 %)	0 (0 %)
Rarely	0 (0 %)	0 (0 %)	0 (0 %)
Never	0 (0 %)	0 (0 %)	0 (0 %)
Who brushes child's teeth			
Child alone	38 (93%)	41 (100 %)	79 (96 %)
Child and adult	3 (7%)	0 (0 %)	3 (4%)
None	0 (0%)	0 (0 %)	0 (0%)
Parent's Belief that Child's Oral Health is Related to Their General Health			
Yes			
No	41 (100%)	41 (100%)	82(100%)
I don't know	0 (0%)	0 (0%)	0 (0%)
	0 (0%)	0 (0%)	0 (0%)

* p < .05

4.3 Child Oral Health Impact Profile Survey

The COHIP total score and individual domain scores were analyzed (Table IV) using a Mann Whitney U and T tests. Pediatric cancer survivors had lower total COHIP scores than control subjects. The controls reported higher oral health quality of life in three domains: Social-Emotional Well-being, School Environment, and Self-Image.

Table IV
Child Oral Health Impact Profile score by child cancer survivors and healthy controls

	Cancer survivors Mean (SD)	Healthy Controls Mean (SD)	P value P <.05
Total Score 19 items	64 (10)	70 (6)	P <.000
Oral Health Well-being 5 Items	17 (3)	18 (2)	P >.05
Functional Well-being 4 items	15 (2)	15 (1)	P >.05
Social-emotional Well-being 6 items	19 (5)	23 (2)	P <.000
School Environment 2 items	6 (2)	7 (1)	P <.01
Self-image 2 items	5 (2)	7 (1)	P <.01

T test compared scores on total score, oral health well-being, functional well-being and social emotional well-being.

Mann-Whitney compared scores on School environment and self-image.

Since the cases and controls differed in income, the COHIP scores for subjects with incomes under \$50,000 were summarized in Table V. There was still a significance difference in total COHIP score and in three domains of the COHIP, comparing by t test and Mann-Whitney U tests.

Table V
Child Oral Health Impact Profile score by annual household income

	Cancer survivors	Health controls
	Under 50 k	Under 50 k
COHIP	Mean (SD) N= 20	Mean (SD) N= 39
Total Score 19 items	64 (10) **	70 (6)
Oral Health Well-being 5 Items	17 (3) *	18 (2)
Functional Well-being 4 items	14 (2)	15 (1)
Social-emotional Well-being 6 items	20 (4) **	23 (2)
School Environment 2 items	7 (1)	7 (1)
Self-image 2 items	6 (2) **	7 (1)

T test compared scores on total score, oral health well-being, functional well-being and social emotional well-being.

Mann-Whitney compared scores on school environment and self-image.

* P <.05

**P<.01

All COHIP questions and responses are included in Tables VI-X.

Table VI
Child Oral Health Impact Profile oral well- being scores between cancer survivors and healthy controls

In the past 3 months, how often have you?	Never (1) N (% of total)		Almost Never (2) N (% of total)		Sometimes (3) N (% of total)		Fairly-Often (4) <i>N (% total)</i>		Almost All the Time (5) N (% of total)	
Oral well- being 5 items	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control
1. Had pain in your teeth/tooth ache	34 (82%)	18 (44 %)	3 (7%)	16 (39%)	3 (7%)	4 (10%)	1 (2%)	3 (7%)	0 (0%)	0 (0%)
2. Had discolored teeth or spots on your teeth	20 (49%)	29 (70%)	6 (15%)	12 (29%)	12 (29%)	0 (0%)	2 (5%)	0 (0%)	1 (2%)	0 (0%)
3. Had crooked teeth or spaces between your teeth	30 (73%)	28 (68%)	7 (17%)	13 (32%)	2 (5%)	0 (0%)	2 (5%)	0 (0%)	0 (0%)	0 (0%)
4. Had bad breath	25 (61%)	31 (76%)	11 (27%)	10 (24%)	5 (12%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
5. Had bleeding gums	31 (76%)	28 (68%)	4 (10%)	11 (27%)	6 (15%)	2 (5%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

Table VII
Child Oral Health Impact Profile functional well- being scores between cancer survivors and healthy controls

In the past 3 months, how often have you?	Never (1) N (% of total)		Almost Never (2) N (% of total)		Sometimes (3) N (% of total)		Fairly Often (4) <i>N (% total)</i>		Almost All the Time (5) N (% of total)	
Functional well- being 4 items	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control
6. Had difficulty eating foods you would like to eat	32 (78%)	36 (88%)	4 (10%)	5 (12%)	5 (12%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
7. Had trouble sleeping	36 (88%)	31 (76%)	2 (5%)	10 (24%)	3 (7%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
8. Had difficulty saying certain words	35 (85%)	33 (80%)	5 (12%)	7 (17%)	1 (2%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
9. Had difficulty keeping your teeth clean	33 (80%)	5 (12%)	5 (12%)	5 (12%)	3 (7%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

Table VIII
Child Oral Health Impact Profile Social/Emotional Well-Being scores between cancer survivors
and healthy controls

In the past 3 months, how often have you?	Never (1) N (% of total)		Almost Never (2) N (% of total)		Sometimes (3) N (% of total)		Fairly- Often (4) <i>N (% total)</i>		Almost All the Time (5) N (% of total)	
Social/Emotional Well-Being 6 items	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control
10. Been unhappy or sad	26 (63%)	35 (85%)	8 (19%)	4 (10%)	6 (15%)	2 (5%)	0 (0%)	0 (0%)	1 (2%)	0 (0%)
11. Felt worried or anxious	19 (46%)	35 (85%)	12 (29%)	5 (12%)	9 (22%)	1 (2%)	0 (0%)	0 (0%)	1 (2%)	0 (0%)
12. Avoided smiling or laughing with other children	18 (44%)	10 (24%)	10 (24%)	5 (12%)	12 (2%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)	0 (0%)
13. Felt that you look different	20 (49%)	30 (73%)	10 (24%)	9 (22%)	11 (27%)	2 (5%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
14. Been worried about what other people think about your . . .	20 (49%)	33 (80%)	9 (22%)	7 (17%)	11 (27%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
15. Been teased, bullied, or called names by other children	23 (56%)	33 (80%)	9 (22%)	7 (17%)	1 (2%)	2 (5%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

Table IX
Child Oral Health Impact Profile school environment scores between cancer survivors and healthy controls

In the past 3 months, how often have you?	Never (1) N (% of total)		Almost Never (2) N (% of total)		Sometimes (3) N (% of total)		Fairly Often (4) <i>N (% total)</i>		Almost All the Time (5) N (% of total)	
School environment 2 items	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control
16. Missed school for any reason	27 (66%)	33 (80%)	7 (17%)	6 (15%)	4 (10%)	2 (5%)	3 (7%)	0 (0%)	0 (0%)	0 (0%)
17. Not wanted to speak/read out loud in class	22 (54%)	30 (73%)	9 (22%)	10 (24%)	9 (22%)	1 (2%)	1 (2%)	0 (0%)	0 (0%)	0 (0%)

Table X
Child Oral Health Impact Profile self-image scores between cancer survivors and healthy controls

In the past 3 months, how often have you?	Never (1) N (% of total)		Almost Never (2) N (% of total)		Sometimes (3) N (% of total)		Fairly-Often (4) <i>N (% total)</i>		Almost All the Time (5) N (% of total)	
Self-image 2 items	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control	Cancer survivor	Healthy control
18. Been confident	1 (2%)	0 (0%)	2 (5%)	0 (0%)	11 (27%)	2 (5%)	13 (32%)	11 (27%)	14 (34%)	28 (68%)
19. Felt that you were attractive (good looking)	1 (2%)	0 (0%)	0 (0%)	0 (0%)	13 (32%)	2 (5%)	14 (34%)	12 (29%)	13 (32%)	27 (66%)

5. DISCUSSION

5.1 General Findings of the Study

To the best of our knowledge, this is the first study to assess the OHRQoL in pediatric cancer survivors. Our convenience sample from the UIC hospital enabled the comparison of OHRQoL between two groups. Our results indicate that pediatric cancer survivors had lower OHRQoL scores than healthy controls, particularly in social-emotional well-being, school environment, and self-image subscales. The results of this study indicate that pediatric cancer has an impact on oral health related quality of life in cancer survivors compared to healthy controls.

The nonequivalent demographics between the study and control groups is a serious limitation of our study. We did not have the resources to obtain a group matched for anything except age and sex. Pediatric cancer survivors' families were more likely to speak Spanish and had higher incomes. This made it difficult to compare the results meaningfully.

The majority of both childhood cancer survivors and healthy controls brushed their teeth daily and without supervision. Most cancer survivors' parents thought their child had no caries, but only half of the parents of healthy controls thought their child had no caries. The low number of cancer survivors with self-reported caries in our study is not in accordance with some studies that suggest that patients with cancer have higher caries prevalence than healthy controls (Pajari U, 1988, Purdell-Lewis DJ, 1988, Fromm, 1986, Kaste, 2009, Dens, 1995, Kaste SC, 1998, Kupeli S, 2006, Avsar A, 2007). This may be a credit to our oncology clinic which emphasizes oral health care, compared to the healthy controls who did not receive special encouragement to support oral health.

In spite of the higher income, the pediatric cancer survivors had a lower oral health quality of life than the control. In contrast, the literature reports that children with higher

incomes families report better oral health related quality of life (de Paula, 2013, Abanto J, 2011, Baker SR, 2010, Locker D, 2007, Pani SC, 2013, Piovesan C, 2010, Scapini A, 2013, Scrapelli AC, 2013). This was a surprising outcome and we don't have an explanation for it.

When evaluating individual COHIP items, no difference was found between the cancer survivor group and the control group in the Oral Well-Being and Functional Well-Being subscales. This finding could be explained from the nonequivalent demographics between the study and control groups in our study. Another explanation to our finding might be late dental effects of cancer were mild or were not yet experienced in the studied group of cancer survivors.

For the Social-Emotional Well-being subscale, cancer survivors reported lower scores than healthy controls. It has been documented that cancer and its treatment are potentially disruptive to the social development and emotional health of children and adolescents with poorer rating of quality of life when compared to general population (Stam et al., 2006, Zeltzer et al., 2008). Our assessment instrument asked whether the cancer survivors are worried or anxious, experience bullying or teasing, feel like they look different, are worried about other people's perception, and whether they are upset or uncomfortable because of their teeth, mouth, and face. Bullying at school was found by Van Dijk, 2007 as an independent predictor of limitation for survivors of neuroblastoma. Our finding means that oral health has an impact on the overall social development and emotional health of children and adolescents.

Moreover, for school environment subscale, cancer survivors reported poorer scores when compared to healthy controls. This was expected, as several studies documented that adverse effects in school environments for childhood cancer survivors exist and are not limited to the acute treatment phase, but may last for the duration of the developmental life course (Ness & Gurney, 2007).

For the last subscale in COHIP, self-image scores, cancer survivors reported poorer scores when compared to healthy controls (Mean= 5 vs 7; $P < .05$). This finding is not surprising given that anxiety and depressive symptoms are well assessed in several studies assessing the general QOL in cancer survivors. These studies documented lower self- image and self-esteem levels (Neff, 1990, Pendley, 1997). However, Maggiolini et al. (2000) found that survivors of leukemia showed a more positive and mature self-image than their controls.

These results are consistent with the findings of other studies in patients with chronic conditions such as sickle cell disease (Ralstrom, 2014), orofacial defects (Ward, 2013), orthodontics, craniofacial, pediatric medicine (Broader et al., 2007), and cystic fibrosis (Patrick et al., 2016).

5.2 Limitations and Strengths of the Study

5.2.1 Limitations of the Study

The primary limitation was the nonequivalent demographics between the study and control groups in our study. Another limitation was the sample size of the study.

A third limitation was that only one site was employed. We understand that demographic variations and population discrepancies may limit the generalizability of our findings to other areas of the United States and countries around the world.

5.2.2 Strengths of the Study

To the best of our knowledge, this study is the first to assess self-reported OHRQoL in childhood cancer survivors. Another strength of the study is using the instrument COHIP, which

has been validated in many different patient populations and has been found to have excellent reliability(Broder and Wilson-Genderson, 2007).

5.3 Conclusion of Study

The following conclusions can be made based on the results of this study:

- Pediatric cancer survivors in our study reported a lower OHRQoL than healthy controls, particularly in social- emotional well-being, school environment and self-image.
- Even though parents were more likely to report excellent oral health in the cancer survivors than in controls, those children reported lower OHRQoL scores.

5.4 Future studies

- Future research should compare equivalent groups.
- Future research should consider a larger, multi-center sample of childhood cancer survivors and their parents.
- Future research should complete clinical and radiographic exam of the cancer survivors to detect late dental effects of cancer therapy.

CITED LITERATURE

1. Abanto J, Carvalho TS, Mendes FM, Wanderley MT, Bönecker M, Raggio DP. Impact of oral diseases and disorders on oral health-related quality of life of preschool children. *Community Dent Oral Epidemiol*. 2011;39(2):105-14.
2. Abanto J, Carvalho TS, Bonecker M, Ortega AO, Ciamponi AL, Raggio DP: Parental reports of the oral health-related quality of life of children with cerebral palsy. *BMC Oral Health* 2012, 12: 15. 10.1186/1472-6831-12-15
3. Alberth M, Kovalecz G, Nemes J, et al. Oral health of long-term childhood cancer survivors. *Pediatr Blood Cancer* 2004;43:88–90.
4. Alpaslan G, Alpaslan C, Gogen H, et al. Disturbances in oral and dental structures in patients with pediatric lymphoma after chemotherapy: A preliminary report. *Oral Surg Oral Med Oral Pathol Oral Radiol Endod* 1999;87:317–321.
5. Anderson DM, Rennie KM, Ziegler RS, et al: Medical and neurocognitive late effects among survivors of childhood central nervous system tumors. *Cancer* 92:2709-2719, 2001
6. Arsenault AL, Robinson BW. The dentino-enamel junction: A structural and microanalytical study of early mineralization. *Calcif Tissue Int* 1989;45:111–121.
7. Avsar A, Elli M, Darka O, et al. Long-term effects of chemotherapy on caries formation, dental development, and salivary factors in childhood cancer survivors. *Oral Surg Oral Med Oral Pathol Oral Radiol Endod* 2007;104:781–789.
8. Baker SR, Mat A, Robinson PG: What psychosocial factors influence adolescents' oral health? *J Dent Res* 2010, 89:1230–1235.

9. Barrera M, Shaw AK, Speechley KN, et al: Educational and social late effects of childhood cancer and related clinical, personal, and familial characteristics. *Cancer* 104:1751-1760, 2005
10. Belfield, P.M. & Dwyer, A.A. (2004). Oral Complications of Childhood Cancer and its Treatment: Current Best Practice, *European Journal of Cancer*, 40, 1035-41.
11. Belson M, Kingsley B, Holmes A. Risk factors for acute leukemia in children: A review. *Environmental Health Perspectives* 2007; 115(1):138-145.
12. Berkowitz, R.J., Feretti, G.A., & Berg, J.H. (1988). Dental Management of Children with Cancer. *Pediatric Annals*, 17(11), 715-725.
13. Best, J.M. (1990). The Dentist and the Pediatric Oncology Patient. *The New York State Dental Journal*, 56(2), 29-30.
14. Brennan, M.T., Woo, S.B., & Lockhart, P.B. (2008). Dental Treatment Planning and Management in the Patient Who Has Cancer. *Dental Clinics of North America*, 52(1), 19-37.
15. Broder HL, McGrath C, Cisneros GJ: Questionnaire development: Face validity and item impact testing of the Child Oral Health Impact Profile. *Community Dent Oral Epidemiol.* 2007, 35: 8-19.
16. Broder HL, Wilson-Genderson M. Reliability and convergent and discriminant validity of the child oral health impact profile (COHIP child's version). *Community Dent Oral Epidemiol* 2007; 35: 20-31.
17. Brown LR, Dreizen S, Handler S, et al. Effect of radiation-induced xerostomia on human oral microflora. *J Dent Res* 1975;54:740-750.

18. Childers, N.K. et al (1993). Oral Complications in Children with Cancer. *Oral Surgery, Oral Medicine, and Oral Pathology*, 75, 41-7.
19. Collett WK, Thonard JC. The effect of fractional radiation on dentinogenesis in the rat. *J Dent Res* 1965;44:84–90.
20. Cowman RA, Baron SS, Glassman AH, et al. Changes in protein composition of saliva from radiation induced xerostomia patients and its effect on growth of oral streptococci. *J Dent Res* 1983;62: 336–340.
21. Cubukcu, C. E., & Sevinir, B. (2008). Dental Health Indices of Long-term Childhood Cancer Survivors Who Had Oral Suspension During Treatment: A Case Control Study. *Pediatric Hematology and Oncology*, 25(7), 638-646.
22. da Fonseca, M. Childhood cancer. In: Nowak AJ, Casa- massimo PS, ed. *The Handbook of Pediatric Dentistry*, 4th Edition; Chicago, Ill. American Academy of Pediatric Dentistry; 2011:225-31.
23. Dahllof G, Bagesund M, Ringden O. Impact of conditioning regimens on salivary function, caries associated microorganisms and dental caries in children after bone marrow transplantation. A 4-year longitudinal study. *Bone Marrow Transplant* 1997;20:479–483.
24. de Paula JS LI, de Almeida AB, Ambrosano GM, Mialhe F: The impact of socioenvironmental characteristics on domains of oral health-related quality of life in Brazilian schoolchildren. *BMC Oral Health* 2013, 28:13:10.
25. Dens F, Boute P, Otten J, et al. Dental caries, gingival health, and oral hygiene of long term survivors of paediatric malignant diseases. *Arch Dis Child* 1995;72:129–132.

26. Dowling E, Yabroff KR, Mariotto A, McNeel T, Zeruto C, Buckman D. Burden of illness in adult survivors of childhood cancers. *Cancer*. 2010;116:3712–3721.
27. Dreizen S, Brown LR, Handler S, et al. Radiation-induced xerostomia in cancer patients. Effect on salivary and serum electrolytes. *Cancer* 1976;38:273–278.
28. Fayle, S.A., & Curzon, M.E. (1991). Oral Complications in Pediatric Oncology Patients. *Pediatric Dentistry*, 13(5), 289-295.
29. Filstrup SL, Briskie D, da Fonseca M, Lawrence L, Wandera A, Inglehart MR: Early childhood caries and quality of life: child and parent perspectives. *Pediatr Dent*. 2003, 25 (5): 431-440.
30. Fleming P, Kinirons MJ. Study of the dental health of children in remission from acute lymphoblastic leukaemia in Northern Ireland. *Community Dent Oral Epidemiol* 1993;21:309–312.
31. Fraumeni JF Jr.: Epidemiologic approaches to cancer etiology. *Annual review of public health* 1982, 3:85-100.
32. Fromm M, Littman P, Raney RB, et al. Late effects after treatment of twenty children with soft tissue sarcomas of the head and neck. Experience at a single institution with a review of the literature. *Cancer* 1986; 57:2070–2076.
33. Hong CH, Brennan MT, Lockhart PB. Incidence of acute oral sequelae in pediatric patients undergoing chemo- therapy. *Pediatr Dent* 2009;31(5):420-5.
34. Howlader N, Noone AM, Krapcho M, et al, eds. *SEER Cancer Statistics Review, 1975-2010*. Bethesda, MD: National Cancer Institute; 2013.

35. Hsu WL, Preston DL, Soda M, et al. The incidence of leukemia, lymphoma and multiple myeloma among atomic bomb survivors: 1950-2001. *Radiation Research* 2013; 179(3):361-82
36. Hudson MM, Ness KK, Gurney JG, Mulrooney DA, Chemaitilly W, Krull KR, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. *JAMA*. 2013; 309:2371–2381.
37. Huntington NL, Spetter D, Jones JA, Rich SE, Garcia RI, Spiro A: Development and validation of a measure of pediatric oral health-related quality of life: the POQL. *J Public Health Dent*. 2011, 71 (3): 185-193.
38. Hutton A, Bradwell M, English M, et al. The oral health needs of children after treatment for a solid tumour or lymphoma. *Int J Paediatr Dent* 2010;20:15–23.
39. Impact of oral diseases and disorders on oral health-related quality of life of preschool children. *Community Dentistry Oral Epidemiol* 2011, 39:105–114.
40. Jokovic A, Locker D, Guyatt G: Short forms of the Child Perceptions Questionnaire for 11-14-year-old children (CPQ11-14): development and initial evaluation. *Health Qual Life Outcomes*. 2006, 4
41. Jokovic A, Locker D, Stephens M, Kenny D, Thompson B, Guyatt G: Validity and reliability of a questionnaire for measuring child oral-health-related quality of life. *J Dent Res*. 2002, 81 (7): 459-463.

42. Jokovic A, Locker D, Tompson B, Guyatt G: Questionnaire for measuring oral health-related quality of life in eight- to ten-year-old children. *Pediatr Dent*. 2004, 26 (6): 512-518.
43. Jones LR, Toth BB, Keene HJ. Effects of total body irradiation on salivary gland function and caries associated oral microflora in bone marrow transplant patients. *Oral Surg Oral Med Oral Pathol* 1992;73:670–676.
44. Kaste SC, Goodman P, Leisenring W, et al. Impact of radiation and chemotherapy on risk of dental abnormalities: A report from the Childhood Cancer Survivor Study. *Cancer* 2009;115:5817–5827.
45. Kaste SC, Hopkins KP, Bowman LC, et al. Dental abnormalities in children treated for neuroblastoma. *Med Pediatr Oncol* 1998;30:22–27.
46. Kaste SC, Hopkins KP, Jenkins JJ III. Abnormal odontogenesis in children treated with radiation and chemotherapy: Imaging findings. *AJR Am J Roentgenol* 1994;162:1407–1411.
47. Kinlen L. Childhood leukaemia, nuclear sites, and population mixing. *British Journal of Cancer* 2011; 104(1):12-18.
48. Kupeli S, Varan A, Özyar E, et al. Treatment results of 84 patients with nasopharyngeal carcinoma in childhood. *Pediatr Blood Cancer* 2006;46:454–458.
49. Kurt BA, Nolan VG, Ness KK, Neglia JP, Tersak JM, Hudson MM, et al. Hospitalization rates among survivors of childhood cancer in the Childhood Cancer Survivor Study cohort. *Pediatr Blood Cancer*. 2012;59:126–132.

50. Linet MS, Kim KP, Rajaraman P. Children's exposure to diagnostic medical radiation and cancer risk: epidemiologic and dosimetric considerations. *Pediatric Radiology* 2009; 39 Suppl 1:S4-26.
51. Little, J., Falace, D., Miller, C., & Rhouds, N. (2008). *Dental Management of the Medically Compromised Patient*. St. Louis, Missouri: Mosby Elsevier.
52. Locker D: Disparities in oral health-related quality of life in a population of Canadian children. *Community Dentistry Oral Epidemiol* 2007, 35:348–356.
53. Ma X, Urayama K, Chang J, Wiemels JL, Buffler PA. Infection and pediatric acute lymphoblastic leukemia. *Blood Cells, Molecules, and Diseases* 2009; 42(2):117-120.
54. Maciel et al. (2009) Oral Health and Dental Anomalies in Patients Treated for Leukemia in Childhood and Adolescence. *Pediatric Blood Cancer*; 53, 361-5.
55. Macleod RI, Welbury RR, Soames JV. Effects of cytotoxic chemotherapy on dental development. *J R Soc Med* 1987;80:207–209
56. Maggiolini A, Grassi R, Adamoli L, Corbetta A, Charmet GP, Provantini K, Fraschini D, Jankovic M, Lia R, Spinetta J, Masera G. Self-image of adolescent survivors of long-term childhood leukemia. *J Pediatr Hematol Oncol*. 2000;22:417–421.
57. Makkonen TA, Edelman L, Forsten L. Salivary flow and caries prevention in patients receiving radiotherapy. *Proc Finn Dent Soc* 1986;82:93–100.
58. Margolin J, Rabin KR, Steuber CP, Poplack, DG. Acute lymphoblastic leukemia. In: Pizzo PA, Poplack DG, eds. *Principles and Practice of Pediatric Oncology*. 6th ed. Philadelphia, PA: Wolters Kluwer Health/ Lippincott Williams & Wilkins; 2010:518-565.

59. McCance, K.L. & Huether, S.E. . McCance, K.L., & Roberts, L.K., (1998). *Biology of Cancer in Pathophysiology: The Biologic Basis for Disease in Adults and Children*. St. Louis, Missouri: Mosby Publishing Company.
60. McDougall, J., & Tsonis, M. (2009). Quality of life in survivors of childhood cancer: A systematic review of the literature (2001-2008). *Support Cancer Care*, 17, 1231-1246.
61. McGinnis JP, Jr, Hopkins KP, Thompson EI, et al. Tooth root growth impairment after mantle radiation in long-term survivors of Hodgkin's disease. *J Am Dent Assoc* 1985;111:584–588.
62. Minicucci EM, Lopes LF, Crocci AJ. Dental abnormalities in children after chemotherapy treatment for acute lymphoid leukemia. *Leuk Res* 2003;27:45–50.
63. Mitby PA, Robison LL, Whitton JA, et al: Utilization of special education services and educational attainment among long-term survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Cancer* 97:1115-1126, 2003
64. Moore SW. Developmental genes and cancer in children. *Pediatric Blood and Cancer* 2009; 52(7):755-760.
65. Moskalewski S, Thyberg J, Lohmander S, et al. Influence of colchicine and vinblastine on the golgi complex and matrix deposition in chondrocyte aggregates. An ultrastructural study. *Exp Cell Res* 1975;95:440–454.
66. Mulrooney DA, Dover DC, Li S, et al: Twenty years of follow-up among survivors of childhood and young adult acute myeloid leukemia: A report from the Childhood Cancer Survivor Study. *Cancer* 112: 2071-2079, 2008
67. Murphy SL, Xu J, Kochanek KD. Deaths: Final Data for 2010. *National Vital Statistics Reports*. Vol 61. No. 4. Hyattsville, MD: National Center for Health Statistics; 2013.

68. Nagarajan R, Neglia JP, Clohisy DR, et al: Education, employment, insurance, and marital status
69. Napenas, J.J. et al (2007). Relationship between Mucositis and Changes in Microflora During Cancer Therapy. Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology, Endodontology, 103(1),48-59.
70. Nasim et al. (2007) Dental Health Status in Children with Acute Lymphoblastic Leukemia. Journal of Pediatric Dentistry, 31(3), 212-15.
71. Nasman M, Bjork O, Soderhall S, et al. Disturbances in the oral cavity in pediatric long-term survivors after different forms of antineoplastic therapy. Pediatr Dent 1994;16:217–223.
72. National Cancer Institute: PDQ Oral Complications of Chemotherapy and Head/Neck Radiation. Bethesda, M.D.: National Cancer Institute. Modified February 28, 2013.
73. Neff EJ, Beardslee CI. Body knowledge and concerns of children with cancer as compared with the knowledge and concerns of other children. J Pediatr Nurs. 1990;5:179–189.
74. Ness KK, Gurney JG. Adverse late effects of childhood cancer and its treatment on health and performance. Annu Rev Public Health. 2007;28:279–302.
75. Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, et al. Chronic health conditions in adult survivors of childhood cancer. N Engl J Med. 2006;355:1572–1582. [PubMed]
76. Pahel BT, Rozier RG, Slade GD: Parental perceptions of children’s oral health: the Early Childhood Oral Health Impact Scale (ECOHIS). Health Qual Life Outcomes. 2007, 5: 6

77. Pajari U, Larmas M, Lanning M. Caries incidence and prevalence in children receiving antineoplastic therapy. *Caries Res* 1988;22:318–320.
78. Pani SC, Mubarak SA, Ahmed YT, Alturki RY, Almahfouz SF: Parental perceptions of the oral health-related quality of life of autistic children in Saudi Arabia. *Spec Care Dentist* 2013, 33:8–12.
79. Patrick, J. R. D., da Fonseca, M. A., Kaste, L.M., Fadavi, S., Shah, N., & Sroussi, H. (2016). Oral Health-related quality of life in pediatric patients with cystic fibrosis. *Special Care in Dentistry*.
80. Pedersen LB, Clausen N, Schroder H, et al. Microdontia and hypodontia of premolars and permanent molars in childhood cancer survivors after chemotherapy. *Int J Paediatr Dent* 2012;22:239–243.
81. Pendley JS, Dahlquist LM, Dreyer Z. Body image and psychological adjustment in adolescent cancer survivors. *J Pediatr Psychol*. 1997;22:29–43.
82. Pinkham,J., Casamassimo,P., Fields,H., McTigue,D. & Nowak,A. (2005). *Pediatric Dentistry: Infancy through adolescence*. St Louis, Missouri: Elsevier Saunders.
83. Piovesan C, Antunes JL, Guedes RS, Ardenghi TM: Impact of socioeconomic and clinical factors on child oral health-related quality of life (COHRQoL). *Qual Life Res* 2010, 19:1359–1366.
84. Punyko JA, Gurney JG, Scott Baker K, et al: Physical impairment and social adaptation in adult survivors of childhood and adolescent rhabdomyosarcoma: A report from the Childhood Cancer Survivors Study. *Psychooncology* 16:26-37, 2007

85. Purdell-Lewis DJ, Stalman MS, Leeuw JA, et al. Long term results of chemotherapy on the developing dentition: Caries risk and developmental aspects. *Community Dent Oral Epidemiol* 1988;16:68–71.
86. Ralstrom E, da Fonseca MA, Rhodes M, Amini H. The impact of sickle cell disease on oral health-related quality of life. *Pediatr Dent* 2014; 36: 24-8.
87. Robison LL, Armstrong GT, Boice JD, Chow EJ, Davies SM, Donaldson SS, et al. The Childhood Cancer Survivor Study: A national cancer institute–supported resource for outcome and intervention research. *J Clin Oncol*. 2009;27:2308–2318.
88. Robison LL, Mertens AC, Boice JD, Breslow NE, Donaldson SS, Green DM, et al. Study design and cohort characteristics of the Childhood Cancer Survivor Study: A multi-institutional collaborative project. *Med Pediatr Oncol*. 2002;38:229–239.
89. Scapini A, Feldens CA, Ardenghi TM, Kramer PF: Malocclusion impacts adolescents’ oral health-related quality of life. *Angle Orthod* 2013, 83:512–518.
90. Scarpelli AC, Paiva SM, Viegas CM, Carvalho AC, Ferreira FM, Pordeus IA: Oral health-related quality of life among Brazilian preschool children. *Community Dentistry Oral Epidemiol* 2013, 41:336–344.
91. Scully, C. & Epstein, J. (1996). Oral Health Care for the Cancer Patient. *Oral Oncology*, *European Journal of Cancer*, 32 (5), 281-92.
92. Siegel RL, Miller KD, Jemal A. Cancer Statistics, 2017. *CA: A Cancer Journal for Clinicians* 2017; 67(1):7-30.
93. Sischo L, Broder HL (2011) Oral health-related quality of life: what, why, how, and future implications. *J Dent Res* 90:1264–1270.

94. Sixou, J. et al (1996). Modifications of the Microflora of the Oral Cavity Arising During Immunosuppressive Chemotherapy. *European Journal of Cancer*, 32 (5), 306-10.
95. Sonis, S., & Kunz, A. (1988). Impact of Improved Dental Services on the Frequency of Oral Complications of Cancer Therapy for Patients with Non-head-and-neck Malignancies. *Oral Surgery, Oral Medicine, and Oral Pathology*, 65(1), 19-22.
96. Stam H, Grootenhuis MA, Caron HN, Last BF (2006) Quality of life and current coping in young adult survivors of childhood cancer: positive expectations about the further course of the disease were correlated with better quality of life. *Psychooncology* 15:31–43.
97. Stene T, Koppang HS. Autoradiographic investigation of dentin production in rat incisors after vincristine administration. *Scand J Dent Res* 1980;88:104–112.
98. Stevens MCG, Mahler H, Parkes S (1998) The health status of adult survivors of cancer in childhood. *Eur J Cancer* 34:694–698. doi:10.1016/S0959-8049(98)00012-4
99. Tsakos G, Blair YI, Yusuf H, Wright W, Watt RG, Macpherson LM: Developing a new self-reported scale of oral health outcomes for 5-year-old children (SOHO-5). *Health Qual Life Outcomes*. 2012, 10: 62
100. Uderzo C, Fraschini D, Balduzzi A, et al. Long-term effects of bone marrow transplantation on dental status in children with leukaemia. *Bone Marrow Transplant* 1997;20:865–869.
101. van Dijk J, Huisman J, Moll AC, Schouten-van Meerteren AYN, Bezemer PD, Ringens PJ, Cohen-Kettenis PT, Imhof SM (2007) Health-related quality of life of child and adolescent retinoblastoma survivors in the Netherlands. *Health Qual Life Outcomes* 5:65–72.

102. Vaughan MD, Rowland CC, Tong X, et al. Dental abnormalities after pediatric bone marrow transplantation. *Bone Marrow Transplant* 2005;36:725–729.
103. Vesterbacka M, Ringden O, Remberger M, et al. Disturbances in dental development and craniofacial growth in children treated with hematopoietic stem cell transplantation. *Orthod Craniofac Res* 2012;15:21–29.
104. Ward E, Desantis C, Robbins A, Kohler B, Jemal A. Childhood and adolescent cancer statistics, 2014. *CA Cancer J Clin*. 2014;64:83-103.
105. Ward JA, Vig KW, Firestone AR, Mercado A, da Fonseca M, Johnston W. Oral health-related quality of life in children with orofacial clefts. *Cleft Palate Craniofac J* 2013; 50:174-81.
106. Whitmyer, C.C., Waskowski, J.C., & Iffland, H.A. (1997). Radiotherapy and Oral Sequelae: Preventive and Management Protocols. *Journal of Dental Hygiene: JDH / American Dental Hygienists' Association*, 71(1), 23-29.
107. Zeltzer L, Qian L, Leisenring W, Tsao J, Recklitis C, Armstrong G, Mertens A, Robison L, Ness K (2008) Psychosocial outcomes and health-related quality of life in adult childhood cancer survivors: a report from the childhood cancer survivor study. *Cancer Epidemiol Biomarkers Prev* 17:435–446.
108. Zhang Y, Lorenzi MF, Goddard K, Spinelli JJ, Gotay C, McBride ML. Late morbidity leading to hospitalization among 5-year survivors of young adult cancer: A report of the childhood, adolescent and young adult cancer survivors research program. *Int J Cancer*. 2014;134:1174–1182.

APPENDIX A

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Initial Review (Response To Modifications)

September 13, 2017

Shahad Alshamali, BDM
Pediatric Dentistry
801 S. Paulina St
Phone: (219) 718-0615

RE: Protocol # 2017-0694
"Oral Health-related Quality of Life in Pediatric Cancer survivors."

Dear Dr. Alshamali:

Please remember to submit translations of all data collection instruments and recruitment/consent documents that will be used for subjects whose primary language is not English. Translations must be accompanied by an Amendment form and a translator's statement attesting to the translator's credentials and accuracy of the translations.

Please note that stamped .pdfs of all approved recruitment and consent documents have been uploaded to OPRSLive, and can be accessed under "Approved Documents" tab. Please remember to use only those approved documents to recruit and enroll subjects into this research project. OPRS/IRB no longer issues paper letters or stamped/approved documents.

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited review process on September 10, 2017. You may now begin your research

Please note the following information about your approved research protocol:

Protocol Approval Period: September 10, 2017 - September 10, 2018

Approved Subject Enrollment #: 600

Additional Determinations for Research Involving Minors: The Board determined that this research satisfies 45CFR46.404, research not involving greater than minimal risk. Therefore, in accordance with 45CFR46.408, the IRB determined that only one parent's/legal guardian's permission/signature is needed. Wards of the State may not be enrolled unless the IRB grants specific approval and assures inclusion of additional protections in the research required under 45CFR46.409. If you wish to enroll Wards of the State contact OPRS and refer to the tip sheet.

Performance Sites: UIC

Research Protocol(s):

Phone: 312-996-1711

<http://www.uic.edu/depts/ovcr/oprs/>

FAX: 312-413-2929

- a) Oral Health-related Quality of Life in Pediatric Cancer survivors; 06/21/2017

Recruitment Material(s):

- a) Telephone Script (Medical Doctor); Version 2; 08/07/2017
- b) Eligibility Criteria Checklist; Version 2; 08/07/2017

Informed Consent(s):

- a) Subject Information Sheet; Version 2; 08/07/2017
- b) Telephone Script PI (Oral Informed Consent/Parental Permission); Version 2; 09/09/2017
- c) Waiver of Documentation of Informed Consent, Permission, and Assent has been granted 45 CFR 46.117; for clinic doctors to obtain subjects' verbal agreement to: a) be screened for eligibility; and b) provide research staff with their contact information to be recruited for the study (minimum risk; if subjects agree they will receive a written information sheet via mail containing all the elements of consent prior to being contacted by phone and by English or Spanish speaking investigator to participate in a phone interview).
- d) Waiver of Informed Consent, Permission, and Assent has been granted for recruitment purposes only under 45 CFR 46.116(d) to identify eligible patient subjects from the clinics' patient rolls and medical records with director's permission from Cancer Clinic at the University of Illinois Hospitals and the University of Illinois Hospital Pediatric Outpatient clinic (minimal risk; information will be destroyed if potential subjects are not eligible or decline to participate).
- e) Waiver of Signed Informed Consent, Permission, and Assent has been granted under 45 CFR 46.117; (Minimum Risk; Subjects will receive via mail information sheet containing all elements of consent and verbal consent will be obtained via phone prior to beginning of the phone interview).

Assent(s):

- a) Assent | Telephone Script; Version 2; 08/03/2017

HIPAA Authorization(s):

- a) The Board determined that this research meets the regulatory requirements for waiver of authorization for recruitment purposes only as permitted at 45CFR164.512(i)(1)(i)(A). Specifically, that the use or disclosure of protected health information (PHI) meets the waiver criteria under 45CFR164.512(i)(2)(ii); the research involves no more than a minimal risk to the privacy of the individuals; the research could not practicably be conducted without the waiver; and the research could not practicably be conducted without access to and use of the PHI.

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category(ies):

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis)., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
06/22/2017	Initial Review	Expedited	07/16/2017	Modifications Required
08/08/2017	Response To Modifications	Expedited	09/10/2017	Approved

Please remember to:

→ Use your **research protocol number** (2017-0694) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the guidance,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"
<http://research.uic.edu/irb/investigators-research-staff/investigator-responsibilities>).

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 413-1518. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Alma Milat, BS
 IRB Coordinator, IRB # 2
 Office for the Protection of Research Subjects

Enclosure(s): Following approved recruitment and consent documents have been uploaded under "approved documents" tab in OPRSLive:

1. **Informed Consent Document(s):**
 - a) Subject Information Sheet; Version 2; 08/07/2017
 - b) Telephone Script PI (Oral Informed Consent/Parental Permission); Version 2; 09/09/2017
2. **Assent Document(s):**
 - a) Assent - Telephone Script; Version 2; 08/03/2017
3. **HIPAA Authorization(s):**
 - a) The Board determined that this research meets the regulatory requirements for waiver of authorization for recruitment purposes only as permitted at 45CFR164.512(i)(1)(A). Specifically, that the use or disclosure of protected health information (PHI) meets the waiver criteria under 45CFR164.512(i)(2)(ii); the research involves no more than a minimal risk to the privacy of the individuals; the research could not practicably be conducted

without the waiver; and the research could not practicably be conducted without access to and use of the PHI.

4. Recruiting Material(s):

- a) Telephone Script (Medical Doctor); Version 2; 08/07/2017
- b) Eligibility Criteria Checklist; Version 2; 08/07/2017

cc: ~~Marcio Da~~ Fonseca, Pediatric Dentistry, M/C 850
~~Anne Koerber~~, Faculty Sponsor, Pediatric Dentistry, M/C 850
Privacy Office, Health Information Management Department, M/C 772

APPENDIX B



Medical Doctor telephone script

Oral Health-related Quality of Life in Pediatric Cancer survivors.

Hello, my name is and I am doctor at The University of Illinois Hospital. I am calling on the behalf of Dr. AlShamali regarding research study we are conducting at the University of Illinois, Chicago. I would like to give you some information about the study and ask you if you are interested in participating after you review the study information. The study assesses the impact of oral health in the quality of life of the pediatric cancer survivor and to compare the oral health and the quality of life of pediatric cancer survivor with healthy outpatients.

The study involves you answering some questions about your child's health, and your child answering some questions about how he or she feels about his or her mouth. This will take about 15-20 minutes.

Your taking part in this study is completely voluntary. If you wish to participate, you will receive by mail one page information sheet about the study and then you will be contacted by Dr. AlShamali by phone to complete the questionnaire. If you wish not to participate, your decision will not affect your care at outpatient clinic at The University of Illinois Hospital.

Are you interested to be contacted?

Thank you.

Appendix C

APPROVAL STARTS 12/5/2017 EXPIRES 9/10/2018 UNIVERSITY OF CHICAGO IRB HST ETHICAL REVIEW BOARD	<p style="text-align: center;">Medical Doctor Telephone script</p> <p style="text-align: center;">Calidad de Vida Relacionada con la Salud Oral en los Sobrevivientes de Cáncer Pediátrico</p> <p>Hola, mi nombre esy su un doctora en el Hospital de la Universidad de Illinois. Estoy llamando de parte de la Dra. AlShamali sobre un estudio que estamos haciendo en la Universidad de Illinois en Chicago. Le quiero dar más información sobre el estudio y si está interesado(a) en participar en el estudio después de repasar la información. El estudio analiza el efecto de la salud oral en la calidad de vida de los niños que han sobrevivido al cáncer, en comparación con niños que no han tenido cáncer. La investigación requiere que le haga unas preguntas en el teléfono acerca de la salud de su hijo y unas preguntas para su hijo acerca de sus boca. La conversación y preguntas se tomaran alrededor de 15-20 minutos.</p> <p>Su participación en el estudio es completamente voluntario. Si desea participar, le mandaremos un ahoja de información sobre el estudio. Y luego lo llamara la Dr. AlShamali por el teléfono para hacerle la entrevista. Si desea no participar, su decisión de ninguna manera afecta el tratamiento ni cuidado en la clínica del Hospital de la Universidad de Illinois.</p> <p>Desea que lo(a) contactemos? Gracias</p> <p>Telephone script (Medical doctor): Spanish translation Version 1 Date: 12/03 /17</p>
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Appendix D

Name	Age	Gender	Cancer survivor	Cancer free >1 year	Healthy ASA I	Intellectual disability or cognitive problems	Language preferred	Phone number	Extra comments
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			
		M/F	Yes/ No	Yes/ No	Yes/ No	Yes/ No			

Eligibility Criteria Checklist Version 2 8/7/17

Appendix E



Subject Information Sheet

Oral Health-related Quality of Life in Pediatric Cancer Survivors.

I am a pediatric dental resident at the University of Illinois at Chicago College of Dentistry. I want to learn more about the health of the teeth and mouth of children who have survived cancer, compared to children with no cancer.

I will telephone you to ask if you and your child will be willing to answer some questions about your child's cancer experience, and about your child's feelings about his or her mouth and teeth. If your child hasn't had cancer, we want to ask the questions of your child's feelings about his or her mouth and teeth, to see if child cancer survivors have different experiences than children with no cancer.

If you decide to participate and to allow your child to participate, I will ask you and your child some questions over the phone. This should take about 20 minutes. I will schedule this at your convenience.

The questions for you will be about your child's health and experience and treatment for cancer. The questions for your child will be about whether your child has any pain in the mouth or teeth, and whether your child is happy and comfortable with her/his mouth or teeth.

The risk of this research is a loss of privacy (revealing to others that you are taking part in this study) or confidentiality (revealing information about you to others to whom you have not given permission to see this information). There are no direct and personal benefits to subjects participating in this study.

We will make sure that the information we collect from you is kept private and used only for this research study. Your information will only be seen by researchers at the University of Illinois at Chicago College of Dentistry. Each subject will be given a code for the sole purpose of connecting the questionnaires of the children and their parent. Only the primary investigator will have access to the code and she will maintain all documentation in a password protected computer in a locked office. The list containing the subject identifiers will be stored and secured separately from the coded data and where it will be stored until it is destroyed at the end of the data collection.

Your taking part in this phone call is completely voluntary. If you wish not to participate, your decision will not affect your or your child's care at any the clinics, including The University of Illinois Hospital.

Contact the Principal Investigator, Dr. Shahad AlShamali, Pediatric Dental Resident, (salsah27@uic.edu), or Faculty Advisor Dr. Anne Koerber (akoerber@uic.edu) (312 996 9341) if you have any questions about this study or your part in it.

If you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

PLEASE KEEP THIS INFORMATION SHEET FOR YOUR RECORDS

APPENDIX F



Hoja de Información Calidad de Vida Relacionada con la Salud Oral en los Sobrevivientes de Cáncer Pediátrico

Soy un residente dental pediátrica en la Universidad de Illinois en Chicago. Quiero aprender sobre la salud oral de los dientes de los niños que han sobrevivido al cáncer, en comparación con los niños que no han tenido cáncer.

Le llamaré para preguntarle si usted y su hijo están dispuestos a contestar algunas preguntas sobre la experiencia de cáncer de su hijo, y sobre el conocimiento de su hijo sobre su boca y dientes. Si su hijo no ha tenido cáncer, queremos hacerle preguntas sobre el conocimiento de su hijo acerca de su boca y sus dientes, para ver si los sobrevivientes de cáncer infantil tienen experiencias diferentes que los niños no afectados por el cáncer.

Si usted decide participar y permite que su hijo/a participe, les hare algunas preguntas por teléfono. Esto debe tomar cerca de 20 minutos y puedo programar la llamada a su conveniencia.

Las preguntas para usted serán acerca de la salud y la experiencia de su hijo y el tratamiento para el cáncer. Las preguntas para su hijo serán sobre algún dolor en la boca o los dientes, y si su hijo/a está contento y cómodo con sus dientes.

El riesgo de esta investigación es una pérdida de privacidad (revelando que usted está participando en esta investigación) perdida de confidencialidad (revelando su información a quienes usted no ha dado permiso para ver esta información. No hay ningún beneficio para los sujetos que participaran en esta investigación.)

Nos vamos asegurar que la información que juntamos se mantenga privada y se use sólo para esta investigación. Su información sólo será vista por investigadores de la Universidad de Illinois en Chicago Escuela de Odontología. A cada sujeto se le dará un código único para conectar los cuestionarios de los niños y sus padres sin usar los nombres. Sólo el investigador principal tendrá acceso al código y mantendrá toda la documentación en una computadora protegida con contraseña en una oficina cerrada con llave. La lista que contiene los identificadores será asegurada separadamente de los datos codificados. La información será almacenada hasta el final de la investigación y luego será destruida.

Su participación en esta llamada telefónica es completamente voluntaria. Si usted no desea participar, su decisión no afectará el cuidado de su hijo/a en las clínicas del Hospital de la Universidad de Illinois.

Comuníquese con la investigadora principal, la Dra. Shahad AlShamali, residente dental pediátrico, si tiene alguna pregunta sobre este estudio o si tiene alguna pregunta sobre el caso. También puede contactar a la consejera de la investigación, la Dr. Anne Koerber (akoerber@uic.edu) (312 -996- 9341).

Si tiene alguna pregunta sobre sus derechos como participante de la investigación, incluyendo preguntas, preocupaciones, quejas o para ofrecer sugerencias, puede llamar a la Oficina para la Protección de Temas de Investigación (OPRS) al 312-996-1711 o al 1-866- 789-6215 (llamada gratuita) o por correo electrónico a OPRS en uicirb@uic.edu.

POR FAVOR GUARDE ESTA HOJA DE INFORMACIÓN PARA SUS ARCHIVOS

APPENDIX G



Telephone script Oral Health-related Quality of Life in Pediatric Cancer survivors.

Hello, my name is Dr. Shahad AlShamali and I am a pediatric dental resident at the University of Illinois at Chicago College of Dentistry. I am working on a research study to assess the impact of oral health in the quality of life of the pediatric cancer survivor and to compare the oral health and the quality of life of pediatric cancer survivor with healthy outpatients. I appreciate your willingness to participate in this study.

If you decide to participate, your and your child's information will only be seen by researchers at University of Illinois at Chicago College of Dentistry. We will make sure that the information we collect from you is kept private and used only for the research study we are discussing. Your taking part in this phone call is completely voluntary. If you wish not to participate, your decision will not affect your child's care at any clinic, not only Pediatric cancer clinic at The University of Illinois Hospital.

I want to ask you whether you received the information sheet by mail? If yes, do you have any questions? If you didn't receive it, do you want us to mail another information sheet if you are interested?

The study involves you answering some questions about your child's health, and your child answering some questions about how he or she feels about his or her mouth. This will take about 15-20 minutes.

May I ask some questions of you and your child right now? [When would you like to schedule the interview?]

APPENDIX H



Telephone script

Calidad de Vida Relacionada con la Salud Oral en los Sobrevivientes de Cáncer Pediátrico

Mi nombre es Dra. Shahad AlShamali, soy un residente dental pediátrica en la Universidad de Illinois en Chicago. Estoy haciendo una investigación sobre el efecto de la salud oral en la calidad de vida de los niños que han sobrevivido al cáncer, en comparación con niños que no han tenido cáncer. Le agradezco por su participación en esta investigación.

Si decide participar, aseguraremos que su información y la información de su hijo(a) se mantendrá privada y nada más se use para el estudio. Nada más los investigadores en la Universidad de Illinois en Chicago van a poder ver la información. Su participación es completamente voluntaria y su decisión de ninguna manera afecta el tratamiento el cuidado de su hijo(a), ni tampoco en la clínica de cáncer pediátrico en el Hospital de la Universidad de Illinois.

Recibió la información sobre la investigación en el correo? Si la recibió, tiene alguna pregunta? Si no la recibió, quiere que le mandemos la hoja con información sobre la investigación.

La investigación requiere que le haga unas preguntas en el teléfono acerca de la salud de su hijo y unas preguntas para su hijo acerca de su boca. La conversación y preguntas se tomara alrededor de 15-20 minutos.

Le puedo hacer a usted y su hijo las preguntas ahora? [Si no puede ahorra, para cuando quiere que llame de regreso?

APPENDIX I



TELEPHONE SCRIPT FOR VERBAL ASSENT TO PARTICIPATE IN RESEARCH

Protocol title: Oral Health-related Quality of Life in Pediatric Cancer survivors.

My name is Dr. Shahad AlShamali and I am a pediatric dental resident at the University of Illinois at Chicago College of Dentistry. I'm asking you to answer some questions because I am trying to learn more ~~about your oral health~~ how you feel about your teeth, gums and mouth and its effect on your life. We would like to be able to help children who have had cancer, and your answers might be helpful. Your (MOTHER/FATHER) said it was ok for you to answer these questions. But even if your parents say "yes" you can still decide not to do this. If you say it is ok, I will ask you 19 questions about your mouth and teeth. Remember, being in this study is up to you and no one will be upset if you don't want to participate or even if you change your mind later and want to stop.

Do you have any questions?

May I ask you these questions about your mouth?

APPENDIX J



TELEPHONE SCRIPT FOR VERBAL ASSENT TO PARTICIPATE IN RESEARCH

Calidad de Vida Relacionada con la Salud Oral en los Sobrevivientes de Cáncer Pediátrico

Hola, soy la Dra. Shahad AlShamali, soy un residente dental pediátrica en la Universidad de Illinois en Chicago. Quería hacerle unas preguntas para aprender sobre su salud oral y que piensa acerca de sus dientes, encías, su boca, y como afectan su vida. Queremos ayudar niños que han tenido cáncer, y su respuesta nos pueden ayudar. Su (mama/papa) nos dio permiso para que le hagamos estas preguntas. Pero si sus padres dieron permiso no están obligados a responder a las preguntas. Si está bien con usted, le voy a hacer diez y nueve preguntas sobre su boca y dientes. Es su decisión si quiere participar y nadie se va enojar si cambia la mente y no quiere contestar las preguntas o si quiere parar.

Tiene alguna pregunta para mí? Le puede hacer las preguntas sobre su boca?

APPENDIX K

PAGE 1

PARENTAL SURVEY TOOL

Parent and/ legal Guardian portion of the questionnaire
Oral Health-related Quality of Life in Pediatric Cancer survivors.

Verbal consent obtained: Yes/No

Thank you for agreeing to participate in our study... Please answer each question to the best of your ability. All of your responses are recorded confidentially.

1. What is your child's gender?

1. Male
2. Female
3. Other

2. What is your child's age? _____ years

3. What is your child's race? (check all that apply)

1. African American / African / Caribbean / Black
2. Asian / Pacific Islander/ Indian subcontinent
3. ~~Caucasian~~ / White/ Middle east
4. Hispanic / Latino
5. Native American
6. Other
7. Prefer not to respond

4. What is the estimated annual income of your household?

1. Less than \$50,000
2. \$50,000-99,999
3. \$100,000-149,999
4. \$150,000-199,999
5. \$200,000 or more
6. Prefer not to respond

5. What type of health insurance or health care coverage does your child have?

1. Private health insurance
2. Medicare /Medicaid
3. SCHIP (CHIP/ Children's Health Insurance Program)
4. Military Healthcare
5. Indian Health service
6. No Coverage of any-kind
7. ~~Don't~~ know
8. Others

6. What type of cancer has your child been diagnosed with?

1. Leukemia
2. Brain and central nervous system (CNS) tumors (nerve tumors)
3. Neuroblastoma

4. Non-Hodgkin lymphoma (NHL)

5. Others

7. At what age your child was diagnosed with cancer? _____

8. Which form of treatment did your child receive for cancer? (Check all that apply)

1. Chemotherapy
2. Hormonal therapy
3. Stem cell/ Bone marrow transplant
4. Surgery
5. Radiotherapy
6. Unsure
7. None of the above

9. How long your child has been cancer free?

1. Less than 1 year
2. 1 year
3. 2 years
4. 3 years
5. 4 years
6. 5 years and above

10. How would you rate the general health of your child in the last 4 weeks?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

11. How would you rate the health of your child's teeth and gums?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

12. What is the total number of separate medications your child is taking?

13. When was your child's latest visit to the dentist (approximately)?

1. 6 months ago or less
2. Between 6 months and 12 months ago.
3. On an emergency basis only (i.e., when he/ she has a toothache, infection)
4. My child has never seen the dentist

14. Why has your child not seen the dentist? (Check ALL that apply)

1. I can't find a dentist who is willing to see my child due to their health issue
 2. There is no dentist in my community where I live.
 3. I am too busy to take my child to see the dentist.
 4. I am afraid to take my child to see the dentist because of their health issues
 5. My child has been too sick to go see the dentist
 6. I don't have dental insurance
 7. Dentists will not accept my dental insurance
 8. Other: (Please explain) _____
15. Do you think your child has cavities now?
1. Yes
 2. No
17. How often are your child's teeth brushed?
1. Everyday
 2. A few times in a week, but not everyday
 3. Once per week
 4. Rarely
 5. ~~Never (skip to question #12)~~
18. Who brushes your child's teeth?
1. My child brushes his/her own teeth
 2. An adult brushes his/her teeth for them
 3. My child will brush first, then an adult finishes the job
 4. My child does not brush his/her teeth
19. I think my child's oral health and teeth are important.
1. Strongly Agree
 2. Agree
 3. Disagree
 4. Strongly Disagree

Thank you

Appendix L

PARENTAL SURVEY TOOL

PAGE 1

PARENTAL SURVEY TOOL

Porción del Cuestionario para los Padres o Guardianes
Oral Health-related Quality of Life in Pediatric Cancer survivors.

Consentimiento oral obtenido: Si/No

Gracias por aceptar su participación en este estudio... Por favor conteste cada pregunta lo mejor posible. Todas las respuestas son anónimas y ninguna información personal se va a obtener.

1. Cual es el sexo de su hijo/a?

1. Masculino
2. Femenino
3. Otro

2. Cual es la edad de su hijo/a..... ~~0023~~

3. Cual es la raza de su hijo/a? (marque todas las que aplique)

1. Africana Americana / Africana / Caribeña/ Negra
2. Asiática / Islas del Pacifico/ Subcontinente Indio
3. Caucásica / Blanca/ Medio Oriente
4. Hispánico / Latino
5. Americano Nativo
6. Otros
7. Prefiere no responder

4. Cual es el ingreso anual de su hogar?

1. Menos de \$50,000
2. \$50,000-99,999
3. \$100,000-149,999
4. \$150,000-199,999
5. \$200,000 o mas
6. Prefiere no responder

4. Que tipo de seguro medico o cobertura de salud tiene su niño?

1. Seguro privado de salud
2. Medicare /Medicaid
3. SCHIP (CHIP/ Children's Health Insurance Program)
4. Seguro Militar
5. Servicio de Salud Indigeno-Nativo
6. Ningún seguro-de ninguna clase
7. No se
8. Otros

6. Con que tipo de cáncer su hijo/a fue diagnosticado?

1. Leucemia

ID #

2. Tumor cerebral o del Sistema Nervioso Central (CNS)
3. Neuroblastoma
4. Linfoma Non- Hodgkin (NHL)
5. Otro

7. A que edad fue su hijo/a diagnosticado? _____

8. Que forma de tratamiento su hijo/a recibió para el cáncer? (Marque todas las que aplique)

1. Quimioterapia
2. Terapia Hormonal
3. Trasplante de células madre/o medula ósea
4. Cirugía
5. Radioterapia/Radiación
6. No esta seguro
7. Ninguna de las anteriores

9. Cuanto tiempo lleva su hijo/a libre de cáncer?

1. Menos de 1 año
2. 1 ~~año~~
3. 2 ~~años~~
4. 3 ~~años~~
5. 4 ~~años~~
6. 5 años y mas

10. Como califica usted la salud general de su hijo/a en las ultimas 4 semanas?

1. Excelente
2. Muy buena
3. Buena
4. Regular
5. Mala

11. Como califica usted la salud de los dientes y encias de su hijo/a?

1. Excelente
2. Muy Buena
3. Buena
4. Regular
5. Mala

12. Cual es el numero total de distintas medicinas que su hijo/a toma? _____

13. Cuando fue la ultima visita de su hijo/a al dentista (aproximadamente)?

1. Hace 6 meses o menos
2. Entre 6 y 12 meses.
3. Solo cuando tiene una urgencia (cuando tiene dolor/infección)
4. Mi hijo/a nunca ha visitado al dentista

ID #

14. Por que su hijo/a nunca ha ido al dentista? (Marque todas las que aplique)
1. No encuentro un dentista que quiera atender a mi hijo/a debido a sus problemas de salud
 2. No hay un dentista en la comunidad donde yo vivo.
 3. Estoy muy ocupado para llevar mi hijo/a al dentista.
 4. Tengo temor de llevar a mi hijo/a al dentista por sus problemas de salud
 5. Mi hijo/a ha estado muy enfermo/a para ir al dentista
 6. No tengo seguro medico
 7. Los dentistas no aceptan mi seguro de salud
 8. Otros motivos (por favor explique)-----
15. Cree usted que su hijo/a tenga caries?
- 1.Si
 - 2.No
17. Con que frecuencia se lavan los dientes de su hijo/a?
- 1.Todos los días
 - 2.Varias veces a la semana pero no todos los días
 - 3.Una vez a ala semana
 - 4.De vez en cuando
 - 5.Nunca (salte a la pregunta 19)
18. Quien lava los dientes de su hijo/a?
- 1.Mi hijo/a se lava sus propios dientes
 - 2.Un adulto le lava los dientes
 - 3.Mi hijo hace parte y luego un adulto termina
 - 4.Mi hijo/a no se lava los dientes
19. Yo creo que la salud oral y los dientes de mi hijo/a son importantes.
- 1.Totalmente de acuerdo
 - 2.De acuerdo
 - 3.No estoy de acuerdo
 4. Totalmente no de acuerdo

Gracias

ID #

APPENDIX M

COHIP

PAGE 1

COHIP SURVEY TOOL

COHIP

Thank you for helping us with our study. We are doing a study to better understand how children feel about their teeth and themselves.

Assent obtained from the child: ☐ Yes ☐ No

Some things to keep in mind:

- Answer the questions as honestly as you can.
- Don't talk to anybody about the questions when answering them.
- Before you answer, ask yourself:
- "Does this happen to me because of my teeth, mouth and face?"
- Choose the answer that best describes you in the past 3 months.

	Never	Almost never	Sometimes	Fairly often	Almost all the time
In the past 3 months, how often have you?					
1. Had <u>pain</u> in your teeth/ toothache.					
2. Had <u>discolored</u> teeth or spots on your teeth.					
3. Had <u>crooked</u> teeth or <u>spaces</u> between <u>your</u> teeth.					
4. Had bad breath.					
5. Had bleeding gums.					
6. Had <u>difficulty eating</u> <u>foods</u> you would like to eat because of your teeth, mouth, or face.					
7. Had <u>trouble sleeping</u> because of your teeth, mouth, or face.					
8. Had <u>difficulty saying</u> certain words because of your teeth, mouth or face.					

DATE: / /

ID#



	Never	Almost never	Sometimes	Fairly often	Almost all the time
In the past 3 months, how often have you?					
9. Had difficulty keeping your <u>teeth clean</u> because of your teeth, mouth or face.					
10. Been <u>unhappy or sad</u> because of your teeth, mouth or face.					
11. Felt <u>worried or anxious</u> because of your teeth, mouth, or face.					
12. Avoided smiling or <u>laughing</u> with other children because of your teeth, mouth, or face.					
13. Felt that you <u>look different</u> because of your teeth, mouth or face.					
14. Been <u>worried about what other people think</u> about your teeth, mouth, or face.					
15. Been <u>teased, bullied, or called names</u> by other children because of your teeth, mouth or face.					
16. <u>Missed school</u> for any reason because of your teeth, mouth, or face.					
17. Not wanted to <u>speak/ read out loud</u> in class because of your teeth, mouth, or face.					
18. Been <u>confident</u> because of your teeth, mouth, or face.					
19. Felt that you were <u>attractive (good looking)</u> because of your teeth, mouth or face.					

Thank you for your time...

DATE: / /

ID#

APPENDIX N

COHIP

PAGE 1

COHIP SURVEY COHIP

Gracias por aceptar participar. Por favor, responda las siguientes preguntas de la mejor manera posible.

Esta sección debe ser completada en colaboración del padre o tutor legal del paciente y el paciente. Esta sección sirve para identificar los impactos sociales y la calidad de vida en la necesidad dental y cita de su hijo(a). Marque una respuesta para cada pregunta.

Autorización del niño: Si ☐ No ☐

Algunos Puntos a Tener en Cuenta:

- Contestar las preguntas lo mas honestamente posible.
- No hablar con nadie acerca de las preguntas mientras las este contestando.
- Antes de contestar, preguntarse a si mismo:
- "Esto me sucede por mis dientes, boca o cara?"
- Escoja la respuesta que mejor lo describe a usted en los tres últimos meses.

	Nunca	Casi nunca	A veces	Muy frecuentemente	Casi todo el tiempo
En los últimos tres meses, ¿con qué frecuencia su hijo(a) ha tenido?					
1. Dolor en los dientes / dolor de muelas					
2. Dientes <u>descoloridos</u> o <u>manchas</u> en los dientes					
3. Dientes <u>torcidos</u> o <u>espacios</u> entre los dientes					
4. Mal aliento					
5. Encías sangrantes					
6. Dificultad para <u>comer</u> alimentos que les gustaría comer					
7. Problemas para <u>dormir</u>					

DATE: / /

ID#

8. Dificultad para <u>decir</u> ciertas palabras					
---	--	--	--	--	--

	Nunca	Casi nunca	A veces	Muy frecuentemente	Casi todo el tiempo
En los últimos tres meses, ¿con qué frecuencia su hijo(a) ha tenido?					
9. Dificultad para mantener sus dientes limpios					
10. Se ha sentido <u>triste</u> o <u>infeliz</u> por los dientes					
11. Se ha sentido <u>preocupado</u> o <u>ansioso</u>					
12. Ha evitado <u>sonreír</u> o <u>mirar</u> con otros niños					
13. Sentido como que lucir <u>parece diferente</u>					
14. Ha estado <u>preocupado</u> por lo que otras <u>personas</u> <u>pensarán</u> acerca de sus dientes, boca o cara					
15. Otros niños se han <u>reído</u> de <u>dónde</u> lo han <u>intimidado</u> o llamado con otros nombres					
16. No <u>asistió</u> a la <u>escuela</u> por cualquier razón de los dientes					
17. No ha querido hablar/leer en voz alta en clase					

DATE: / /

ID#

18. Se ha sentido <u>seguro</u> de sí mismo					
19. Se sintió atractivo (bien parecido)					

Gracias

DATE: / /

ID#

VITA

Shahad Alshamali, B.D.M

Education:

- 2016 – Present University of Illinois at Chicago – College of Dentistry
Pediatric Dentistry Residency, PGY2
Masters in Oral Sciences
Projected Completion: June 2018
- 2015 – 2016 University of Maryland– College of Dentistry
Advanced one year Program in Pediatric Dentistry for
Internationally-Trained Dentists
- 2010 – 2013 Kuwait University, Faculty of Dentistry
Bachelor's of Dental Medicine (B.D.M.)
Honors: Graduation with Distinction
- 2006 – 2010 Kuwait University, Faculty of Dentistry
Bachelor's of Medical Science degree (B.Med.Sc.)
Honors: Graduation with Distinction

Board Examinations:

- NBDE Part I – Pass
NDBE Part II – Pass
Component I of the 2018 National Dental Specialty Examination in Pediatric Dentistry.

Licensure:

- Kuwait Dental License

Work Experiences:

- 2013 Completed three months intensive clinical training
program in Pediatric dentistry department at Al-Amiri hospital.
Kuwait City, Kuwait
- 2013 Completed one-year working as general dentist in Al-
Shuhada Polyclinic.

Kuwait City, Kuwait

2013 – 2014 Completed one-year internship in general dentistry residency program in the Ministry of Health.

Kuwait City, Kuwait

Presentations:

- 2018 Oral Health-related Quality of Life in Pediatric Cancer survivors.
Presented at the UIC Clinic and Research Day, Chicago, IL
- 2017 Clinical And Radiographic Success Of Mineral Trioxide Aggregate Vs Ferric Sulfate As A Pulpotomy Treatment In Primary Molars: A Review of the Literature
Presented at the UIC Clinic and Research Day, Chicago IL
- 2013 The prevalence of oral candidiasis in studied sample of asthmatic patients who are on inhaled corticosteroids.
Poster presenter 2013 IADR / Unilever Hatton competition in Seattle, Washington, USA
- 2013 The prevalence of oral candidiasis in studied sample of asthmatic patients who are on inhaled corticosteroids.
Poster and case presenter at Kuwait Dental Association

Research:

- 2016 - 2018 Oral Health-related Quality of Life in Pediatric Cancer survivors.
University of Illinois at Chicago Department of Pediatric Dentistry Chicago, IL
- 2017 Primary tooth vital pulp therapy: A systematic review and meta-analysis.
Coll JA, Seale NS, Vargas K, Marghalani AA, Al Shamali S, Graham L.
- 2012 Necrotizing Sialometaplasia, Case report
University of Arizona Department of Anesthesiology and Pharmacology
Tucson, AZ

Honors and Awards:

- 2018 Paul P Taylor award for the best paper published in AAPD (co-author)

2017	UIC Clinic and Research Day Award -2 st place
2014	Amir's Award for Excellent Academic Performance, Amir of the State of Kuwait
2013	Winner of the regional 2013 IADR / Unilever Hatton competition in Seattle
2013	2 nd place winner of Kuwait Dental Association Poster competition
2011	1 st place winner of the Kuwaiti IADR Hatton competition in Kuwait
2011	Amir's Award for Excellent Academic Performance, Amir of the State of Kuwait
2011	1 st place winner as part of Team Kuwait University in the AEEDC student Competition – Dubai
2011	Dean's List for Academic Achievements, Faculty of Dentistry

Affiliations:

2016 – Present	Illinois Society for Pediatric Dentists (ISPD)
2016 – Present	American Academy of Pediatric Dentistry (AAPD)
2013- Present	Kuwait Dental Association
2011-2014	The International Association for Dental Research (IADR)

Additional Language Proficiencies:

Arabic