

**Perceived Barriers and Facilitators to Dental Treatment among Caregivers of  
Children with Cancer**

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THESIS

Submitted as partial fulfillment of the requirements  
for the degree of Master of Science in Oral Sciences  
in the Graduate College of the  
University of Illinois at Chicago, 2013

Chicago, Illinois

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This thesis is dedicated to my co-residents, family, and colleagues whom have supported me throughout my education and completion of this study.



## **ACKNOWLEDGEMENTS**

I would like to thank Dr. Sahar Alrayyes, my thesis advisor, for providing me with support and guidance both during my training and completion of my thesis. Dr. Alrayyes' patience and encouragement helped motivate and guide me through this process. Thank you for being a friend and great teacher.

Secondly, I would like to thank Dr. Anne Koerber. Thank you for providing your positive critiques, expertise, and encouragement in pursuing a qualitative study. Many of the residents rely on your guidance for completion of our thesis, yet, you find time and support for each and every one of us.

Also, I would like to thank Dr. William Frese, who helped me shape and critically think about my research topic. Thank you for encouraging me to take a risk and to make a commitment to pursuing a qualitative study. Your feedback was always beneficial and helped further my knowledge.

A particular thank you to my co-residents, for their support, encouragement, and patience as I found my way through this thesis.

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## TABLE OF CONTENTS

<u>CHAPTER</u>	<u>PAGE</u>
1. INTRODUCTION	
1.1 Background .....	1
1.2 Statement of the Problem.....	2
1.3 Specific Aims .....	2
1.4 Research Questions.....	2
2. REVIEW OF LITERATURE	
2.1 Cancer .....	3
2.2 Treatment of Cancer .....	4
2.3 Oral Side Effects of Cancer and Chemotherapy/ Medications.....	5
2.4 Rationale for Dental Assessment for the Immunocompromised patient.....	8
2.5 Policies/Guidelines on Dental Treatment of Pediatric Oncology Patients.....	9
2.6 Pediatric Oncology and Dental Recommendations.....	10
2.7 Barriers and Facilitators to the Utilization of Dental Care.....	11
3. METHODOLOGY	
3.1 Sample Selection.....	15
3.2 Inclusion Criteria .....	15
3.3 Sample Size.....	15
3.4 Study Design.....	16
3.5 Recruitment of Subjects.....	16
3.6 Interview Process .....	16
3.7 Interview Questionnaire Development.....	17
3.8 Data Analysis.....	17
3.9 IRB Approval.....	20
3.10 CRC Approval.....	20
4. RESULTS	
4.1 Results .....	21
5. DISCUSSION	
5.1 Discussion .....	37
5.2 Limitations of the Study .....	39
5.3 Future Research.....	39
5.4 Recommendations.....	40
6. CONCLUSION .....	42
CITED LITERATURE .....	43



## TABLE OF CONTENTS (continued)

<u>CHAPTER</u>	<u>PAGE</u>
APPENDICES	
APPENDIX A .....	49
APPENDIX B .....	54
APPENDIX C .....	55
APPENDIX D .....	56
APPENDIX E .....	59
VITA .....	60



## LIST OF TABLES

<u>TABLE</u>	<u>PAGE</u>
I. DEMOGRAPHIC CHARACTERISTICS OF PARENT AND CHILD ONCOLOGY PATIENTS INTERVIEWED REGARDING ORAL HEALTH AND DENTAL TREATMENT.....	22
II. DIAGNOSIS OF PEDIATRIC ONCOLOGY PATIENTS INTERVIEWED REGARDING ORAL HEALTH AND DENTAL TREATMENT.....	23
III. FREQUENCY OF REPORTED CHEOTHERAPY SIDE EFFECTS REVEALED IN INTERVIEW OF PARENTS OF CHILD ONCOLOGY PATIENTS.....	24
IV. DEFINITIONS OF ORAL HEALTH PROVIDED BY PARENTS OF CHILD ONCOLOGY PATIENTS DURING INTERVIEWS.....	26
V. DEFINITIONS OF ORAL HEALTH IMPORTANCE PROVIDED BY PARENTS OF CHILD ONCOLOGY PATIENTS DURING INTERVIEWS.....	26
VI. ORAL HEALTH RECOMMENDATIONS PROVIDED BY PEDIATRIC ONCOLOGISTS BY PARENT REPORT.....	29
VII. PERCEIVED BARRIERS TO ORAL HEALTH CARE PROVIDED BY PARENTS OF CHILD ONCOLOGY PATIENTS DURING INTERVIEWS.....	33
VIII. PERCEIVED FACILITATORS TO ORAL HEALTH CARE PROVIDED BY PARENTS OF CHILD ONCOLOGY PATIENT DURING INTERVIEW.....	36



## LIST OF FIGURES

<u>FIGURE</u>	<u>PAGE</u>
1. Pediatric oncology patients last dental visit.....	27
2. Type of dental care received by pediatric oncology patients.....	27



## **LIST OF ABBREVIATIONS**

AAP	American Academy of Pediatrics
AAPD	American Academy of Pediatric Dentistry
ALL	Acute Lymphoblastic Leukemia
DMFT	Disease, missing, filled teeth
DMFS	Disease, missing, filled surfaces
IRB	Institutional Review Board
PI	Primary Investigator
STD	Standard Deviation
UIC	University of Illinois at Chicago
WBC	White Blood Cells



## **Summary**

A semi-structured interview of parents with children diagnosed with cancer was conducted to determine what perceived barriers and facilitators to dental visits are faced by this patient population. The study included the parents of pediatric oncology patients, whom were between the ages of 1-17 and diagnosed with cancer or a brain tumor within the last year. Patients were treated at the University of Illinois, Chicago Outpatient Care Center.

Open-ended questions were addressed to the parents of children with cancer to determine the parents' understanding of oral health knowledge, the child's oral health concerns, chemotherapy oral side effects, and barriers and facilitators to dental care.

Interview recordings were transcribed and analyzed for common perceived barriers and facilitators to dental treatment as expressed by the parent. Common barriers were time, lack of importance, and parental knowledge. Facilitators that were commonly expressed were the ability to coordinate medical and dental appointments, increased information and knowledge of oral health care, direct referral to a dentist on site by the oncologist, and referral to a skilled dentist.

Findings of this study suggest that although parents acknowledge the importance of oral health, their attitude towards oral health decreases when faced with barriers of time and the child's illness. Parents reported that ease of coordinating care between medical and dental appointments, as well as receiving oral health care for their child from dentists knowledgeable with treating a child with leukemia, would facilitate dental care for their child. Further collaboration between oncology centers and dentists is



indicated to increase parental knowledge and motivation regarding oral health care, as well as to assess barriers to dental care for the pediatric cancer patient.



## 1. INTRODUCTION

### 1.1 **Background**

In the United States, cancer is the disease that causes the most deaths between the ages of 1 and 14 years (Childers et al, 1993; Pinkham, 2005). 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 (AAPD, 2004; Barker, G. 1999; Childers et al., 1993; Da Fonseca, M. 2004; Lunn, R. 1998; Singh et al., 1996). Reduced salivary flow and emesis are common side effects of medications used during cancer therapy, which further harm the oral cavity by increasing acidity, breakdown of the tooth enamel structure, and potentiating caries progression. Decayed teeth, gum disease, and cavities harbor dental plaque and bacteria. Oral bacteria can develop into a source of infection for a cancer patient with decreased immunity (Belfield, 2004; Berkowitz, 1988). The American Academy of Pediatric Dentistry (AAPD) recognizes that the pediatric dental professional plays an important role in the diagnosis, prevention, stabilization, and treatment of oral and dental problems that compromise the child's quality of life before, during, and after cancer treatment (AAPD, 2004). It is imperative that the pediatric dental professional evaluates and provides necessary treatment coordinated with cancer therapy.



## 1.2 **Statement of the Problem**

According to the AAPD, a complete oral examination along with oral hygiene instructions, radiographs and preventive measures should be considered for each cancer patient, ideally prior to and throughout cancer therapy for both primary and secondary preventative reasons (AAPD, 2004). Yet, to date, there are limited studies that provide data on whether children receive dental treatment and recommendations in accordance to the AAPD guidelines.

## 1.3 **Specific Aims**

The objective of this study is to assess the barriers and facilitators for the parent or caregiver obtaining dental treatment for their child whom has cancer. The study aims address areas of medical and dental professional collaboration in treating the pediatric oncology patient.

## 1.4 **Research Questions**

1. What oral health side effects do pediatric oncology patients experience?
2. What dental services do pediatric oncology patients receive?
3. What information are pediatric oncologists delivering to their patients regarding dental care?
4. What are barriers and facilitators to receiving dental care for a pediatric oncology patient?



## 2. REVIEW OF LITERATURE

### 2.1 Cancer

In the United States, cancer is the second most common cause of death among children 1 to 14 years old (CDC, 2012). The Center of Disease Control (2012) states that more than 16 out of 100,000 children and teens in the United States were diagnosed with cancer in the last year. Data published by the National Cancer Institute's Surveillance, Epidemiology and End Results Program in 2009 demonstrate the incidence, mortality, and survival rates of childhood cancers. Data reveals that acute lymphoblastic leukemia (ALL) has the highest incidence (32%) amongst pediatric cancers. The incidence is higher in boys than in girls, and Caucasian children show a 30% higher frequency than African American children (Smith, 2009)

The bone marrow produces white blood cells (WBC), red blood cells, and platelets. The bone marrow releases WBC to help the body fight off invading organisms or infections. White blood cells provide the primary defense against microbial infections and are critical for mounting an immune response. White blood cells are defected in some diagnoses of cancer. Chemotherapy targets leukemic cells and other rapidly dividing cells of the bone marrow. Thus, suppression of the bone marrow inhibits production of these cells (Little, 2008; Pinkham, 2005).

Leukemic cells produce abnormal DNA and continue to divide and replicate, inhibiting the bone marrow's ability to produce properly functioning white blood cells. Leukemia, in particular, is a rapidly progressive disease that results from accumulation of immature, functionless, white blood cells in the marrow and blood (Little, 2008).



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).

The pediatric cancer patient will receive a multidisciplinary treatment that will assist in eliminating the disease. Improvements in treatment of cancer have been able to increase the five- year survival rate of patients with ALL to 85% (Pinkham, 2005).

## 2.2 **Treatment of Cancer**

Acute lymphoblastic leukemia (ALL) accounts for about 75% of all childhood leukemia with a peak incidence at age 4 years (Pinkham, 2005). As a child is diagnosed with cancer, intensive therapies including chemotherapy, immunotherapy and radiation therapy are initiated to eradicate the disease. These therapies target rapidly dividing cells that can lead to destruction of the tissues with side effects including nausea, hair loss, and anorexia.

With a diagnosis of cancer, the child will enter a multimodal approach of therapies that will be completed in phases. The phases of cancer include: induction, consolidation/intensification, and maintenance phases. The goal of the first phase, the induction phase, is to kill all of the leukemic cells in the blood and bone marrow. The consolidation and maintenance phases aim to eradicate any potential leukemic cells that may regenerate (Little, 2008).



Targeting the production of these cells in the bone marrow leads to a depleted amount of white blood cells, red blood cells, and platelets, causing an increased risk of infection, bruising, and bleeding for chemotherapy patients.

### 2.3 **Oral Side Effects of Cancer and Chemotherapy/Medications**

The prevalence and management of oral side effects in cancer patients are well-established (Belfield, 2004; da Fonseca, 2004; Fayle, 1991; Scully, 1996; Sonis, 1998). Oral side effects associated with chemotherapy and radiation therapies include: mucositis, xerostomia, changes in tooth morphology, oral mucosal infections (*candidiasis*, herpes simplex, varicella/zoster, cytomegalovirus), gingival inflammation, and possible increase in caries occurrence or progression (Belfield, 2004; Cheng et al, 2011; da Fonseca, 2004; Javed, 2011; Nasim, 2007; Scully, 1996; Whitmyer, 1997).

Mucositis manifests as generalized red, tender, and painful mucosa. Chemotherapy or irradiation targets highly replicating cells (with a higher mitotic index) and thus younger patients with a higher mucosal turnover rate are often effected (Childers et al, 1993; Cubucku, 2008). The incidence of mucositis among cancer patients has been documented as frequent as 50-54% (Belfield, 2004; Cheng et al; 2011).

Radiation therapy, to the head and neck region, is utilized in certain forms of cancer. Radiation therapy can alter oral structures as well as damage salivary glands (Whitmyer, 1997). Long-term sequelae to the oral dentition have been well-documented (Cubukcu, 2008; Kaste 1997, Scully, 1996). Dental abnormalities, as a result of radiation therapy amongst children treated for acute lymphoblastic leukemia, include



dental root stunting, microdontia, hypodontia, enlarged pulp chambers, and over-retention of primary teeth (Kaste, 1997). Scully et al (1996) similarly reported long-term complications to the oral cavity including enamel hypoplasia, microdontia, delay or failure of tooth development and eruption, altered root formation, and maldevelopment in the craniofacial skeleton when pediatric cancer patients were treated with radiation therapy.

In addition to the changes of oral structures, radiation therapy damages salivary glands, salivary flow rate, pH and production of saliva (Whitmyer, 1997). Salivary flow rate decreases, creating a xerostomic environment that favors accumulation of dental plaque on tooth surfaces, resulting in a more cariogenic environment (Javed, 2011). The saliva produces a more acidic pH environment that is also conducive for dental caries (Belfield, 2004). 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 et al, 1988, Scully et al, 1996).

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.

It is recognized that reduction of salivary flow rate, due to chemotherapy treatments, favors dental plaque accumulation which can lead to periodontal inflammation and caries in the immunocompromised patient. Hegde et al. (2011) investigated the periodontal health status of children with and without ALL. In this study, gingival inflammation was more often observed in children with ALL as compared to healthy controls. The study also concluded that there is a direct relationship between the duration of chemotherapy and incidence of gingival inflammation. Similar findings were reported in a study that documented the prevalence of gingivitis and periodontitis, 91% and 16% respectively, in children with ALL (Ponce-Torres et al, 2010).

Studies have attempted to establish the prevalence of caries in children with cancer (Hegde et al, 2011; Kinirons, M., 2008; Maciel et al, 2009; Nasim et al, 2007). It has been hypothesized that changes in the oral cavity, eating habits, and hygiene practices promotes a cariogenic environment for the pediatric cancer patient. Dental decay introduces pathogenic bacteria that can lead to dental infections that are harmful to the immunocompromised patient. Hedge et al (2011) studied the DMFT (decayed-missing-filled teeth) scores of children and their health counterparts. Overall, the DMFT score was significantly higher for the children with ALL. 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). Pajari et al (1998) also compared the prevalence of caries among children with and without cancer (ALL). The study found that among 4-5 year olds, the mean dmfs (disease-missing-filled surfaces of the primary dentition) was higher significantly higher ( $p < .01$ ) than the controls. A more recent study (2005) indicated that the lifelong caries incidence in children diagnosed with ALL was 2.7 new carious lesions per year (Pajari et al, 2005).

Other studies (Maciel et al, 2009; Kinirons et al, (2008) have found contradictory results regarding prevalence of caries in pediatric cancer patients. Maciel et al (2009) compared the DMFT scores of patients with ALL and a control group and found that there was no significant difference between the two groups. Kinirons et al (2008) studied dental caries experience in 54 subjects whom had ALL and also found that there was no significant difference for dental caries experience and furthermore, that there was no significance between length of chemotherapy treatment and dental caries experience.

## 2.4 **Rationale for Dental Assessment for the Immunocompromised Cancer**

### **Patient**

Treatment of the cancer patient includes therapies such as chemotherapy and radiation that can be directly and indirectly harmful to the oral status of the pediatric cancer patient. Oral side effects reported can potentially cause acute and long-term sequelae (Belfield, 2004; Childers, 1993; Kaste et al, 1997, Hedge, 2011). Changes in the oral cavity, along with fluctuations in dietary and hygiene practices during cancer treatment can induce a change in the oral flora promoting a more cariogenic



environment and increased risk of opportunistic infections such as *Candidiasis*. Due to the immunocompromised state of the cancer patient, it is important to remove any potential sources of infection that may cause further morbidity. Evaluation, treatment, and prevention of any oral and dental preexisting pathology are important aspects of the overall treatment outcome in cancer patients (Chambers et al, 1995; da Fonseca, 2004).

## 2.5 **Policies/Guideline on Dental Treatment of Pediatric Oncology Patients**

The American Academy of Pediatric Dentistry (AAPD) recommends that all patients with cancer have an oral examination before initiation of oncology therapy. The AAPD (2004) recognizes that treatment of preexisting or concomitant oral disease is essential to minimize complications of the pediatric oncology patient. The objective of dental examination prior to cancer therapy is to identify and eliminate existing and potential sources of infection and local irritants. Additionally, it is important that the dentist provides information to the parent and patient about oral care to minimize oral problems. Providing anticipatory guidance, the dentist will be able to inform the parent and patient of possible acute and long-term effects of cancer therapy in the oral cavity. The relationship between the dentist and patient will allow for the opportunity to establish a dental home and provide a resource to the patient for acute and long-term dental care.

In 2003, the American Academy of Pediatrics developed a policy statement, *Oral Health Risk Assessment Timing and Establishment of the Dental Home*. The assessment recommends that physicians identify high caries risk individuals at an early



age and incorporate aggressive strategies, including anticipatory guidance, behavior modifications (oral hygiene and feeding practices), and establishment of a dental home by age 1 (AAP, 2003).

American Academy of Pediatrics' *Guidelines for Pediatric Cancer Centers* also acknowledges the importance of multidisciplinary, state-of-the-art care for the pediatric cancer patient. Among the personnel listed that should be provided by a pediatric cancer center is a surgical specialist with pediatric expertise in dentistry (AAP, 2004).

## 2.6 **Pediatric Oncology and Dental Recommendations**

Pediatric oncologists form an intimate relationship with the pediatric oncology patient and their families throughout the course of treatment. Oncologists are provided the opportunity to address many key points of chemotherapy treatment, in particular oral health care. To date, no studies have explored oncologists' knowledge, perceptions, and role in providing oral health care information to their patients.

Studies have primarily focused on the pediatricians' role and support in dental health by providing an oral assessment, fluoride varnish, and/or anticipatory guidance (Close et al, 2010; dela Cruz et al, 2004; Lewis et al, 2000; Yu et al, 2002). Review of these studies has provided valuable information as to what may also be applied to all physicians whom care for children.

Beil (2010) found that referrals provided by primary care physicians lead to an increase in dental visits among young children. Studies have concluded that lack of referral to dental providers by medical providers has been attributed to inadequate training, referral environment, and lack of knowledge (de la Cruz et al, 2004; Lewis et al.



2000). Close et al (2010) reviewed medical providers' perceived barriers to implementation of oral health assessment and fluoride application in North Carolina called "Into the Mouth of Babes." Reported barriers included difficulty integrating dental procedures into dental practice, resistance among office personnel, and difficulties referring children in need of a dentist.

To date, no studies specifically document pediatric oncologists' behavior in dental referrals and/or oral assessment practices. A study by Ramirez et al. (2009) showed those oncologists are more likely to address acute side effects than long-term side effects with patients undergoing chemotherapy. Of 140 patients, mucositis was mentioned to 98 subjects, and a dental/periodontal condition was discussed with one patient.

Glenny et al (2004), in a study conducted in the United Kingdom, surveyed current practices of cancer centers with regard to oral care for children with cancer. Twenty-two different cancer centers and their practices toward oral health care for children with cancer were interviewed. Glenny et al (2004) reported that of 22 cancer sites, 9 recommended that the child attend a hospital-linked dental clinic. Eight out of the 22 clinics reported that patients were expected to undergo a dental check-up before commencing cancer treatment.

## 2.7 **Barriers and Facilitators in the Utilization of Dental Care**

Factors that influence the utilization of dental care have been attributed to disparities of race/ethnicity, parental education, family income, and insurance (Gilbert, 2002; Isong et al 2012; Liu et al, 2007; Mofidi, 2002; Pourat et al; 2010, Yu et al, 2002).



Yu et al. in 2002 reviewed data from the 1999 National Survey of America's Families (NSAF) and reported that overall, 47% of children were not in compliance with the AAPD dental recommendations of visiting a dentist twice a year. Yu et al (2002) concluded that factors that were associated with lack of compliance to dental care were children whom were African American, uninsured, from low income families and children whom have parents that are less than college educated.

Mofidi et al (2002) also found that barriers to dental care among Medicaid insured children included negative experiences with the dental care system, searching for providers, transportation, and arranging for an appointment were choices were severely limited.

Studies have linked disparities between ethnicity and oral health care (Liu et al 2007; Pourat et al; 2009, Vargas et al, 2002; Yu et al, 2002). Vargas and Ronzio (2002) found that children from racial/ethnic minority groups were more likely to be episodic users or to have never been to the dentist. Children in the 2-to-5 year old group, with perceived dental needs were more likely to be episodic users of dental care. A study by Liu et al. (2007) echoed the findings, stating disparities among dental insurance and racial differences contributed to lack of dental care. Pourat and Finocchio (2009) reported that children on Medicaid, especially Latinos and African Americans, experience high rates of tooth decay, yet they visit the dentist less often than privately insured patients. When controlling for the type of insurance, African American (39%) and Latino (36%) children were still more likely than white children to have never had a visit or to have visits at longer intervals.



The parent's perception of their child's oral health and the parent's willingness to facilitate dental care for their child has been identified as a variable that influences oral health care for children. Studies have found that the maternal perception of their child's oral health motivated visits to the dentist, and children of mothers with low schooling level were at greater risk of not receiving dental care (Goettems et al, 2012; Talekar et al, 2005).

Similar influences have been reported to effect dental care among children with special needs (Broder et al, 2002; Agili et al, 2004; Kane, 2008). Children with leukemia may be considered as children with special medical needs due to the complexity of their disease and the specialized medical treatment required. Barriers to dental care among children with special needs have been identified as lack of willingness or knowledge to treat children with special health care needs, parent education, transportation, and insurance (Agili et al, 2004; Broder et al, 2005; Kagihara, 2011; Kane et al, 2008).

Agili et al (2004) surveyed parents regarding the access to dental care for special needs patients and found that the reasons for lack of routine dental care include the dentist is unwilling to treat the child, the health plan was not accepted by the dentist, the parent was overwhelmed with the child's disability, time, and dental care was not perceived as important to the parent.

Broder et al (2002) studied barriers and facilitators to dental care among caregivers of HIV patients through a qualitative, focus group evaluation. Results indicated that barriers to dental care encompassed family attitudes and beliefs (dental fear, dental knowledge, attitude toward health care), family stress (busyness, social support, illness), logistics (scheduling, coordination with other appointments), quality of



dental care, interpersonal communication (dentist/staff behaviors, language), and access to care (transportation, costs).

Limited studies have identified potential barriers to dental care among child with cancer. Collard et al (2001) interviewed caregivers of children with ALL to determine the dental experiences of the child and the attitude of parents towards dental care. The study found similar results to the aforementioned studies; seeking specialized care, time, a low dental priority, and convenience were contributing factors to dental care. Convenience (37%) and trust (34%) were two of the most common underlying decisions when considering the utilization of dental care by the parent.

Overall, disparities to dental care exist between children with or without special needs. Lack of utilization of dental care has been contributed to low income household, time, low parental education level, access to care, insurance, transportation, low parental perception of oral health, overwhelming stress with a child's concomitant disability, and finding a provider willing to treat the child whom has special health care needs.



### **3. MATERIALS AND METHODS**

#### **3.1 Sample Selection**

The sample included children diagnosed with cancer or a tumor who were active patients being treated at the University of Illinois Hospital Pediatric Oncology Outpatient Care Clinic, and their parents who were present in the clinic when the primary investigator was available for interviewing.

#### **3.2 Inclusion Criteria**

The inclusion criteria were as follows: Conversational English-speaking parents of children diagnosed with cancer or a tumor. Children of this study were ages 1-17 years old, diagnosed with cancer or a tumor within the last year, in maintenance or induction phases of chemotherapy, and (if over the age of 6) that provided verbal assent. The oncologist identified appropriate parents for interview, excluding those who were too early in treatment or who were likely to have emotional difficulties during the interview. She also excluded parents who did not speak English. Parents who did not speak and understand English were excluded from this study.

#### **3.3 Sample Size**

Sixteen dyads of pediatric patients and parents participated in this study. The initial intent was to interview more dyads if the findings continued to reveal new information. However, the sample was maintained at 16 because a saturation of information was obtained with those interviews.



### 3.4 **Study Design**

This qualitative study consisted of a semi-structured interview of parents of child oncology patients.

### 3.5 **Recruitment of Subjects**

Medical charts were screened by oncologist Dr. Mary Lou Schmidt to determine which parent-child dyad qualified for the study. Eligible children were identified by Dr. Schmidt when she reviewed her daily schedule, and were selected from the children present at the Pediatric Outpatient Care Center for a scheduled appointment. Ten subjects were rejected for this study because they did not meet the inclusion criteria for age and diagnosis within the last year. An interceptive method was used to approach parents, in which the PI recruited subjects after they were non-randomly identified by Dr. Schmidt. Parent participation was voluntary. The PI approached the identified parent-child pair prior to their visit with Dr. Schmidt, provided information regarding the study and solicited informed consent (Appendix A). All eligible pairs who were present when the interviewer was available were offered the option to participate. None of the parents approached for this study refused to participate.

### 3.6 **Interview Process**

The parent was asked to answer a five question demographic survey prior to the interview process (Appendix B). The PI conducted all interviews individually using the interview protocol (Appendix C) in a private examination room at the University of Illinois



Pediatric Outpatient Clinic. The interview was recorded on a digital recorder (Sony Digital ICD-BX 112).

Interviews were transcribed the same day by the PI. The PI destroyed the audio recording once transcription was complete. No identifying variables were retained in the transcription.

### 3.7 **Interview Questionnaire Development**

The semi-structured protocol (Appendix C) explored oral health knowledge, oral health concerns, chemotherapy effects on oral health, and barriers and facilitators to oral health. Fifteen open-ended questions offered the parent the opportunity to express thoughts and describe their experiences regarding these various topics.

The parent subject was asked about the child's chemotherapy treatment, his/her knowledge of oral health care, and barriers/facilitators to dental health. The PI allowed participants flexibility to respond in their own words.

### 3.8 **Data Analysis**

Demographic variables of the sample were collected and analyzed to determine the distributions amongst the sample. Transcripts were examined and coded to address the research questions of this study:

1. What oral health side effects do pediatric oncology patients experience?
2. What dental services do they receive?
3. What information regarding oral health care is provided by oncologists?
4. What are barriers and facilitators to dental care?).



Research question #1 was addressed by asking the parent to report any changes in oral health regarding the mouth, teeth, and eating habits (see Appendix C). Parents were asked to explain the child's history of visiting a dentist, the date of the child's last dental visit in relation to the initiation of chemotherapy treatment, the type of dental treatment rendered at that dental visit, if there was any current oral/dental concerns, and if there were any negative experiences during the last dental visit to capture the factors that contribute to answering research question #2.

Question #3 was measured by asking the parent to recall any information provided to them by the oncologist regarding the child's mouth, teeth, and dentists, including if the parent was provided a referral to a dentist provided by the oncologist.

Lastly, question #4 was approached with various questions asking the parents to consider what factors make it difficult and what would make it easier to see a dentist (Appendix C). Previous studies (Broder et al, 2005; Collard; 2001) were referenced to develop common reported variables/themes regarding barriers and facilitators to dental care. Themes were coded according to the following: *family attitude/belief*, *family stress*, *logistics*, *quality of care*, and *access to care*.

Replies displaying a negative attitude towards dental care, dental fear, lack of knowledge, and expressing a low priority of dental care were grouped under the '*family attitude/belief*' theme. If the parent explained that the number of children in the household, lack of social support including a babysitter or single-parent household, and stress with the child's illness or managing appointments influenced the child's dental care, these factors were grouped under the theme '*family stress*.' When the parent expressed that they did not have time, the child had too many appointments, they were



unable to obtain dental appointments for multiple siblings, and they had trouble coordinating medical and dental care the variables were coded for the theme '*logistics*.' If the parent expressed that they felt they previously had not receive the standard of care for dental care for their child, if they were seeking specialized dental care, or perceived the dentist as having a lack of knowledge regarding how to treat their child, the PI grouped these factors with the theme '*quality of care*.' Lastly, if the parent explained that transportation, money, or insurance coverage limited the child's dental care the responses were grouped with the theme '*access to dental care*.'

A comparable approach was used to code themes expressed as facilitators to dental care for the pediatric oncology patient. Responses that described the parent was seeking dental information/dental referral regarding dental services, if they perceived the child was in pain or had a dental problem, or stated that they were more likely to take their child to the dentist if they were told to do so, the PI grouped these responses under the theme of "*family attitude and belief*" for facilitating dental care. When the parent expressed that they were more willing to take the child to the dentist when there was assistance with childcare or when they had more free time, the PI grouped these findings under the theme "*family stress*.' Transcripts were coded for the theme '*logistics*' when the parent expressed that receiving assistance in coordinating the dental visit or having the dentist examining the patient at the medical visit as facilitating dental care. If the parent stated that they were more willing to take the child to the dentist if they felt the child would receive specialized care and receive care from a dentist knowledgeable in treating children, especially children with leukemia, the responses were coded for the theme '*quality of care*.' The transcripts were also coded



for themes of '*access to care*' when the parent expressed that they would be more willing to take the child to the dentist if the child had dental insurance, if the dentist accepted their insurance, the dental office was in near proximity to the medical center, and if the parent had transportation.

Each transcript was individually reviewed by three analysts. Data analysis was conducted by the PI, a pediatric dentist, and a graduate college student. Each analyst was asked to mark the data extraction sheet as she read the transcript for themes. Results were provided to the PI, who created a joint summary of the analysis. If results were conflicting, the PI reviewed the transcript to resolve the issue. The PI then created a list of responses to each topic, and grouped the responses into themes.

### 3.9 **IRB Approval**

This study was approved by the Institutional Review Board of the University of Illinois at Chicago. Review Board, approval #2013-0007. See Appendix D.

### 3.10 **CRC Approval**

This study was approved by the Cancer Research Center of the University of Illinois at Chicago. See Appendix E.



#### **4. RESULTS**

Sixteen parent-patient dyads were interviewed. Mothers were primarily interviewed. Education levels amongst the mothers varied and two forms of payment, governmental and private insurance, were identified (Table I).

More male than female pediatric oncology patients participated in this study and ethnicities of Caucasian, African American, and Hispanic were identified. Also, a range of diagnosis was evident in the same with acute lymphoblastic leukemia (ALL) showing a higher frequency (Table II).



**TABLE I**  
**DEMOGRAPHIC CHARACTERISTICS OF PARENT AND CHILD ONCOLOGY**  
**PATIENTS INTERVIEWED REGARDING ORAL HEALTH AND DENTAL TREATMENT**

<b>DEMOGRAPHICS</b>	<b>Distribution ( n=16)</b>
<b><i>Race/Ethnicity:</i></b>	
Caucasian	31%
African American	25%
Hispanic	44%
<b><i>TOTAL</i></b>	<b>100%</b>
<b><i>Gender (adult)</i></b>	90% female
	10% male
<b><i>Gender (child)</i></b>	56% female
	44% male
<b><i>Education Level of Adult:</i></b>	
Some High School	6%,
High School	38%,
Some College	25%,
College	31%,
<b><i>TOTAL</i></b>	<b>100%,</b>
<b><i>Method of Payment:</i></b>	
Governmental Insurance	63%,
Private Insurance	37%,
Self-pay	0%,
<b><i>TOTAL</i></b>	<b>100%,</b>
<b><i>Mean age of patient:</i></b>	5.5 years (SD=4.9)
<b><i>Mean time in treatment:</i></b>	6 months (SD=3.7)



**TABLE II**  
**DIAGNOSIS OF PEDIATRIC ONCOLOGY PATIENTS INTERVIEWED**  
**REGARDING ORAL HEALTH AND DENTAL TREATMENT**

<b>DIAGNOSIS</b>	<b>NUMBER OF PARTICIPANTS</b>
Acute Myelogenous Leukemia	1
Astrocytic Neoplasm	1
Post-transplant lymphoproliferative disorder	1
Ewing's Sarcoma	2
Wilm's Tumor	2
Retinoblastoma	4
Acute Lymphoblastic Leukemia	5
<b>TOTAL</b>	<b>16</b>

Systemic and oral side effects of chemotherapy were reported by the parents regarding their child's chemotherapy treatment (Table III). Oral side effects were defined as those directly involving the oral cavity and oral mucosa. These side effects included xerostomia, mucositis, halitosis, tooth sensitivity and bruxism. Although 68% reported oral side effects, only 2 patients reported mouth sores.

Additional serious side effects reported were nausea/vomiting and decrease in appetite (9 of 16). These side effects were defined as indirectly affecting the oral cavity. For example, decrease in appetite may encourage harmful eating habits (i.e. frequent



snacking, high sugar content foods) and acid produced from emesis could indirectly effect enamel and indicate higher risk of caries progression.

**TABLE III**  
FREQUENCY OF REPORTED CHEMOTHERAPY SIDE EFFECTS REVEALED  
IN INTERVIEWS OF PARENTS OF CHILD ONCOLOGY PATIENTS (n=16)

<b>SIDE EFFECT REPORTED</b>	<b>FREQUENCY REPORTED</b>
None	5
Nausea/Vomit	5
Xerostomia	4
Decreased Appetite	4
Halitosis	3
Mouth Sores	2
Hair loss	2
Fever	1
Tooth Sensitivity	1
Bruxism	1
Allergy	1

The parents of this study were judged as having a conventional definition of oral health (Table IV). Parents were able to name various characteristics of oral health including presence/absence of cavities, esthetics, and periodontal condition. Additionally, all of the parents acknowledged that oral health was “very important”



(Table V). However, when parents were asked to compare the importance of oral health care to “all of [their] other concerns,” the level of priority of oral health care varied and often decreased (Table V).

**TABLE IV**  
DEFINITIONS OF ORAL HEALTH PROVIDED BY PARENTS OF CHILD  
ONCOLOGY PATIENTS DURING INTERVIEWS (n=16)

DEFINITION OF ORAL HEALTH	FREQUENCY REPORTED
Presence of cavities	10
Hygiene practices (brushing, flossing)	7
Color	5
Chipped/Broken teeth	4
Periodontal condition	4
Breath	3
Effect on Systemic Health	2
Routine Check-up	1

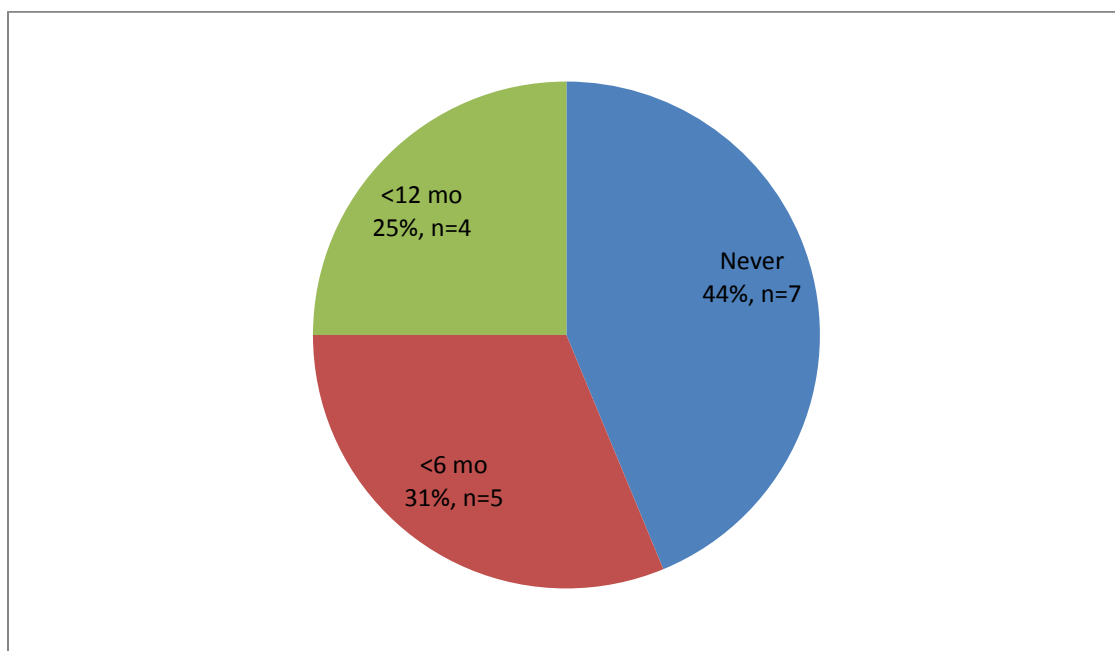


**TABLE V**  
DEFINITIONS OF ORAL HEALTH IMPORTANCE PROVIDED BY PARENTS OF  
CHILD ONCOLOGY PATIENTS DURING INTERVIEWS (n=16)

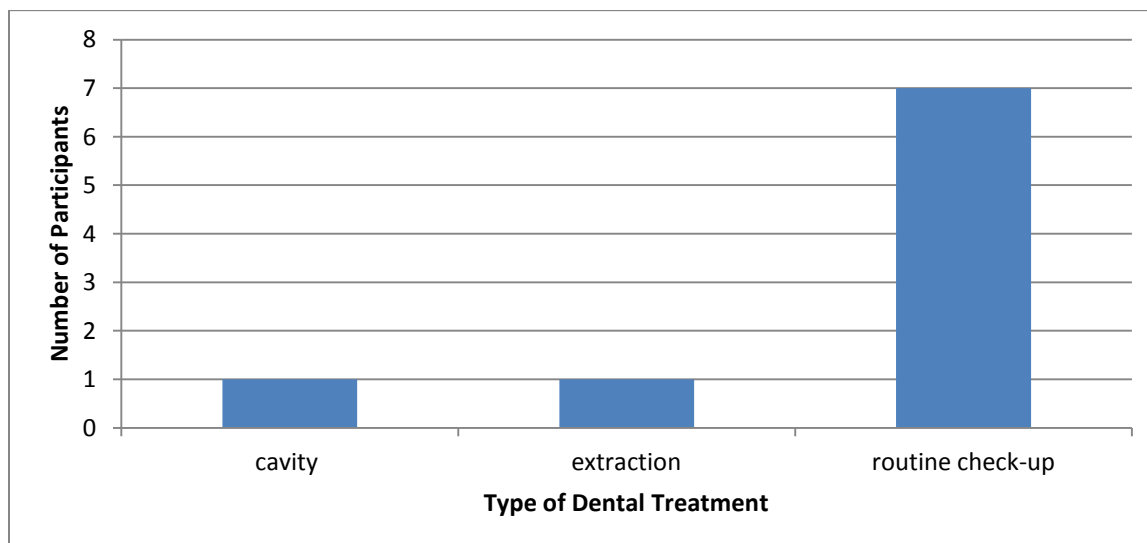
IMPORTANCE OF ORAL HEALTH	FREQUENCY REPORTED
Very important	16
<i><b>Importance of dental health when compared to other concerns:</b></i>	
Dental not as important	9
Medical more important	3
Dental somewhat important	2
Both equally as important	2

Patients were not in compliance with visiting a dentist by the age of 1 (AAPD, 2004) (Figure 1). 44% had never visited the dentist. The remaining patients reported that they had been to the dentist either within the last 6 months or the last year. Of the patients who did see the dentist prior to chemotherapy, the parents revealed that they were not told to do so by the oncologist, but rather had taken in their child for a routine dental exam (Figure 2). None of the patients reported being referred to a dentist by the oncologist, for a dental exam prior to or after their chemotherapy was initiated.





**Figure 1:** Pediatric Oncology Patients' Last Dental Visit



**Figure 2:** Type of Dental Care Received By Pediatric Oncology Patients at Last Dental Visit N=9



The parent was asked to recall what information was mentioned to them by the pediatric oncologist regarding mouth, teeth, and oral health (Table VI). Of the parents that were able to recall information relevant to oral health (n=14), four stated that no information was provided to them. Information regarding oral health care delivered to the parent via a pediatric oncologist varied from anticipatory guidance to oral health instructions.

*“She [the oncologist] explained that some of the chemo can cause his teeth to rot or go bad, it can cause blisters around his mouth, tongue and throat, and there is medicine to treat the blisters and sores.” [15-TP]*

*“She [the oncologist] did say to avoid the pacifier because her teeth [the patient’s] can move forward.”[7-CA]*

*“Nothing.” [3-MB, 4-ER, 6-JM, 12-AR]*

The variety of the information provided to the pediatric oncology parent indicates that there is an inconsistency of oral health care recommendations provided (Figure 3). Oral health care information provided by the pediatric oncologist often did not address potential acute or long-term side effects of chemotherapy.

*“I’m not sure if there is going to be an effect [on the teeth] later.” [13-EL]*

*“I have lots of papers at home, I’m quite sure that info is in those papers.” [2-BM]*

Furthermore, this information demonstrates that attempts of the pediatric oncologist to provide oral health recommendations are made, yet the information delivered is ineffective, overwhelming, or not prioritized by the parent.



**TABLE VI**  
**ORAL HEALTH RECOMMENDATIONS PROVIDED BY PEDIATRIC**  
**ONCOLOGISTS BY PARENT REPORT, n=16**

RECOMMENDATION	FREQUENCY
Nothing	4
Recommendations	3
Oral side effects	3
Nurse checked teeth	2
Asked about last dental visit	2
Cannot recall	2

Responses were solicited from the parent concerning potential barriers to dental care among their children with cancer (Table VII). Barriers were grouped under themes including: *attitudes/belief* (parental knowledge, attitude toward dental care, dental fear), *family stress* (illness, number of children, lack of child/social support), *logistics* (time, inflexible appointment times, number of medical *appointments*), and *quality of dental care* (*knowledge and skill of dentist*), and *access to care* (transportation and insurance).

Many of the parents replied that the strongest barrier to dental care was logistics. The number of medical appointments the child had made it difficult for the parents to coordinate medical and dental appointments and even more difficult to find additional time to take the patient to the dentist.



*"Schedules...there is maybe one day a week that I can take my other son to the doctor too. It's hard to find time. I have to make appointments on my free day because chemo takes up the other days of the week."*[6-JM]

*"It's mostly a work issue, if there was a Saturday appointment, no problem."*[4-ER]

*"Well, it's hard because we need to take work time off. My wife and I use our vacation days for doctor's appointments."*[12-JA]

*"Our schedules. Her dad has been laid off, my other son is born premature and he is sick, we've been going back and forth to doctors and work and we don't have time."*[12-AR]

Family stress, due to concern about the child's illness, care of other siblings, lack of spousal support, and coordinating care for multiple siblings was a main concern for some parents expressing difficulty in scheduling appointments with the dentist.

*"Another thing that makes it hard for moms that have more than one kid is that most [dental] offices won't book all of my sons on the same day because they don't want to risk losing a whole afternoon of no patients if we don't show up."*[1-RB]

*"In my case, we are a family of 7, so it seems like there is a doctor's appointment every other week for something."*[5-BP]

*"I can't get off from work or a babysitter to be able to take all of my kids to the dentist. I'm a single parent and I'm trying to do everything on my own."*[14-KB]

*"When I have time at home and for his 5 other siblings, then I can take of his teeth too."*[2-BM]

*"I'm busy, tied up a lot."*[15-TP]



Parental attitude, belief, dental fear, and parental dental knowledge also factored in perceived barriers to dentistry as expressed by parents. Parents placed a low priority to dental care due to no evidence of the child having dental pain or concerns.

*"With dental, I think it's one of those, nothing is wrong until you really feel it, so it's more of preventive thing to go to the dentist. So, I guess, I think, 'Oh well there's nothing really wrong', so I won't go."* [5-BT]

*"There's no need...I looked at her teeth and I don't think there is a need."* [13-EL]

*"I just don't think my child needs to see a dentist right now, nothing is bothering her."* [3-MB]

*"The truth is that he had a bad experience, the procedure was hurting him and the dentist kept going. The dentist wouldn't stop the procedure and kept telling me that he wasn't feeling it."* [1-RB]

Other parents expressed that dental care was not as important because they perceived that the child was too young and the deciduous nature of primary teeth influenced their decision making. Interestingly, some parents report lack of information or misguided information regarding a child's first dental visit.

*"These are [her] baby teeth, so she will have new teeth that come in because these baby teeth will fall out."* [12-AR].

*"We did call our dentist to see when we should get him in and they told us to not worry about it yet."* [4-ER]

*"We were waiting until she was 2 because we weren't really sure when to take her. We don't know how young they should be before they go to the dentist. My son is 4 and he still hasn't gone either."* [12-AR]



Many parents expressed that their focus was toward the child's medical health at this point in time, and they were not concerned about the child's dental health.

*"I would say unfortunately dental doesn't seem like a huge priority to me right now, unless there was something that I saw wrong." [4-ER]*

Interestingly, two patients stated that they were seeking a dental specialist who would be familiar with their child's illness and know how to treat their child.

*"If dentist were more informed on what is going on. In M's situation, the dentist was very freaked out and didn't have a lot of experience with this." [10-ML].*

*"It's important that the dentist he goes to knows what they are doing and they are safe with m child...a dentist that will explain everything to him so he is not scared and they don't hurt him." [13-KB]*

Lastly, another barrier to dental care was access to care due to insurance and transportation. Parents expressed that insurance limited their choices of selecting a dentist and/or lack of insurance prevented them from taking the child to the dentist. Also, transportation to the dentist and location of the dentist was an identified as a barrier.

*"Insurance, it's hard to find someone that is good with kids and accepts our insurance, and getting here, we live far away." [16-BR]*

*"Transportation is also hard getting here and trying to take him to all of his appointments. It would be easier if the dentist was part of the hospital." [14-KB]*



**TABLE VII**  
**PERCEIVED BARRIERS TO ORAL HEALTH CARE PROVIDED BY PARENTS OF**  
**CHILD ONCOLOGY PATIENTS DURING INTERVIEWS**

<b>BARRIER THEMES</b>	<b>FREQUENCY</b>
<b><i>Family Attitude/Belief:</i></b>	
Parental dental knowledge	5
Dental Fear	2
Attitude toward dental health	2
<b><i>Family stress:</i></b>	
Illness	3
Number of children	2
Lack of social support/childcare	2
<b><i>Logistics:</i></b>	
Busyness (time)	4
Unable to coordinate with medical appointments	3
Inflexible appointment times	3
<b><i>Quality of Care:</i></b>	
Specialized dental care sought	2
<b><i>Access to Care:</i></b>	
Insurance	3
Transportation	2



Similar themes (*attitude/belief, family stress, logistics, quality of care, and access to care*) were used to determine which factors would facilitate oral health care for the pediatric oncology patient. Facilitators to dental care amongst caregivers of children with cancer were also focused on convenience, flexibility of scheduling, and time. Interviews with the parents of children with cancer revealed that the key facilitator to dental care was logistics. Items described as barriers by the parents (time, difficulty coordinating appointments, etc.) were also items that if aided, would help facilitate dental care. For example, a barrier to dental care reported was time. In turn, the major contributor to facilitating dental care for the pediatric oncology patient was the caregiver's ability to coordinate medical and dental appointments at the same visit.

*"The doctors can give you a day or they can make an appointment for you when you are here."* [9-CO]

*"If I could coordinate taking him while I am here, that would be helpful."* [4-ER]

*"If there was a dentist here [at the Outpatient Care clinic] that could see her."* [3-MB]

*"If I could make an appointment before I leave here today."* [6-JM]

Parents also reported that the ability to manage appointments for multiple siblings and to have less 'family stress' would help them coordinate dental visits for their children.

*"I'm a stay at home mom, when I was working I could not get him to all of his visits, which is why I chose not to work anymore."* [5-BT]

*"If I could make appointments for my other kids at the same time."* [1-RB]



Parents found that locating a dental in which their child received quality dental care from a specialist familiar with the child's illness would make the parent more comfortable and would help facilitate dental care ('*quality of care*').

*"If I could find a dentist that was specialized in treating a child, like a child with leukemia, that would be better for me and make me feel more comfortable."* [6-JM]

*"If the dentist was specialized in providing care for my child."* [13-EL]

This study also determined that access to care, insurance and transportation were factors that contributed to facilitating dental care for some of the pediatric oncology patients. Dental insurance coverage was reported by 2 families a factor that limited receiving dental care for their child (Table VII).

*"If my insurance was accepted."* [12-AR]

*"As long as his insurance is accepted and I didn't need more referrals, I would be able to make the appointment."* [2-BM]

This study also found that parents were misinformed or uninformed about dental resources available to the patient. Parents believed that the nurse who had checked the child's mouth was sufficient for a dental examination. Overall, very few of the patients were aware of the University of Illinois' Pediatric Dentistry Program and its location (across the street) as a resource for their child. Thus, information regarding dental knowledge and resources for the patient were identified as contributing to dental care ('*attitude/belief*').

*"She [the nurse] came over and looked at his teeth and just looked at them and said 'excellent teeth.'"* [15-BR]



*“I would love to get information about a dentist for BM...“I didn’t know there was a dental clinic near here.” [2-BM]*

*“There was always someone here too, a resident, I think, that would check his teeth.” [1-RB]*

**TABLE VIII**  
PERCEIVED FACILITATORS TO ORAL HEALTH CARE PROVIDED BY PARENTS  
OF CHILD ONCOLOGY PATIENTS DURING INTERVIEWS

FACILITATOR THEMES	FREQUENCY
<b><i>Family Attitude/Belief:</i></b>	
Parental dental knowledge	2
<b><i>Family stress:</i></b>	
Social support/childcare	1
<b><i>Logistics:</i></b>	
Ability to coordinate with medical appointments	5
Proximity of dentist to hospital location	2
<b><i>Quality of Care:</i></b>	
Specialized dental care received	2
<b><i>Access to Care:</i></b>	
Insurance	3
Transportation	1



## 5. DISCUSSION

### 5.1 **Findings of this Study**

This was a qualitative study of the barriers and facilitators to obtaining oral health care for child cancer patients, by interview of their parents. Barriers and facilitators were time issues, priority of concomitant illness, family stress, quality of care, and access to dental care. The major contributor to preventing or facilitating dental care to the pediatric oncology patient was logistics. This finding was consistent with Collard et al (2001), which reported that many of the parents perceived the strongest barrier to dental care is logistics. Parents did not take their child for dental evaluations due to pressures of time and inability to coordinate medical and dental care. Similar findings to Broder et al (2008) were found regarding factors contributing to the utilization of dental care among pediatric oncology patients. These causes included lack of information/dental knowledge, family stress, seeking quality care, and access to care.

Studies have identified that low dental utilization among children is predicted by parental education, income, maternal perception of the child's oral health, and the mother's pattern of utilizing oral health care (Goettems et al, 2012; Camargo et al, 2012). This study did not examine parental education and income, but did identify that the maternal perception of the child's oral health care status motivated dental utilization. Similar to the findings of Collard et al 2001, parents accord low priority in dental care due to lack of knowledge or they did not perceive their child to have a dental problem.

Although these interviews took place in a pediatric oncology unit that works closely with a college pediatric dentistry department, parents revealed a disappointingly low rate of communication regarding oral health from the oncology team.



Lack of dental resources and dental information also contributed to receipt of dental care. Information regarding oral health care was limited and was not consistently provided to all pediatric oncology patients by oncologists and in some instances, by dentists. Of interest is that some parents were told by a dentist to wait until the child was older to initiate dental care. Results of this study show that in light of the AAPD guidelines (2004), many patients had not visited the dentist by age 1 and therefore, also had not visited the dentist prior to or after initiation of chemotherapy.

Undoubtedly, a child's illness such as cancer creates a change in family dynamics. Parents faced with caring for a sick child and coping with the child's illness prioritize medical care for their child. However, despite the emotional strain these parents face, most acknowledge that oral health care is important and would be motivated to obtain oral health care for their child if it was convenient.

Potential acute side effects of chemotherapy treatment were identified by this study. These included xerostomia, mucositis, bruxism, and tooth sensitivity. Side effects were reported by the parent of the patient and may have been directly or indirectly a result of chemotherapy treatment. A low number ( $n=2$ ) of patients reported mouth sores. This may be attributed to the parent's perception of side effects experienced by the child and not a true description of side effects actually experienced by the patient.

The study revealed that oral health care information provided by the pediatric oncologists was inconsistent. Some parents recalled the oncologist discussing chemotherapy oral side effects with the patient. However, no long-term effects were discussed with any of the parents. References to oral health care were made to some



parents by the oncologist (for example, eliminating a nonnutritive sucking habit). However, recommendations and anticipatory guidance regarding chemotherapy side effects were not consistently identified.

## 5.2 **Limitations of the Study**

This study has the usual limitations of a qualitative study. Only a small group of subjects from one cancer center were interviewed. Since open ended questions were used, the responses can't always be directly compared between subjects.

Qualitative research aims to discover the interviewee's own framework of meanings without imposing the researcher's assumptions (Pope and Mays, 2006; Sandelowski, 2007). The caregivers of this study were interviewed by a dentist, and thus their responses may have been restricted or altered to accommodate the dentist's reaction or judgment of the caregiver's actions.

The caregivers of this study were asked to recall information and thus their account of discussions and information may not be accurate. However, it does reflect what the caregivers remember.

## 5.3 **Future Research**

Future studies could focus on more outpatient care clinics to obtain a more diverse sample. Information from caregivers could also be obtained through focus group discussions which might stimulate other memories and descriptions of experiences not obtained through an interview. Furthermore, interviews by a more



neutral, non-dental and non-oncology researcher might have obtained more accurate reflections of caregivers' opinions.

Further research can also address the oncologists' role and understanding of dental care during chemotherapy treatment. Acquiring information from the oncologist's perspective may help to better understand and shape a future framework for medical and dental collaboration in treating pediatric oncology patients.

Lastly, future research can attempt to quantify the specific barriers and re-affirm the findings of this study. A randomized approach and involvement of multiple oncology centers may further validate the findings of this study.

#### 5.4 **Recommendations**

1. Develop and test methods of improving oncologist-dentist collaboration to improve the oral health care of children with cancer.
2. Educate oncologists about dental care and management of chemotherapy/radiation oral side effects so that they are able to provide pediatric oncology patients with information regarding chemotherapy/radiation therapy side effects and resources/referrals to a dental home.
3. Educate dentists about providing dental care for pediatric oncology patients and chemotherapy/oral side effects so that they are able to provide effective dental care to pediatric oncology patients.
4. Establish collaboration between medical and dental facilities that address barriers and facilitators to dental care. In particular, the ability to coordinate appointments



with a multidisciplinary approach would help address a major barrier to caregivers of children with cancer.



## **6. CONCLUSIONS**

- Parents of pediatric oncology patients perceive logistics as the major barrier or facilitator to dental care. The greatest barrier to dental care for the pediatric oncology patient is time. The ability to provide dental and medical care in the same visit would significantly reduce this.
- Pediatric oncologists are providing inconsistent information regarding acute and long-term oral side effects of chemotherapy.
- Pediatric oncology patients are not receiving dental care along with chemotherapy treatment, contrary to recommendations.
- Dentists were reported to not provide proper dental recommendations for the child's first visit for the pediatric oncology patient.
- Medical and dental collaboration is needed to address the barriers to dental care for pediatric oncology patients.



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## **APPENDICES**



## APPENDIX A

### College of Dentistry RESEARCH STUDY

#### ***Perceived Barriers and Facilitators to Dental Treatment among Caregivers of Children with Cancer***

Hello!

A UIC Pediatric Dentistry resident is asking you to participate in an audiotaped interview regarding your child and his or her dental health.

**What you need to know:**

- The interview is voluntary. Participation is not mandatory. You have the right to not participate in the interview.
- Approximately 25 minutes of your time is being requested to complete the interview.
- There is no compensation.
- There is no penalty for not participating.
- There may be minimal risk involved with your participation (your child's name will be recorded on a piece of paper and may be mentioned in the audiotaped recording).
- The recording will only be reviewed by the person whom interviews you and will be deleted once the study is complete.
- You will be asked questions regarding your child's oral (dental) health and dental experiences

Please let the investigator know if you are interested in participating. If you have any questions regarding this information, please address them to:

Denise Maniakouras, DDS  
801 South Paulina  
Chicago, IL 60612  
(708)769-0029

Sahar Alrayyes, DDS, MS  
801 South Paulina  
Chicago, IL 60612  
(312)996-6416



**APPENDIX A (continued)**

Leave box empty - For office use only

**University of Illinois at Chicago  
Research Information and Consent for Participation in Social Behavioral Research**

**Perceived Barriers and Facilitators to Dental Treatment Among Caregivers of Children  
with Cancer**

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title: Denise Maniakouras, DDS, Pediatric Dentistry Resident  
Department and Institution: UIC College of Dentistry, Department of Pediatric Dentistry  
Address and Contact Information: 801 South Paulina Chicago, IL 60612, phone: (312)996-7530  
or email at [dmania2@uic.edu](mailto:dmania2@uic.edu) .

**Why am I being asked?**

You are being asked to be a subject in a research study about dental treatment provided to children with cancer. Your child's doctor has identified that your child meets the criteria of this study. In participating in this study, you will be able to provide information about your experience with dental care for your child and areas needed for improvement.

You have been asked to participate in the research because you are the parent of a child, ages 1-17 years old, which has been diagnosed with cancer.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago. **If you decide to participate, you are free to withdraw at any time without affecting that relationship.**



Approximately 40 subjects may be involved in this research at UIC. All subjects will be patients of the University of Illinois, Chicago, Hospital.

### **What is the purpose of this research?**

We want to learn more about the dental needs of pediatric patients who undergo chemotherapy. We are trying to learn what type of dental care is provided to these pediatric oncology patients and how we can help pediatric oncology patients receive proper dental care. The purpose of the interview will be to identify your attitudes about dental care, if your child has received or will receive dental treatment during cancer therapy, and the barriers and facilitators you identify to obtaining dental treatment for your child during chemotherapy.

### **What procedures are involved?**

This research will be performed at the University of Illinois, Chicago Outpatient Care Centers. The research will take place in a private, closed examination room.

You will need to participate in the study once, and will not be asked any further questions after the interview is completed. You will be asked to complete a demographic survey prior to the interview. The interview will take approximately 20-25 minutes to complete. You will be asked open-ended questions regarding any dental care your child has received prior to and during cancer diagnosis, and what your opinions are regarding dental care.

The interview will be audiotaped. The tapes will be transcribed and all names removed from the transcripts.

The interview will be held prior to or after your child's visit with the oncologist. Only you, your child, and me, the principal investigator, will be present.

If your child needs dental treatment, or if you wish a dental referral or consultation, or if you do not have a dental home, a referral to the UIC College of Dentistry, Pediatric Dentistry Department, will be provided.

### **What are the potential risks and discomforts?**

A 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).

Your child's chemotherapy treatment will be discussed during the interview. If this creates any feelings of distress or discomfort, please notify the researcher (me) and the interview will be terminated. You do not have to complete the interview once it has begun.



**Are there benefits to taking part in the research?**

Taking part in this research study will not benefit you personally, but we may learn new things that will help others. By participating in this study, we will learn what the challenges are in receiving dental treatment for your child. The information that you will provide to us, will help us address the challenges you have in hopes of making it easier for children with cancer to receive dental treatment.

**What other options are there?**

You have the option to not participate in this study.

**What about privacy and confidentiality?**

The people who will know that you are a research subject are members of the research team. . Otherwise information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare or if required by law.

Study information which identifies you and the consent form signed by you will be looked at and/or copied for checking up on the research by the University Office for the Protection of Research Subjects.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

Audiotaped recordings will be kept on a protected file on a privacy secured database computer of the University of Illinois, Chicago. After completion of this study, all audiotaped material will be permanently destroyed. The only persons that will hear and read the audiotaped recordings are members of the research team.

**What are the costs for participating in this research?**

There are no costs to you for participating in this research.

**Will I be reimbursed for any of my expenses or paid for my participation in this research?**

You will not be offered payment for being in this study.

**Can I withdraw or be removed from the study?**

If you decide to participate, you are free to withdraw your consent and discontinue participation at any time. You have the right to leave a study at any time without penalty.



The Researchers also have the right to stop your participation in this study without your consent if: They believe it is in your best interests and/or feel that you do not meet the criteria for this research study.

### **Who should I contact if I have questions?**

Contact the researchers Denise Maniakouras, DDS, Sahar Alrayyes, DDS at (312)996-7530 or (312) 996-6414 or email address: [dmania2@uic.edu](mailto:dmania2@uic.edu) or [salray1@uic.edu](mailto:salray1@uic.edu)

- if you have any questions about this study or your part in it,
- if you have questions, concerns or complaints about the research.

### **What are my rights as a research subject?**

If you feel you have not been treated according to the descriptions in this form, or 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](mailto:uicirb@uic.edu).

### **Remember:**

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

### **Signature of Subject or Legally Authorized Representative**

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Signature of Person Obtaining Consent

\_\_\_\_\_  
Date (must be same as subject's)

\_\_\_\_\_  
Printed Name of Person Obtaining Consent



**APPENDIX B****Dental Care of Pediatric Oncology Patients**

- 1. My highest level of education is:**
  - a. Completed Elementary/Grade School
  - b. Some High School
  - c. Completed High School
  - d. Some College
  - e. Completed College Degree or Greater
  
- 2. My marital status is:**
  - a. Single Parent, Separated, Divorced, or Widowed—little help with parenting
  - b. Spouse- helps with parenting
  - c. Family or other helps considerably with parenting
  
- 3. What is your child's ethnic background? (circle all that apply)**
  - a. Caucasian
  - b. African-American
  - c. Hispanic
  - d. Asian
  - e. Asian Indian
  - f. Other
  
- 4. What type of insurance does your child have?**
  - a. Private
  - b. Medicaid/Public Aid/government insurance
  - c. None
  
- 5. How many children are under the age of 12 in your home?**
  - a. 1-3 children
  - b. 4-6 children
  - c. more than 6 children



## APPENDIX C

Hi. My name is Denise. Is it ok for me to call you Mrs. Mendoza? And what is your child's name, Tommy? Ok, Mrs. Mendoza and Tommy, as we discussed my name is Denise and I'm going to be asking about the health of Tommy's mouth and teeth, and about how that fits into his overall treatment. I've turned on the tape recorder so that I can remember what we say here. Is it ok with you for me to tape record our conversation? (wait for reply) Do you have any questions for me?

1. Tell me about Tommy's chemotherapy. How has it been going?
2. I'd like to talk a bit about dental health. Tell me how you decide whether a child's mouth and teeth are healthy. What do you notice that makes you think everything is ok, or that something is wrong?
3. Tell me about your views on healthy teeth and mouth. (Prompt: What makes it important for your child's mouth to be healthy? Prompt: how important does his/her healthy mouth seem when you compare it to all your other concerns?)
4. Tell me everything you remember about what your child's doctor/oncologist said to you about Tommy's mouth and teeth?
5. Tell me everything you remember about what your child's doctor/oncologist said to you about dentists?
6. Tell me your views on dentists for children like Tommy. What is your experience with them?
7. Tell me about how necessary dentists are for children like Tommy. Tell me about your child's dentist. (Elicit: is the dentist a pediatric dentist or a family dentist? How did they find this dentist?) When was the last time Tommy saw this dentist?
8. Tell me about the health of Tommy's mouth since he began treatment at this clinic. (Prompt) Have you noticed any changes in his mouth or teeth?(Prompt) Does he have any pain or dry mouth? Any other problems?
9. Tell me if a dentist has been helping Tommy with any of these problems.
10. What things get in the way of Tommy getting to the dentist?
11. What do you think would make it easier for Tommy to see a dentist?



## APPENDIX D

### 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)**

February 7, 2013

Denise Maniakouras, BS, DDS  
Pediatric Dentistry  
801 S. Paulina St.  
chicago, IL 60612  
Phone: (708) 969-0029

**RE: Protocol # 2013-0009**  
**“Perceived Barriers and Facilitators to Dental Treatment Among Caregivers of Children with Cancer”**

Dear Dr. Maniakouras:

Your Initial Review (Response to Modifications) was reviewed and approved by the Expedited review process on February 6, 2013. You may now begin your research.

Please note the following information about your approved research protocol:

**No research activities involving human subjects may be initiated, including but not limited to recruitment, enrollment, and data collection, until receipt of Cancer Center-Protocol Review Committee (CC-PRC) approval. If the CC-PRC recommends changes to the research as a result of their review, an amendment must be submitted to the UIC IRB for review and approval.**

<b><u>Protocol Approval Period:</u></b>	February 6, 2013 - February 6, 2014
<b><u>Approved Subject Enrollment #:</u></b>	40
<b><u>Performance Sites:</u></b>	UIC
<b><u>Sponsor:</u></b>	None
<b><u>Research Protocol:</u></b>	

a) Perceived Barriers and Facilitators to Dental Treatment Among Caregivers of



Children with Cancer; Version #2, January 24, 2013

**Recruitment Material:**

- a) Recruitment Script with verbal Assent language; Version #2, January 24, 2013
- b) Flyer; Version #2, January 24, 2013

**Informed Consent/Parental Permission:**

- a) Waiver of Informed Consent for Recruitment Purposes [45 CFR 46.116(d)]
- b) Consent/Parental Permission; Version #3, January 24, 2013

**HIPAA Authorization:**

- a) Waiver of Authorization for Recruitment Purposes [45 CFR 164.512(i)(1)(i)]

**Additional Determinations for Research Involving Minors:**

The Board determined that this research satisfies 45 CFR 46.404, research not involving greater than minimal risk. Therefore, in accordance with 45 CFR 46.408, 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 45 CFR 46.409. If you wish to enroll Wards of the State contact OPRS and refer to the tip sheet.

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

**(6)** Collection of data from voice, video, digital, or image recordings made for research purposes.

**(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
01/02/2013	Initial Review	Expedited	01/04/2013	Modifications Required
02/04/2013	Response To Modifications	Expedited	02/06/2013	Approved

Please remember to:

→ Use your **research protocol number** (#2013-0009) on any documents or correspondence with the IRB concerning your research protocol.



→ Review and comply with all requirements on the enclosure,  
**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**  
 (<http://tiger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf>)

**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) 413-3202. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Teresa D. Johnston, B.S., C.I.P.  
 Assistant Director  
 Office for the Protection of Research Subjects

Enclosures:

- 1. UIC Investigator Responsibilities, Protection of Human Research Subjects**
- 2. Informed Consent/Parental Permission:**
  - a) Consent/Parental Permission; Version #3, January 24, 2013
- 3. HIPAA Authorization:**
  - a) Certificate of Waiver of Authorization for Recruitment Purposes [45 CFR 164.512(i)(1)(i)]
- 4. Recruiting Material:**
  - a) Recruitment Script with verbal Assent language; Version #2, January 24, 2013
  - b) Flyer; Version #2, January 24, 2013

cc: Indru C. Punwani, Pediatric Dentistry, M/C 850  
 Sahar Alrayyes, Faculty Sponsor, Pediatric Dentistry, M/C 850  
 Privacy Office, Health Information Management Department, M/C 772



## APPENDIX E



914 S. Wood St. (M/C 700)  
Room 318 MCA

Robert Molokie, MD, Chair  
Meha Singh, MS, Quality Assurance

February 15, 2013

Sahar Alrayyes, D.D.S.  
Assistant Professor  
Department of Pediatric Dentistry

RE: PRC # 2013-0007

Decision: Approval

Dear Dr. Alrayyes:

This letter is to inform you that the University of Illinois Cancer Center Protocol Review Committee (CC-PRC) administratively approved your protocol entitled, **"Perceived Barriers And Facilitators To Dental Treatment Among Caregivers Of Children With Cancer"** on February 14, 2013.

If you have not already done so, you may now submit this protocol to the UIC Institutional Review Board (IRB). Please enclose a copy of this letter.

Thank you for your attention to this letter. Please feel free to contact Meha Singh at 312-355-3046, if you have questions.

Sincerely,

A handwritten signature in black ink, appearing to read 'R. Molokie'.

Robert Molokie, M.D.  
Chair  
University of Illinois Cancer Center  
Protocol Review Committee

UIC

Phone (312) 355-4226 Fax (312) 355-1085



## **VITA**

**NAME:** Denise Maniakouras

**EDUCATION:** B.S. Biology  
University of Illinois  
Chicago, IL, 2007

Doctor of Dental Surgery  
University of Illinois, Chicago  
Chicago, IL, 2011

Specialty Certificate  
University of Illinois, Chicago  
Chicago, IL, 2013

**TEACHING EXPERIENCE:** Resident and Teaching Assistant  
Department of Pediatric Dentistry  
University of Illinois, Chicago,  
2012

**HONORS:** Frances Best Watkins Award  
Hellenic American Dental Society  
Scholarship  
General Assembly Scholarship

**PROFESSIONAL MEMBERSHIP:** American Academy of Pediatric  
Dentistry  
American Dental Association  
Illinois Society of Pediatric  
Dentists  
Illinois State Dental Society  
Chicago Dental Society  
Hellenic American Dental Society