

**PARENTAL PERCEPTION OF ORAL HEALTH EXPERIENCES FOR
MEDICALLY COMPROMISED CHILDREN: EVALUATING THE ROLE OF
IN-HOUSE HOSPITAL DENTAL SERVICES**

A Thesis

by

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ABSTRACT

The purpose of this study was to determine if children with complicated medical conditions, requiring coordination of care between a dentist and physician, had better oral health experiences if their primary hospital contained in-house dental services.

A 20 question survey was sent to 609 parents of children diagnosed with blood disorders, cancers or solid organ transplants who received their medical care at one of two tertiary care pediatric hospitals: one with an in-house dental service (Children's Medical Center Dallas-CMCD) or one without (Phoenix Children's Hospital-PCH).

The study yielded 172 (28.2 percent) completed surveys—85 patients from CMCD and 87 patients from PCH. Overall, 22.7 percent of parents reported that they had difficulty getting dental care that they or their physician believed was necessary. The primary barrier to care was parents did not know where to find a dentist willing to treat their child because of his or her medical condition. Children who received medical care at CMCD were 2.85 times less likely to have difficulty getting dental care than children treated at PCH ($p<0.02$). Additionally, children who received their dental care at CMCD were three times more likely to have an easier time getting care compared to those seen at a private dental office ($p<0.05$). Overall, Spanish speaking families were 2.1 times more likely to have unmet dental needs ($p<0.05$) and 2.31 times more likely to have difficulty getting dental care ($p<0.02$) than English speaking families.

The data suggest that children with complicated medical conditions may have better oral health experiences if their primary medical hospital has an in-house dental service.

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CHAPTER I

INTRODUCTION AND LITERATURE REVIEW

Children with special health care needs (CSHCN) as defined by the Maternal and Child Health Bureau (MCHB) are those children, “who have or are at increased risk of developing a chronic physical, developmental, behavioral or emotional condition and who require health-related services of a type or amount beyond that required by children generally.”¹ Based on this definition of CSHCN, the most recent available national data in 2011 show that more than 19.8 percent (14.5 million) of the United States pediatric population is considered to have a special health care need, which represents an 11 percent increase since 2003.² With ongoing advancements in medical care, these rates are only expected to rise. Children with complicated medical conditions are living longer and thereby increasing the need of secondary and tertiary care services. In fact, over the last three decades the life expectancy for CSHCN has improved to such a degree that 90 percent of CSHCN now live past their 20th birthday.³ For example, five-year survival rates of children diagnosed with acute lymphoblastic leukemia have increased from less than 10 percent in the 1960s to almost 90 percent due to improvements in treatment regimens.⁴ In addition to medical advancements, deinstitutionalization of more than 75 percent of individuals with intellectual/developmental disabilities in the past 30 years has also contributed to the increased number CSHCN seeking health care in the community.⁵ A 2002 survey of dental pediatric residency programs reported that over the course of five years the

number of CSHCN seen in their clinics had increased by 54 percent.⁶ While these children typically receive the appropriate health services related to their primary diagnosis, some other basic health care needs, such as dental care, are sometimes lost in the shuffle.

The limited literature on oral health status of CSHCN suggests that they have poorer oral health outcomes compared to children without special needs. Results from screenings of Special Olympics participants suggest that CSHCN have both more dental problems and more untreated dental disease than their peers.⁷ Among children with more severe special needs, Nelson et al. discovered that almost 20 percent had an unmet dental need.⁸ The reasons for worse oral health among CSHCN are multi-factorial and not limited to the child's medical disability alone.⁹ Some of the primary reasons include lack of financial resources, dependence on parent or caregiver for daily oral hygiene, compromised immunity, special diets or medications that exacerbate poor oral health, and developmental delays that make behavior management challenging.⁹

The United States Surgeon General's report in 2000, identified CSHCN among those groups who are experiencing difficulty gaining access to dental care in the United States.¹ Interestingly, the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) reported that one of the most commonly needed but not received health services among CSHCN was dental care: more than 5.4 percent of CSHCN needed, but did not obtain this service.¹⁰ Although this percentage has decreased from the 2001 and 2005 NS-CSHCN reports, dental care is still one of the most common unmet health needs, second only to mental health services.¹¹ It has been

well established that untreated oral disease can lead to pain, abscesses, systemic health problems, school absences due to illness, hospitalization and other social and health disturbances.¹²⁻¹⁵ With poorer oral health status being reported in CSHCN, there is an increased urgency to address the oral health deficiencies endured by this vulnerable population.^{16, 17}

Unfortunately, the literature shows that the supply of providers equipped to treat CSHCN is not meeting the demand. According to a preliminary analysis by Kerins et al. in 2009, the United States oral health delivery system as it currently exists has extremely limited capacity to care for the increasing number of CSHCN. The ratio of CSHCN to potential available and able dental providers in the United States was an alarmingly high 1,792 children per provider.¹⁸

Many general dentists are reluctant to treat CSHCN due to various factors: insufficient pre-doctoral training, inadequate reimbursement rates, lack of trained personnel, challenging behavior management and time consuming care.¹⁹ These barriers make it difficult to identify general dentists willing to treat CSHCN. In a 2001 national survey of general dentists, Casamassimo et al. found that approximately 70 percent of general dentists rarely or never treat CSHCN. This is not surprising given that only 25 percent of those surveyed had hands-on experience working with CSHCN in dental school.²⁰ Management of the dental needs for these patients requires a working understanding of complex medical conditions and medications not normally encountered in routine practice. Providers who attempt to deliver high quality care to CSHCN report that it is very time-consuming because of the need for multiple medical consultations.

Inadequate pre-doctoral training compounded by medical complexities and poor reimbursement rates create a system that gives little incentive for private general dentists to treat CSHCN. As a result, this responsibility has fallen predominantly on pediatric dentists and institutions such as dental schools and hospitals, who have received more exposure to CSHCN and have advanced training in behavior management, sedation and general anesthesia.

Although pediatric dentists are trained and willing to see CSHCN, they have limited capacity. While 95 percent of pediatric dentists report routinely treating CSHCN, there are only 5,953 practicing pediatric dentists across the United States. If pediatric dentists allotted 10 percent of their total appointments to CSHCN, only 31 percent of all CSHCN would have access to one dental appointment per year. This means that the number of pediatric dentists in the workforce would need to triple in order to meet the dental needs of CSHCN.¹⁸

With the number of CSHCN growing and a limited number of private practitioners able and willing to provide dental care, hospital dental services have become the source of care for many of these children. Especially for CSHCN that live with complicated medical conditions, a hospital setting may be the only opportunity to receive quality dental care. However, while there are many children's hospitals that operate throughout the United States, not all provide dental services. In fact, less than 40 percent of children's hospitals providing major tertiary medical care have comprehensive dental clinics that provide preventative, routine and some specialized care.²¹ To make matters worse, these hospitals with comprehensive dental clinics are

spread unevenly across the country with seven states having 49 percent of them. Excluding California and Texas, only 17 children's hospitals with comprehensive dental clinics exist west of the Mississippi River.¹⁸ For children that live with complicated medical conditions, but do not have access to a hospital with an in-house dental service, the question of their perceived quality of dental care remains largely unexplored. Currently there are no published studies that compare the oral health experiences of CSHCN who have access to a hospital with an in-house dental service versus those CSHCN that do not.

The goal of this study was to determine whether children with complex medical conditions, requiring coordination of care between dentist and physician, have better oral health experiences if their primary hospital contains in-house dental services. To answer this question, two tertiary care pediatric hospitals were included in this study: Children's Medical Center Dallas, Texas (CMCD) which has an in-house dental service and Phoenix Children's Hospital, Arizona (PCH) which currently does not. The target population were parents of children who have medical conditions that require significant cross communication between the dentist and physician. The authors tested the null hypothesis that there is no difference in parent perception of oral health experiences in children with complex medical conditions that receive their medical care at CMCD vs PCH.

CHAPTER II

SUMMARY AND CONCLUSIONS. PARENTAL PERCEPTION OF ORAL HEALTH EXPERIENCES FOR MEDICALLY COMPROMISED CHILDREN: EVALUATING THE ROLE OF IN-HOUSE HOSPITAL DENTAL SERVICES

Introduction

Children with special health care needs (CSHCN) face unique challenges to maintaining good oral health. With recent medical advancements, many children are now living with complex medical conditions that increase oral health risks, compete for monetary resources and limit access to dental care. Therefore, it is reasonable to anticipate that many of these children will develop dental needs during their childhood creating a relatively new challenge for existing dental providers. The literature suggests that the dental health care system as it currently exists lacks the capacity to meet the needs of the growing CSHCN population. As suggested by Casamassimo²¹, the ideal oral health care system for CSHCN should be accessible, affordable and staffed by competent providers that are knowledgeable about their oral health needs. Theoretically, it would appear that hospital dental clinics would be best equipped to care for these children because they tend to be staffed by dentists who:

1. Have access to the medical physicians records—integrated care;
2. Are familiar working with this population—experienced;
3. Can offer more payment mechanisms to cover costs—affordable, and

4. Are located in the child's hospital—accessible.

However, with only 40 percent of major tertiary pediatric hospitals providing comprehensive dental services, the majority of children with complex medical conditions do not have the option of getting their dental care at a dental clinic within their primary hospital.¹⁸ The question of where, how often and to what satisfaction level are these children getting dental care remains largely unexplored. Currently there are no published studies that compare the oral health experiences of CSHCN who have access to a hospital with an in-house dental service versus those CSHCN that do not.

The goal of this study was to determine whether children with complex medical conditions, requiring coordination of care between dentist and physician, have better oral health experiences if their primary hospital contains in-house dental services. The target population was parents of children who have medical conditions that require significant cross communication between the dentist and physician. The authors tested the null hypothesis that there is no difference in the parents' perception of oral health experiences in their children with complex medical conditions who receive their medical care at a hospital that contains in-house dental services versus one that does not.

Materials and Methods

All study procedures and the survey instrument were approved by the governing institutional review boards of Children's Medical Center Dallas, Phoenix Children's

Hospital and Texas A&M University College Station. Institutional Review Board approval required chiefs of each department to be on the IRB.

Patient Selection

Children with complex medical conditions that required significant communication between physician and dentist were selected as the target population. Of the multiple potential medical conditions, children with blood disorders, cancer and organ transplants were selected for the study for the following reasons:

1. They are relatively common chronic complex medical conditions among children;
2. They require significant communication between physician and dentist and failure to do so could significantly compromise health outcomes; and
3. Many tertiary pediatric hospitals see high volumes of children with these diagnoses.

Coagulation Disorders

This group was composed of children with inherited bleeding disorders (ie. Hemophilia A, Hemophilia B and Von Willenbrand Disease), since other acute blood disorders are not followed long-term and may not necessitate dental treatment during their short course. In contrast, patients with inherited bleeding disorders may be at increased risk of significant bleeding from invasive dental procedures for their entire life and therefore require competent dentists that can manage their dental care. Fear of inducing bleeding in the oral cavity can contribute to oral hygiene neglect, which only leads to more oral disease. Dental treatment involving nerve blocks, extractions, and

invasive scaling require appropriate hematologic consults and careful technique, otherwise the patient's hematologic status is at risk of being significantly compromised.

Leukemia

Oral health status is compromised in patients with leukemia and affected children require dental care before, during, and after the course of treatment. Common oral conditions include poor wound healing, increased rate of decay, opportunistic infections, gum abscess, recurrent herpetic stomatitis, xerostomia and mucositis. Oral complications can compromise the protocols of chemotherapy and thereby directly affect patient survival. Access to a knowledgeable dentist who understands when and how to properly manage patients with leukemia is essential to minimize pain and discomfort and improve quality of life.

Solid Organ Transplant (SOTP)

Communication between the organ transplant team and dentist is important to reduce the incidence of pre- and post-transplant complications. Odontogenic inflammation and infections can compromise successful organ transplant, especially since most of these patients are immunosuppressed. Currently, patients on the waiting list for organ transplant must be evaluated and cleared by a dental professional, with the goal of stabilizing his or her oral health prior to transplantation. If a patient is unable to find a dentist comfortable to provide either the treatment or clearance, the transplant surgery may be delayed. In addition, consultation with the patient's physician is necessary to ensure appropriate timing for dental treatment, stable patient laboratory values and proper usage of medications and/or alterations in medications.

Hospital Selection

Two tertiary care pediatric hospitals were included in this study: Children's Medical Center Dallas, Texas (CMCD) which has an in-house dental service and Phoenix Children's Hospital, Arizona (PCH) which currently does not. These hospitals were chosen for the following reasons:

1. Both are the major tertiary care children's hospital in their respective metropolitan cities;
2. Each hospital saw enough medically complex children to warrant having independent hematology, oncology and solid organ transplant departments; and
3. Cities appeared to be comparable with respect to numbers of pediatric dental specialists available and demographic variables.

Survey Development

A 20 question ad hoc survey was developed by the authors using previous literature for question content and modified validated questions from the Oral and Craniofacial Data Resource Center and the survey instrument used in the Nelson et al. 2011 study. Face validity of the survey was established by having experts in the field (pediatric dental residency faculty, physicians and statisticians) evaluate the questionnaire and make revisions. The survey was then translated into Spanish by a certified hospital Spanish translator. The authors pre-tested the questionnaire for internal consistency at the CMCD dental clinic on 25 English speaking and 25 Spanish speaking dental patients that were not

included in the study. Revisions were made to questions that were found to be confusing, had inconsistent responses or caused frequent data entry errors.

Study Procedures

In order to better homogenize the patient sample, the criteria were narrowed within each medical condition to include specific diagnoses and treatment time frames. A patient population was generated by searching patient rosters in each hospital for the following ICD-9-CM codes.

Coagulation Disorders Criteria

1. Patient had a diagnosis of Hemophilia A (ICD9 286.0), Hemophilia B (ICD9 286.1) or Von Willebrand's disease (ICD9 286.4);
2. Patient's age ranged between three and 12 years old; and
3. Family spoke English or Spanish.

Organ Transplant Criteria

1. Patient had diagnosis of Kidney Transplant (ICD9 996.81) or Liver Transplant (ICD9 996.82);
2. Patient was diagnosed between June 2012 and June 2015; and
3. Family spoke English or Spanish.

Oncology Criteria

1. Patient has a diagnosis of Acute Lymphoid Leukemia (ICD9 204.00 or ICD9 204.01) or Acute Myeloid Leukemia (ICD9 205.00 or 205.01);
2. Patient was diagnosed between June 2012 and June 2015;
3. Pt was \geq two years old at time of diagnosis; and

4. Family spoke English or Spanish.

The survey and cover letter were mailed to the parents of each child in the database who met the study inclusion criteria. Returning completed surveys was considered as consent to participate in the study. If no response was received within two weeks, one follow-up telephone call was made to the parents to see if he or she would rather complete the survey by phone.

Data Analysis

The data were entered and analyzed using SAS 9.3 edition. First, multiple logistic regression models were built to compare outcomes for children who received their medical care at CMCD and PCH, when controlling for language, payer source, medical diagnosis, area of residence and travel time to hospital. Second, children who sought dental care at a dental clinic associated with a hospital were compared on outcomes to children who usually sought dental care at a private dental office by constructing multiple logistic regression models and then controlling for language, payer source, medical diagnosis, area of residence and travel time to hospital. Finally, bivariate analysis was conducted to test for differences between English and Spanish speakers on different outcomes irrespective of primary hospital designation.

Results

A total of 609 families received a survey via mail or a phone call; 172 surveys were completed, representing an overall response rate of 28.2 percent. Sixty-eight

responses were received by mail and 104 by phone. Eighty-seven surveys were received from PCH (response rate 33 percent) and 85 (response rate 24 percent) from CMCD.

(Table 1)

The distribution of diagnoses were: 42 percent (n=73) had leukemia, 32 percent (n=55) had a solid organ transplant and 26 percent (n=44) had a chronic coagulation disorder. The majority of children were male (60 percent). Most children came from English speaking homes (67 percent, n=118) with the remaining third coming from Spanish speaking households. Ninety percent (n=115) of the sample was covered by a private or public insurance plan that would pay for at least some part of the child's dental bills. The majority of children (75 percent, n=125) lived less than one hour away from their primary hospital, while 16 percent (n=27) traveled from one to two hours away, and the remaining nine percent traveled greater than two hours. Correspondingly, those families that lived in metropolitan areas represented 74 percent of the sample, while the remaining 26 percent lived in small towns/rural areas. Of the 85 children who received their medical care at CMCD, only 29 (34 percent) received their dental care at CMCD's in-house dental clinic, while the other two-thirds received dental care in a private dental office. At PCH, 94 percent received dental care at a private office, which was expected considering that PCH did not have an in-house dental service.

The raw data not adjusted for potential confounding variables showed that at PCH, 87 percent of parents perceived their child's oral health as excellent/good/average vs 95 percent at CMCD; 83 percent saw their dentist at least once a year vs 93 percent at CMCD; 77 percent were very or somewhat satisfied with the care they receive vs 89

percent at CMCD; 83 percent did not have an unmet dental need vs 90 percent at CMCD; 61 percent reported it to be very easy or easy to get dental care vs 65 percent at CMCD; 72 percent had never had difficulty getting dental care that they or their physician believed was necessary vs 82 percent at CMCD.

Outcomes

The dependent outcome variables considered in the analyses included:

1. Parent reported oral health status (excellent/good/average vs not good/very poor);
2. Frequency of dental visits (at least once/year vs less than once/year);
3. Parent reported satisfaction rates (very satisfied/somewhat satisfied vs neutral/somewhat dissatisfied/very dissatisfied);
4. Currently has unmet dental needs (yes vs no);
5. Parent reported ease of access (very easy/easy vs neutral/somewhat easy/not easy);
6. Dental infection during course of medical treatment (yes vs no);
7. Difficulty getting dental care that parent or physician thought was necessary (yes vs no);
8. Time waited to get a dental appointment (< two weeks vs > two weeks); and
9. Medical doctor recommended child to be seen by dentist (yes vs no).

Logistic regression analyses are summarized in Tables 2 and 3 and depicted in Figures 1, 2 and 3 for outcome variables that demonstrated a statistically significant difference between the two groups. Since only about a third of patients at CMCD

received their dental care at CMCD's in-house dental clinic, two logistic regression models were created: one comparing PCH patients with CMCD patients (Table 2) and another comparing patients treated at CMCDs in-house dental service vs all children from both PCH and CMCD treated in a private practice setting (Table 3).

PCH vs CMCD

Results from models for each outcome measure, adjusting for language, payer source, medical diagnosis, area of residence and travel time to hospital, indicated that parents of children treated at PCH were 3.58 times more likely to say that their child had unfavorable (not good/very poor) oral health than parents whose children were treated at CMCD ($p < .05$). In addition, parents of children at PCH were 2.85 times more likely to have difficulty getting dental care that they or their physician believed was necessary compared to children treated at CMCD ($p < .02$). For all other outcome measures, while the odds ratios favored children seen at CMCD, there was no statistical significance associated with those trends (Table 2).

Private Dental Office vs Hospital Dental Clinic Logistic Regression

When comparing those who received their dental care at CMCD's dental clinic versus those who received dental care at a private office, irrespective of their primary medical hospital, the following significant differences between the two groups were found:

1. Children treated at an in-house hospital dental clinic were 3.04 times more likely to have an easier time getting dental care than children treated at private dental offices ($p < 0.051$);

2. Children treated at private dental offices were 6.02 times more likely to have to wait longer than two weeks to see a dentist compared to children treated at in-house hospital dental clinics ($p<0.02$); and
3. Children seen at an in-house hospital dental clinics are 2.6 times more likely to have their medical doctor recommend they see a dentist than children who get their dental care at a private dental office ($p<0.05$)

For all other outcome measures, while the odds ratios favored children seen in CMCD's in-house dental clinic, there was no statistical significance associated with those trends (Table 3)

Barriers to Dental Care

Twenty-three percent ($n=39$) of parents reported that they had difficulty getting dental care that they or their physician believed was necessary. When asked to select the most common reasons their child had difficulty getting dental care, the order of most frequently reported barrier to least frequently reported barrier was: medical condition (52 percent), finances (26 percent), behavior (eight percent), didn't have time (eight percent) or lacked transportation (six percent) (Figure 4). There were significantly fewer parents at CMCD who reported medical condition as a barrier compared to those whose children receive their medical care at PCH ($p<0.02$).

English vs Spanish Bivariate Analysis

Differences in outcome measures were compared between English and Spanish speaking households, irrespective of their primary hospital. We found that Spanish speaking households were 2.1 times more likely to have unmet dental needs ($p<0.05$),

2.25 times less likely to have easy access to dental ($p < 0.01$), 2.31 times more likely to have difficulty getting dental care that the parents or physician believed was necessary ($p < .02$) and 5.65 times more likely to wait longer than two weeks to see a dentist ($p < .0001$). Interestingly, Spanish-speaking families were 2.34 times less likely to get their dental care at a private dental office than English-speaking families ($p < 0.02$).

Discussion

This study intended to determine if children with complex medical conditions, requiring coordination of care between dentist and physician, had better oral health experiences as perceived by their parents if their primary hospital contained in-house dental services. In addition to physicians, dentists and nurses, parents play an important role in the overall delivery of health care for their child. Parent perceptions and perceived access to care may differ from those believed by health care providers and policy makers. Understanding parents' experiences obtaining oral health care for their children is key to developing the appropriate systems that will ensure patient centered care. While studies exist that characterize the oral health status of CSHCN as a whole, this pilot investigation is the first of its kind to compare oral health experiences focusing on children with complex medical conditions whose primary medical hospital offers dental services and those whose hospital does not.

Our survey targeted the more medically complex subpopulation of CSHCN, whose diagnoses often require cross communication between physician and dentist—chronic blood disorders, cancer and solid organ transplants. Failure to obtain appropriate dental care could result in significant negative health outcomes for these patients. Of note, our patient population did not include CSHCN that were developmentally delayed, and therefore our data cannot be generalized or extrapolated to those children with intellectual disabilities, many of whom present with more behavioral challenges at dental appointments.

Our finding that parents of children from CMCD were 2.85 times less likely to have difficulty getting dental care that they or their child's physician believed was necessary suggests that patients whose primary hospital had an in-house dental service did not have as many perceived barriers to dental care, regardless of whether or not they chose to receive dental care at their hospital. It is possible that for children that have difficulty finding care with pediatric and general dentists in the community, the hospital dental clinic served as an alternative option that facilitated access.

While it was anticipated that most children treated at PCH would receive their dental care at private dental offices, it was not expected that only one-third of children that got their medical care at CMCD also got their dental care at CMCD. It was surprising to find that the majority of CMCD patients received their dental care at private dental offices despite the fact that their primary hospital offered dental services.

Interestingly, when comparing children that received their dental care at CMCD's in-house dental clinic versus children from PCH and CMCD that went to

private dental offices, there were no longer any statistically significant differences in perceived oral health status and difficulty getting dental care. One possible explanation for this shift, is that the two-thirds of children that received their medical care at CMCD and received dental care at a private office may have already established a dental home prior to their medical diagnosis and therefore had less difficulty obtaining care as well as better perceived oral health status.

It appears that while most parents were satisfied with dental care at private offices, they felt like that care was not as easy to access ($p < .051$) and they waited longer for it ($p < .02$) compared to parents whose children were seen at hospital dental clinics. Such results suggest that while it is certainly possible to find private practice providers who will adequately care for medically compromised children, it may take more time to locate them, which makes sense given the shortage of providers who see CSHCN and take their insurance.

The finding that children seen at CMCD's dental clinic were 2.6 times more likely to have their medical doctor recommend they see a dentist than those children who get dental care at a private practice indicates that physicians may play an important role in determining where their patients receive dental care. Providing resources for medical specialists to educate patients on how to access dental care at their hospital and within the private practice setting could be of great service to their patients.

For all other outcome variables, there were no statistically significant differences between the children seen in an in-house hospital clinic vs private practice. However, for every single outcome variable the odds ratios favored obtaining dental care at a hospital

dental clinic. While these data supported our hypothesis, it is important to note that most children at PCH had positive oral health experiences, as 87 percent of parents reported their child's oral health as excellent/good/average, and 77 percent were very or somewhat satisfied with the care they receive.

Consistent with previous literature, this study incidentally found that parental limited English proficiency was a significant risk factor for poor oral health outcomes among CSHCN. The isolated nature of private dental offices removes oral health from general health system considerations and may serve as an added challenge to Spanish speaking families who already face significant barriers to access. Making efforts to integrate systemic and oral health systems mitigates the challenges of navigating two independent, complicated health delivery systems.

This pilot study was able to successfully gather information from a patient population that can be difficult to access to collect research data. It was our experience that understanding and complying with the special ethical and regulatory protections for children with complex medical conditions was more challenging than conducting research with healthy children in general.

Limitations/Weaknesses

The data gathered was limited by the nature of the survey methodology. Since questionnaires were sent from each patient's primary hospital, parents may have felt pressured to answer responses in a way that was favorable to each hospital, thereby introducing a social desirability bias. Additionally, it was not possible to assess and control for the degree to which the children were afflicted by their medical diagnosis. In

order to keep the survey short to enhance response rate, it was not possible to control for all potentially confounding variables including marital status, parent's education and dental home status. Since this study lacks a professionally-determined, clinical component of oral health measures, a definitive estimate of the oral health status was not possible.

Future Directions

While our findings provide a general sense of parent perceived oral health experiences for medically compromised children and the role of hospital dental clinics, further research should be conducted in different sites. It would be beneficial to utilize focus groups to better assess the finer intricacies of oral health experiences that are difficult to capture in cross sectional studies.

Conclusions

Parents of children whose primary hospital had an in-house dental service were less likely to report having difficulty getting dental care and more likely to report favorable oral health status, regardless of whether or not their child received dental care at their hospital's dental clinic.

Parents of children who received dental care at their hospital's dental clinic were more likely to report having an easier time getting dental care and less likely to report having to wait a long period of time to get an appointment.

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APPENDIX A: SURVEY INSTRUMENT

Please circle the letter corresponding to the most appropriate response, fill in the blank if appropriate.

1. How would you describe the health of your child's mouth? Circle one number.

Very Poor	Not Good	Average	Good	Excellent
1	2	3	4	5

 2. How often does your child see a dentist?
 - a. More than once a year
 - b. About once a year
 - c. Once every two or three years
 - d. There are usually more than three years between dental visits
 - e. My child has never seen a dentist (**skip to question 5**)

 3. Where does your child usually receive his or her dental care?
 - a. Private dental office
 - b. Child's School
 - c. Community Health Center
 - d. Dental School
 - e. Dental Clinic associated with a Hospital

3a. If you circled "e", what is the name of the hospital? _____

 4. How satisfied are you with the quality of dental care that your child receives at the dentist? Circle one number.

Very Dissatisfied	Somewhat Dissatisfied	neutral	Somewhat Satisfied	Very Satisfied
1	2	3	4	5

4a. If somewhat dissatisfied or very dissatisfied, please specify why?

 5. Does your child currently have any unmet dental needs (For example, unfilled cavities, infected teeth, untreated gum problems)?
 - a. No
 - b. Yes
 - c. Don't Know

 6. Has your child ever had to go to the emergency room due to a dental infection (for example, a cavity, abscess or facial swelling) that was not related to dental trauma?
 - a. No
 - b. Yes

 7. What is the primary diagnosis for your child's medical condition?
 - a. Bleeding disorder
 - b. Cancer
 - c. Needing or has had a solid organ transplant
 - d. Other _____

7a. What was the date that your child was diagnosed with this medical condition?: _____(Month/Year)
- Please answer the following questions regarding access to dental care **only** since your child was diagnosed.*
8. In your opinion how easy has it been for your child to get dental care? Circle one number.

	Somewhat		Easy	
Not easy	Easy	Neutral	Easy	Very Easy
1	2	3	4	5

 9. Has your medical doctor recommended that your child be seen by a dentist?
 - a. Yes
 - b. No

 10. Were you told to have your child see a dentist before any medical surgery?
 - a. Yes
 - b. No
 - c. My child has not had any medical surgery

11. Has your child ever had a delay in medical treatment because of difficulty obtaining their dental care? (For example, child could not receive an organ transplant due to a delay in getting dental clearance.)
- a. Yes
b. No
12. Has your child developed any dental infection during the course of their medical treatment?
- a. Yes
b. No
13. Has your child ever had difficulty getting dental care that you or their physician believed was necessary?
- a. Yes
b. No (**skip to question 16**)
14. Which of these choices best describes the reason(s) your child had difficulty getting the dental care that you or their physician believed was necessary? (Circle all that apply)
- a. Couldn't afford care
b. Dentist refused to accept family's insurance plan
c. Problems getting to dental office
d. Didn't know where to find a dentist willing to treat my child because of his or her medical condition
e. Was refused services because of child's medical condition
f. Didn't have time or took too long
g. My child cannot behave cooperatively at the dentist
h. Other _____
15. How much of a problem was it that your child was delayed in getting the dental care that you or their physician believed was necessary? Circle a number.
- | | | | | | |
|---------|---|---|---|---|---------|
| Not a | | | | | Big |
| Problem | | | | | Problem |
| | 1 | 2 | 3 | 4 | 5 |
16. When you first decided to see a dentist, how long was it until your child actually saw one?
- a. Less than one day
b. 1-6 days
c. 1 week but less than 2 weeks
d. 2-4 weeks
e. 1-2 months
f. 3 months or more
- 16a. Was this wait longer than you would have liked it?
- | | | | | |
|--------------|--------------|-------------|-------------|--------------|
| A lot | | | Shorter | A lot |
| longer | Longer | About right | than I like | shorter |
| than like it | than like it | | it | than like it |
| | | | | |
| | 1 | 2 | 3 | 4 |
| | | | | 5 |
17. Are you covered by any public or private insurance plan that would pay for any part of your child's dental bills (including Medicaid)?
- a. Yes
b. No
18. What type of insurance do you have?
- a. Private health insurance
b. Medicaid
c. CHIP
d. None
e. Other _____
19. How far do you travel to get to the hospital that treats your child's medical condition?
- a. < 1 hour
b. Between 1-2 hours
c. >2 hours
20. Which of the following best describes the town in which you live?
- a. Metropolitan area (population greater than 500,000)
b. Metro area (population greater than 100,000 and less than 500,000)
c. Small city (population 50,000 to 99,999)
d. Small town (population 20,000 to 49,999)
e. Rural (population less than 20,000)

Other Comments:

<i>Thank you for your participation in this study. Please return the survey in the enclosed, stamped envelope</i>

APPENDIX B: TABLES AND FIGURES

Table 1: Patient Demographics

	Children's Medical Center Dallas	Phoenix Children's Hospital
Attempted to Survey	348	261
Completed Surveys	85	87
Response Rate (percent)	24.4	33.3
DIAGNOSES		
Solid Organ Transplant	21 (24.7)	34 (39.1)
Blood Disorder	24 (28.2)	20 (23.0)
Cancer	40 (47.1)	33 (37.9)
PRIMARY LANGUAGE		
English	47 (55.3)	71 (81.6)
Spanish	38 (44.7)	16 (18.4)
INSURANCE		
Private	31 (36.5)	53 (60.9)
Public	49 (57.6)	32 (36.8)
None	5 (5.9)	2 (2.3)
AREA OF RESIDENCE		
Metropolitan City	57(67.9)	69 (80.2)
Small City/Rural town	27 (32.1)	17 (19.8)
TIME TRAVELED TO HOSPITAL		
<1 hour	60 (73.2)	65 (75.6)
>1 hour	22 (26.8)	21 (24.4)

Cell values are n (percent), unless otherwise specified.

Table 2: Comparison of children who receive their medical care at CMCD vs PCH. Logistic regression model comparing children who receive their medical care at CMCD vs PCH (controlling for language, type of insurance, diagnosis, area of residence [metropolitan area or not] and travel time to the hospital) (Referent Group: CMCD children)

Parameter	P- <value	Odds Ratio	95perce nt CI
Better parent reported oral health status (excellent/good/average vs not good/very poor)	0.05	3.582	1.03, 12.45
See dentist more frequently (at least once/year vs once/2 or more years)	0.10	2.629	0.829, 8.228
Better parent reported satisfaction (very satisfied/somewhat satisfied vs neither satisfied nor dissatisfied/somewhat dissatisfied/very dissatisfied)	0.38	1.562	0.572, 4.264
Less likely to have Unmet dental Needs	0.52	1.32	.571, 3.05
Better parent reported ease of access (very easy/easy vs neutral/somewhat easy/not easy)	0.37	1.397	.675, 2.890
More likely to have medical doctor recommends child see dentist	0.71	1.145	.566, 2.317
Less likely to have dental infection during course of medical treatment	0.18	3.5	.55, 4.2
Less likely to have difficulty getting dental care that parent or physician believed was necessary	0.02	2.85	1.2, 6.76
Less likely to wait longer than 2 weeks for dental care	0.62	1.22	.559, 2.67

Figure 1: Visual Representation of Table 2

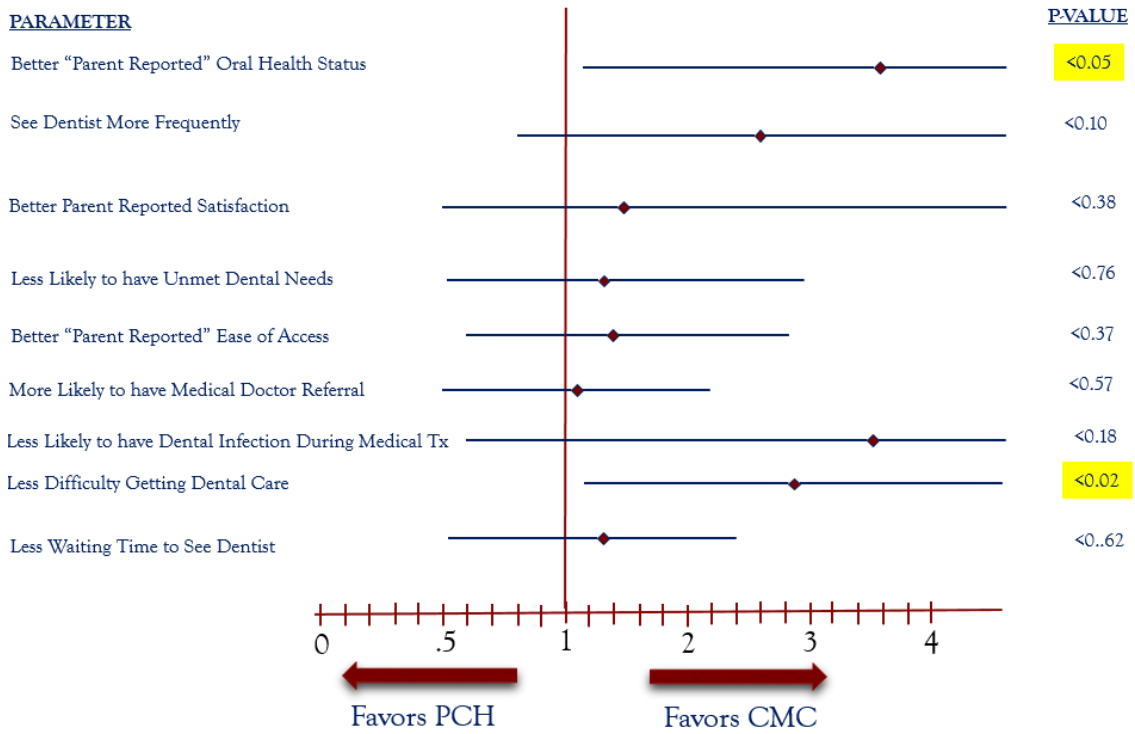


Table 3: Comparison of children who receive their dental care at hospital dental clinic vs private practice.

Logistic regression model comparing children who receive their dental care at CMCD's In-house Dental Clinic vs Private Dental Practice (controlling for language, type of insurance, diagnosis, area of residence [metropolitan area or not] and travel time to the hospital) (Referent Group: CMCD In-house dental clinic)

Parameter	P- <value	Odds Ratio	95percent CI
Better parent reported oral health status (excellent/good/average vs not good/very poor)	0.47	1.824	.351, 9.586
Better parent reported satisfaction (very satisfied/somewhat satisfied vs neither satisfied nor dissatisfied/somewhat dissatisfied/very dissatisfied)	0.77	1.274	.243, 6.672
Less likely to have Unmet dental Needs	0.33	1.99	.50, 7.87
Better parent reported ease of access (very easy/easy vs neutral/somewhat easy/not easy)	<u>0.051</u>	3.036	.995, 9.268
More likely to have medical doctor recommends child see dentist	0.05	2.652	1.026, 6.854
Less likely to have difficulty getting dental care that parent or physician believed was necessary	0.17	2.53	.66, 9.7
Less likely to wait longer than 2 weeks for dental care	0.02	6.02	1.4, 25

Figure 2: Visual Representation of Table 3

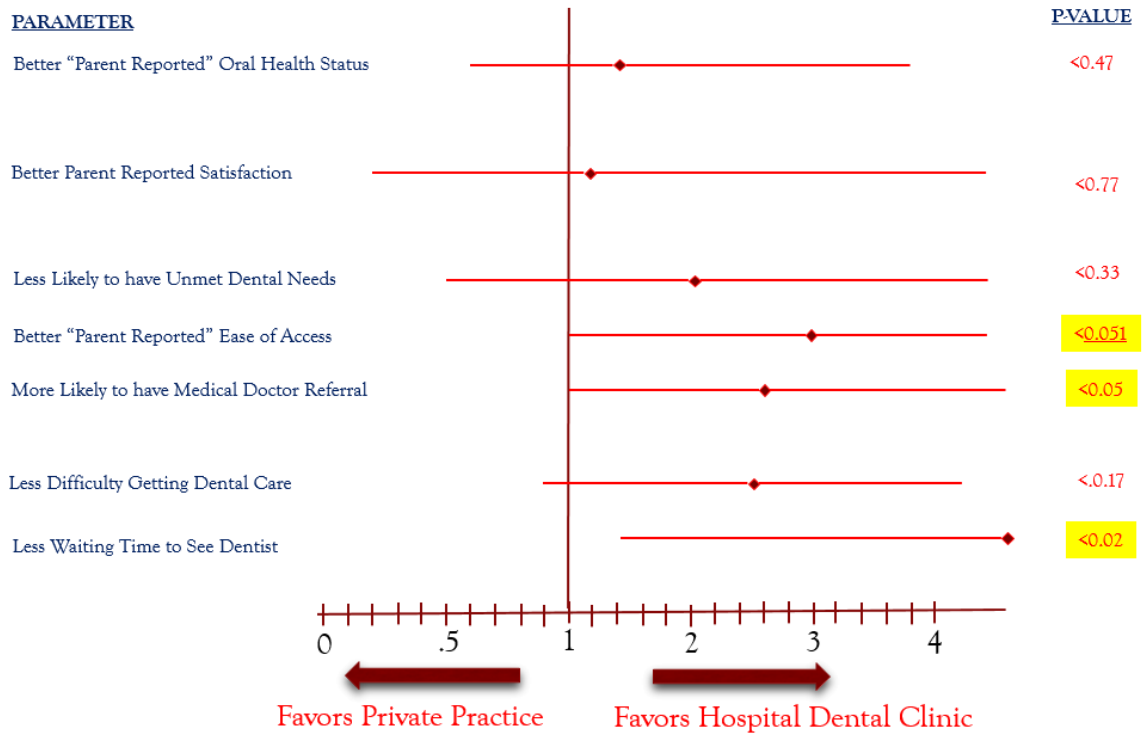


Figure 3: Summary of Outcome Trends

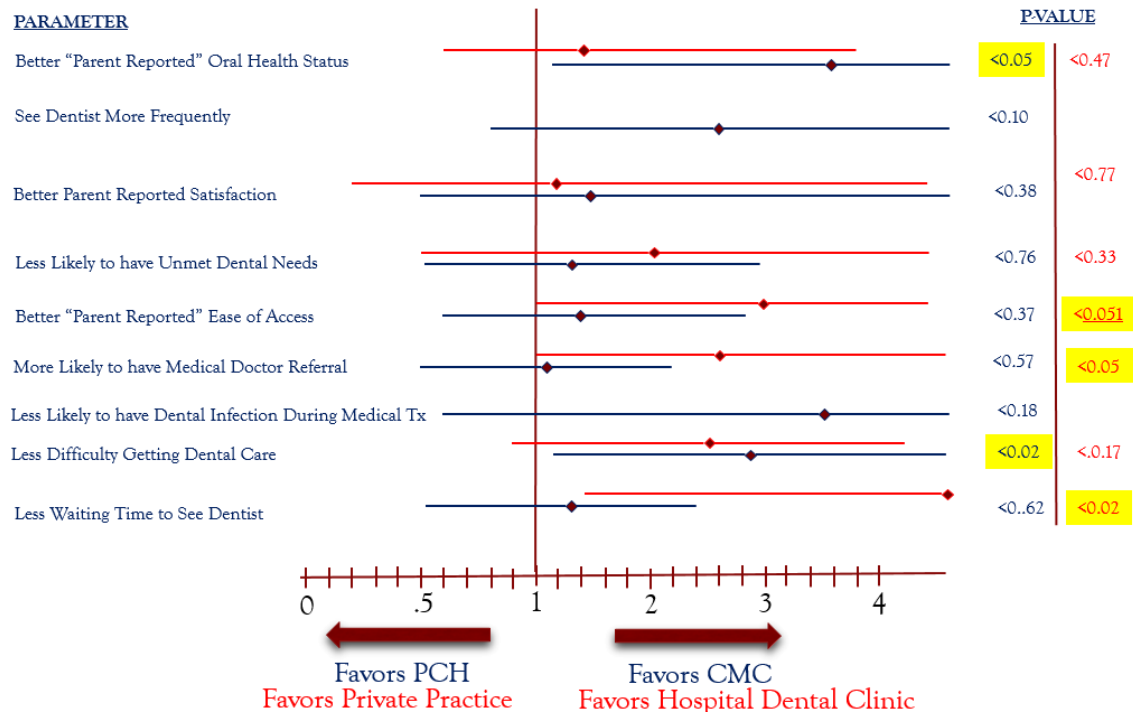


Figure 4: Barriers to Dental Care

