ACCESS TO DENTAL SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS:
A PILOT STUDY AT BRITISH COLUMBIA CHILDREN’S HOSPITAL
DEPARTMENT OF DENTISTRY

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE

in

The Faculty of Graduate Studies

(Craniofacial Science)

THE UNIVERSITY OF BRITISH COLUMBIA
(Vancouver)

August 2013

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ABSTRACT

Objectives: This pilot project, conducted at the Dental Department of BC Children's Hospital (DD-BCCH), aimed to 1) identify issues that affect access to dental services for Children with Special Health Care Needs (CSHCN), 2) assess parental perceptions of the oral health status of their child and 3) determine the practicality and feasibility of survey research with this patient population.

Methods: Caregivers of CSHCN who were patients of the DD-BCCH were recruited by letter, posted advertisement and direct request. Information on caregiver's perceptions of enabling factors and barriers to dental services and their understanding of their child's oral health status were collected using a pre-tested survey instrument. In addition, demographic information, referral source, insurance coverage, medical diagnosis, and anticipated dental treatment were gathered from the child's dental record. Quantitative data was analyzed descriptively and qualitative comments from parents by thematic analysis.

Results: Common medical diagnoses for the sample of CSHCN (n=50) were genetic disorder/syndrome, developmental delay, sensory impairments and autism. Caregivers from mid-to-upper income levels formed 50% of the sample. Payment methods reported by parents included private dental insurance (52%), public benefits (36%), or out-of-pocket funds (24%). Of the sample, 50% were referred by a medical professional and most children (90%) had had a dental appointment within the last year. About 50% of caregivers reported the following barriers to obtaining dental care prior to attending at BCCH: dentist not trained or comfortable treating or managing the child's
behaviour; complexity of child’s medical condition and financial barriers. We were unable to determine a true parental perception of the oral health of the child because many parents answered the survey after the oral examination had been completed.

Conclusions: 1) The complexity of the child’s medical status, limited ability of dental providers to deliver care and financial obstacles were commonly-reported barriers to dental care identified by parents 2) Parental perceptions of the oral health status of the child were not able to be reliably assessed. 3) A mail out survey was not a suitable method to obtain information about issues of access to dental services for CSHCN within the population at the DD-BCCH.
PREFACE

Ethical approval for the study was granted by The University of British Columbia and Children’s and Women’s Hospital Behavioural Research Ethics Boards (BREB). (Certificate numbers H11-01585/ CW11-0241
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ACKNOWLEDGEMENTS

I would like to express gratitude to all the people who without their help this work would have not been possible:

Dr. Rosamund Harrison and Dr. Karen Campbell, my supervisors, for suggesting the topic of access to dental care for children with special needs. What was originally thought to be a mere requirement for graduation has turned into a true professional inspiration that has shaped how I will practice pediatric dentistry and provided a vision for the future. Thanks for the countless hours that you have invested helping me organize my thoughts. I also appreciate your guidance and the patience that you have demonstrated during this arduous, but rewarding process of thesis completion.

2011 iACT Trainee Clinical Investigator Seed Grant Award #F11-03383, Child & Family Research Institute for their direct financial support of this project.

To all the parents and caregivers of children with special health care needs at the dental department at British Columbia Children’s Hospital for showing me a capacity for endurance, determination and kindness in the face of adversity. You are an inspiration to me as mother and professional.

To my colleagues and all my local and overseas friends who accompanied me along the way. Thanks for listening to me, for the laughs and all the wonderful memories.

My parents and sisters who have always rooted for me, have always encouraged me, pushed me to move forward, and picked me up when I have fallen. Your love and support have made all of this possible.
My husband Jason, you are my hero. You put up with my continual physical and emotional absences during the past three years. You coached me through this process like the “pro” you are. Your unconditional and relentless support was my rock. I cannot thank you enough for investing all the financial and emotional resources necessary to succeed without even a pinch of selfishness.
DEDICATION

I wish to dedicate this work to my son Liam who has wonderfully transformed my life, informing who I am as a woman, wife, mother and professional.
1 INTRODUCTION

1.1 Definitions

1.1.1 Definition of Children with Special Health Care Needs (CSHCN)

   There are multiple definitions of CSHCN [1-4]. For example, according to the BC Ministry of Children and Family Development, children with special health care needs (CSHCN) encompass “…children and youth up to 19 years of age who require significant additional, medical/health and social/environmental support – beyond that required by children in general – to enhance or improve their health, development, learning, quality of life, participation and community inclusion”¹

   In the United States, CSHCN are defined by the Maternal and Child Health Bureau (MCHB) as, “those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional conditions and also require health care-related services of a type and amount beyond that required by children generally” [2]. The American Academy of Pediatric Dentistry (AAPD) has defined special health care needs as, “…any physical, developmental, mental, sensory, behavioral, cognitive or emotional impairment or limiting condition that requires medical management, health care intervention and/or use of specialized services programs”[4]. The AAPD definition will be used for the purposes of this thesis.

1.1.2 Definition of Quality of Care

   Quality of care is a relative concept. As such, quality depends on the beliefs and perceptions of the individuals who receive the “service” and their individual definitions of

what “service” actually means. In 1990, the US Institute of Medicine (IOM) defined quality of care as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” [5].

Lohr et al [13], identified the main concerns in relation to quality of care for those with special needs

- Under-use of preventive services
- Lack of treatment of secondary medical conditions
- The limited knowledge of medical practitioners in relation to effective therapies for the treatment of patients with complex medical conditions
- Difficulties in communication (such as people with mental illness, autism, speech impediments, amongst others)
- An intricate medical system that makes coordination of services difficult
- Financial limitations due to either absent or inadequate dental coverage

1.1.3 Definition of Access to Care

Access has been defined as the degree to which health care providers and services meet the needs and expectation of the clients. To meet these needs the health care services ought to be obtainable, easy to get to, timely, reasonably priced and the facilities should have the characteristics and locations that lead to a patient having assurance in the services received [6]. Others have defined access as “the ease with which health care is obtained”[7]. Individuals with and without special health care needs (SHCN) face obstacles when attempting to obtain health care. However, those with SHCN experience more difficulties including challenges obtaining a specific health care service or specialist referral, not receiving all the care required, having inadequate health insurance and failure to obtain prescription medications [3, 8, 9].
1.2 Epidemiology of Children with Special Health Care Needs

CSHCN have complex medical conditions that require a range of services from multiple health care providers. Under the umbrella of CSHCN are several genetic, behavioral, developmental and acquired conditions. The list of conditions is lengthy and includes amongst others; children born prematurely, children born weighing under 2.5 kg, children with cleft lip and palate, craniofacial abnormalities, cerebral palsy, spina bifida, heart and limb deformities, developmental delay, ectodermal dysplasia, hemifacial microsomia, X-linked amelogenesis imperfecta, osteogenesis imperfecta, dentinogenesis imperfecta, attention hyperactivity disorder, Autism Spectrum Disorder, cancer and infectious diseases.

1.2.1 Etiology

Birth related injury such as anoxia, acquired conditions (after birth) like cancer, developmental deficiencies and accidental injuries are some of the factors that could lead to a child being diagnosed with a special health care need. In addition to genetic mutations that occur as a result of maternal exposure to teratogens, mutagens and carcinogens. Maternal tobacco use, exposure to prescription and non-prescription drugs; alcohol consumption and malnutrition during pregnancy may all be linked to the etiology of genetic mutations that may result in some form of disability. However, in many instances the etiology of the disability or medical condition is unknown.[9]

1.2.2 Prevalence

The proportions of children with special needs in Canada and the United States
appear to be quite different from one another; thus comparisons are problematic.

In the US in 1985, 18% of children less than 18 years of age were estimated to have an existing special health care need [10]. Yet, over fifteen years later in 2001, only 13% of all children were reported to have a special health care need [3]. Both surveys used standardized screening questions based on the MCHB definition of CSHCN and included any child up to the age of 18. The 1985 study included those children who needed a specialized service and therefore presumably also "fit" the definition of CSHCN, but were not accessing the service at the time of the survey. In contrast, the 2001 study only included children who were currently using extra or specialized services. This difference in data collection criteria may account for the difference in reported prevalence between the two surveys.

Statistics Canada determined in 2006 that 3.7% of Canadian children under the age of 14 had a disability. Further, males were reported to be generally more affected by all types of disabilities compared to females 2. The estimates for CSHCN were obtained from the 2006 National Census data. Screening questions asked if there were people within the household who had “disabilities”. The number of affirmative answers created a new target “sub-group” of 8,500 subjects for a follow-up survey. This later survey addressed specific issues for populations with disabilities. Excluded from the survey were people living on First Nations reserves and residents of such institutions as facilities for people with disabilities, nursing homes, hospitals, establishments for offenders and shelters for persons lacking a fixed address. The data from this “second survey” is currently used to estimate the prevalence and distribution of children with

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The term “disability” is somewhat narrow and does not really represent the full scope of the definition of CSHCN that has been used in our study. More recent data from the 2011-2012 British Columbia Ministry of Education estimated that about 50,497 or 9% of the 549,836 school-aged children enrolled in the public education system had some form of special health care need. The Ministries' categories for CSHCN included the following: Autism Spectrum Disorder (ASD), learning disabilities, physical disabilities/chronic health impairment, deaf or blind, behaviour disabilities, mild intellectual disabilities, sensory disabilities, moderate to profound intellectual disability and physical dependence. These enhanced criteria for inclusion seem to represent more accurately the current situation of CSHCN in British Columbia. However, the Ministry of Education findings are likely to be an underrepresentation as they do not account for 0-4 year old children nor do they include the 70,500 children enrolled in the independent (private) school system.

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1.3 Access to Health Care for Children with Special Health Care Needs

Many factors are barriers to the necessary health care for all vulnerable populations. Such barriers include a complex medical condition, ethnicity, socio-economics, language barriers, rural residence and challenges with navigating an intricate health care system [11-14].

The delivery of medical services is markedly different between Canada and the US. In Canada, health care is universal and therefore it is assumed that every permanent resident and/or Canadian citizen is has “coverage” under their provincial health care plan. However, having access to basic health services does not necessarily guarantee that testing or treatments are proper and timely. Further, because of the limitations of their provincial health plan, many low and middle income Canadians are unable to obtain ancillary health care services such as eye care, dental care, mental health counselling and prescription drugs. Furthermore, only limited financial resources are allocated for health promotion strategies to improve the quality of life of individuals with disabilities, especially for children [15, 16].

In the US, health care is funded by the public system, private insurance or out-of-pocket. The evidence about the relationship between health insurance coverage and access to medical services for CSHCN is somewhat unclear [10, 17, 18]. Analysis of data from the US National Health Survey on Disability (1994-1995), estimated that approximately 89% of CSHCN had some type of medical coverage [10]. More often than not, this coverage was private insurance. Not surprisingly, children who had insurance were more likely than uninsured children to have a usual source of medical care. However, no significant differences were observed in access to medical care
between children who had public and those who had private coverage. It is noteworthy that about 8% of the caregivers in the sample reported that the most prevalent unmet need for their CSHCN was for dental care.

In the US in 2004, 18% of families of CSHCN reported that their child had an unmet need for a health care service [3]. The unmet need may be related to primary or specialty care, auxiliary services and/or equipment needs. This finding was supported by the National Survey of Children with Special Health Care Needs [19] who concluded that CSHCN had high unmet needs for medical services. This problem was especially true for those of lower socio-economic backgrounds, African American families and for those with more complex medical conditions. Results from both studies may have been affected by the recall bias that is characteristic of survey-based research.

A joint Canada/US Survey of Health of adults reported that “health disparities on the basis of race, income, and immigrant status are present in both countries, but appear to be more pronounced in the United States” [20]. In the same analysis, it was apparent that barriers to obtain medical care were different between the two countries. Financial barriers were the main issue in the US whereas long waiting times were a noted challenge in Canada.

Being unable to obtain required medical care adds stressors to the already difficult life and family circumstances that CSHCN and their caregivers face. A study conducted in the District of Columbia Washington D.C. in 2002, using random telephone assessments, found an association between the mental state of a child and that of their caregiver [21]. About 69% of the families of CSHCN reported that their child experienced a mental health problem such as depression, in addition to his or her main disability. An important correlation between the CSHCN’s reported mental illness and a
higher probability of the parent reporting symptoms of mental health issues was also reported. Parents who reported mental health issues were also more likely to report an unmet health care need for their child. Nevertheless, possible reasons for the findings are that depression might affect the ability of the caregiver to advocate for their child and/or obtain the required healthcare services. Additionally, it was possible that when the child is depressed he/she may have compounded the behavioural problems that hinder the ability to obtain required services. However, results cannot be generalized to other populations as the study participants did not represent a range of ethnicities or income groups.

In conclusion, the evidence available from the USA and Canada reveals that CSHCN face several challenges when accessing health care services. Some of this research also explored the issue of dental care and the evidence suggests that dental care is one of the health care services that present many barriers [10].

1.4 Oral Health Status of Children in Canada and British Columbia

According to the 2007-2009 Canadian Health Measures Survey (CHMS) the prevalence of treated and untreated dental caries in Canadian children was approximately 47.8% for 6-11 year olds and 59% for 12-19 year olds. This prevalence is based only on a clinical inspection which determined the number of decayed, missing and filled primary and permanent teeth per participating child. This percentage is likely an under-estimate because no radiographs were exposed. [22] Further, the burden of caries was disproportionately distributed amongst Aboriginal children, children whose families had public dental coverage, lower levels of education and middle income. Nevertheless, 84% and 91% of adolescents and children respectively were found to
have visited a dental professional within the past 12 months. Dental trauma indicated by the presence of a fractured tooth was prevalent in about 7% of 6-11 year old children. Still, about 5% of children and 10% of adolescents stated that they experienced persistent pain in their mouths.

Population-based dental health data for BC children are limited. A 2009-2010 dental survey of British Columbia’s kindergarten-aged children using clinical inspection alone, reported that about 17% of 5-year old children in BC had visible caries\(^5\). For Aboriginal children, the prevalence was 28.5% of children. Of course, even “healthy” children face barriers when accessing dental care. Some of the reported reasons children in British Columbia do not obtain the dental care that they require are related to the: [23]

- Child’s inability to cooperate in a regular dental setting
- Lack of dental providers experienced in the management of children, and
- Financial limitations due to either absent or inadequate dental coverage

1.5 Oral Health Status of Children with Special Health Care Needs

There are conflicting reports regarding the oral health status of CSHCN. They have been reported to have less than desirable oral health: untreated caries, malocclusions, periodontal disease and poor oral hygiene [11], [24],[12],[13],[25],[26]}. Further, Dr. James Crall, [12] at the American Academy of Pediatric Dentistry’s Symposium on Lifetime Oral Health Care for Patients with SHCN in 2007 summarized the situation by declaring “the knowledge base concerning the oral health status of individuals with SHCN is incomplete and fragmented”. This claim was justified by the

fact that most surveys depend largely on parental descriptions of their children’s dental issues (not that of a dental provider), use a broad definition for CSHCN, and most research participants are those children with the most accessible and common conditions. A 2005 narrative review of the literature concluded that the risk and potential adverse outcomes of poor oral health and caries are more substantial in medically compromised children [24]. Multiple chronic diseases are associated with poor oral health because of the following factors: social disadvantage, frequent exposure to medications with high sugar content, a cariogenic diet, poor or non-existing oral hygiene and/or behavioral problems.[27]

The US National Survey of Children’s Health in 2003 compared 17,001 CSHCN to a control group of children without special needs (CWOSN). The study groups were matched by age, ethnicity and socioeconomic status. The most prevalent dental conditions reported by both groups were “cavities, crooked teeth, broken teeth, grinding and tooth pain”. These dental conditions were based on parental perception of dental health in both groups. It was interesting to note that for both groups, CWOSN actually reported slightly more “cavities” (70%) in the 1 to 5 year old group compared to the group of CSHCN (64%). However, parents of CSHCN reported more teeth discoloration, pain and broken teeth when compared to CWOSN. For the group of 6 to 11 year olds, the prevalence of “cavities” was around 55% and “crooked teeth” was a source of concern for both CSHCN and CWOSN (31% and 35%). The 12 to 17 year olds had a similar distribution for decayed and crooked teeth. However, broken teeth were more prevalent in the CSHCN. Overall, CSHCN with speech or behavior disorders, learning disabilities, physical impairments, developmental delays or autism tended to have more dental problems than the rest of the CSHCN population.
Increased income levels were associated with better reports of dental health for both CWOSN and CSHCN. [13]

The oral health status of CSHCN with specific medical conditions such as autism has also been studied [25]. Findings from a subset of 495 children with autism from the 2003 survey of Children’s Health indicated that 52% of caregivers of children with autism reported that their child’s teeth were in excellent or very good condition compared to 69% of CWOSN. Nevertheless, amongst the caregivers who reported fair to poor oral conditions in their child, the most common issues were “pain” or a “broken front tooth”, teeth needing “repair” and/or poor oral hygiene. Caries was reported more often by parents of CWOSN (55%) compared to children with autism (34%). Caution should be exercised in interpreting this large survey as dental health status was based only on caregiver reports.

Similar findings were described in a survey of parents of children with autism in Toronto where 57% of parents believed that their child had excellent to good oral status. However, about 23% of the children had experienced a toothache and 36% had a dental restoration performed within the last twelve months. [28]

A recent study surveyed parents of CSHCN recruited from 15 pediatric dental practices in Massachusetts that provided services to the most medically compromised children. [26] Caries prevalence in these groups of CSHCN, as reported by their parents, was lower than in the general population. Orthodontic needs were the same as for children of comparable age. However, results may have been biased by the fact that respondents were mostly Caucasian, from two parent families and of relatively high socio-economic status.
A study from the Netherlands that assessed the oral health status of children with severe disabilities reported that 57.4% of the children surveyed had untreated caries. The proportion of caries-free children with disabilities was only 30%, in contrast to 50-55% of caries free children in the general population of Dutch children. The children who appeared more severely affected with caries were the children from ethnic backgrounds other than Dutch. The results are based on actual dental examinations performed by experienced clinicians and not solely on parental perceptions. [29]

The consequences of untreated dental disease on children’s development and overall health have been reported by Mouradian et al [11]. Untreated caries in children has been linked to failure to thrive and to local and systemic infection, malocclusion and school absenteeism. Untreated dental disease may also lead to an increased burden on medical emergency services, increased use of intravenous antibiotics and higher costs to the health care system related to hospitalizations and general anesthesia. CSHCN who have unmet dental needs could be at a higher risk for complications such as “deferred bone marrow and organ transplants, cardiac surgeries, failure to thrive, breathing difficulties, septicemia, brain abscesses and other serious complications.[11] Such complications could potentially jeopardize the already fragile health of many of these individuals.

CSHCN may have a prevalence of oral disease that is quite similar to that of healthy children. However, the risk for complications from severe and untreated oral disease is higher in these medically compromised children [11, 30]. In addition CSHCN rely on their caregiver’s ability to identify need and seek care since some CSHCN are often unable to communicate need, pain or discomfort.
1.6 Access to Dental Care: Child, Parent and Family Perspective

1.6.1 Dental Insurance Coverage and Financial Considerations

Dentistry occupies a unique position in Canada’s health care system. Dental care is privately funded by “out-of-pocket” payments and employee benefits (extended private insurance plans), or publicly funded by charitable funds or government assistance programs such as Healthy Kids in British Columbia and Medicaid or State Children’s Health Insurance Program (SCHIP) in the US. The Healthy Kids (HK) program in BC\(^6\) provides a limited amount of dental coverage for children who are economically disadvantaged or have parents on income assistance. However, this coverage is insufficient in many instances and also restrictive as not all providers may accept the level of fees and may wish to “balance-bill” the patient’s family for the differential between fee schedules. Such a barrier to care results in either the child not being able to receive treatment or the family having to pay for the remainder of the cost not covered by HK.

Kane at el, 2008 [31] assessed the health care needs of CSHCN in Alabama and reported that having both medical and dental insurance did not guarantee that a child received dental care. Further, they also reported a strong correlation between unmet medical needs and unmet dental needs; poverty was a strong predictor of unmet dental needs. In an earlier survey in Alabama, 20% of parents reported their children did not receive needed dental care because the dentist did not accept their particular dental insurance [32]. In contrast to these findings, a national study in 2009 [33], reported that although financial barriers were an issue, type of insurance was not an important factor.

hindering access to dental care. The studies differ in that the first study collected information from one state only, whereas the latter study analyzed national data.

In conclusion, financial considerations are always present in a fee-per-service model of care. Financial barriers and insufficient insurance coverage are common barriers preventing both healthy children and those with special needs from receiving dental services. However, their inability to obtain needed dental care does not appear to be related per se to the type of insurance coverage [9, 26, 34, 35].

1.6.2 Utilization of Dental Services by CSHCN

Differences in utilization and expenditures for dental services between CSHCN and healthy children have been investigated by analysis of the 2004 Medical Expenditures Panel Survey [36]. Surprisingly, CSHCN utilized and spent a comparable amount for dental services ($1,166.67 annually) when matched with a sample of healthy children ($1,136.50 annually). This survey used parental interviews conducted at six different opportunities over a period of two-and-one-half-years to document information on utilization and expenditure. The finding that CSHCN and healthy children spend about the same amount of money on dental care services suggests that, at a minimum, the American Academy of Pediatric Dentistry Guidelines for periodicity of dental treatment recommendations are not being followed. The current guidelines for management of patients with SHCN stipulate that the frequency of dental visits for a child should be based on the individual’s risk [37]. CSHCN are considered at high risk for oral disease due to their difficulty maintaining oral hygiene, the nature of their disabilities and prescribed medications. This increased risk is particularly true for those with more complex behaviour or more complicated medical conditions. Therefore,
CSHCN should adhere to a more continuous and frequent recall/preventive schedule which may lead to increased annual costs for preventive maintenance.

Access to dental care and utilization of services has also been investigated for adults with developmental disabilities. A study in Ontario [38] concluded that about 70% of adults with developmental disabilities (AWDD) reported no difficulties accessing dental care. In fact, the majority of respondents (82%) had seen a dentist within the past year. About half of the sample of 250 AWDD saw or utilized dental services every six months including preventive care and only 5.5% went to the dentist only for emergencies. Unfortunately, this study was biased by sampling and recall bias. Most of the individuals who completed the survey were individuals with Down syndrome who lived in urban areas where typically there are more services available.

To date, little is known about the utilization of dental services by CSHCN in Canada and specifically in British Columbia. However, a recent report funded by the BC Dental Association found that CSHCN represent about 45% of all children receiving dental care under general anesthesia at British Columbia Children's Hospital. These BC children require this specialized level of care because of their complex medical conditions and the behavioural challenges that often accompany such conditions [39].

1.6.3 Urban or Rural Residence

The effect of rural residence on access to care has been investigated in the US [40]. In a follow-up study, [41] researchers analysed the data available from the National Survey of CSHCN to identify whether rural residence increased the likelihood of a CSHCN having unmet dental needs. In the study, the rural population was more likely to be white, non-Hispanic, poor, uninsured or have publicly funded insurance for dentistry
and included mothers that had lower levels of education. Overall, after controlling for other confounders, the main finding was that “rural residence itself does not act as a barrier to obtaining dental care once a need is recognized by a parent”. However, again the results were based on subjective parental perceptions of dental needs.

In Canada, little is known regarding the issues that rural populations of CSHCN face when attempting to obtain dental care. The definition of rural in the Canadian context is customarily the “rural and small town” definition which refers to the population living in towns and municipalities outside the commuting zone of larger urban centres (i.e. outside the commuting zone of centres with population of 10,000 or more). Nevertheless, clear differences between the oral health status of the rural and urban population in general have been reported. According to a 2007 report by the Canadian Institute for Health Information only 11% of dentists were located in rural areas or small towns. This shortage of providers in rural areas, especially in BC where no pediatric dentist appears to be practicing in a rural area, might be an important barrier to access to care for the pediatric patient in general and even more for the CSHCN who resides outside of an urban or metropolitan area.

1.6.4 Perceptions of Need for Dental Care

The importance of dental health in the mind of the public has been previously investigated. A study that surveyed inner-city mothers of 3rd and 4th grade children from different racial groups, found that mothers valued or believed dental care to be

\[41\]

\[42, 43\]

\[44\]

\[7\]

\[8\]
important. However, only 50% of children in this sample received the dental care required after their parent was notified of the need for treatment. The reason these mothers cited for not seeking dental care for their children was the high cost and consequently lower priority within the household budget [44]. Other investigators analyzed data from the Third National Health and Nutrition Survey to determine parental perceptions of their children’s oral health. Most parents felt that their children had excellent to good oral health [45]. This finding suggests that underestimation of need is likely a contributory factor to access to care for the pediatric population. Age of the child also influences the parent’s perception of oral health. Younger children are often reported by caregivers to have better oral health than older children. One possible explanation is that parents may not believe that poor oral health is a possibility for such young children.[45]

Since children rely upon adults to seek care on their behalf, the importance of parent or caregiver awareness in relation to their dental needs is crucial. For some CSHCN, this awareness becomes even more relevant since children more severely compromised might not be able to express pain or discomfort and thus rely almost entirely on their parents to interpret their needs.

An analysis by Kenney et al of the 2003 National Survey of Children’s Health revealed that approximately 19% of parents reported an unmet dental need for their CSHCN. [13] This percentage is higher than those reported in other surveys of CSHCN which ranged from 10% [9], for most conditions to 20% for the more severely medically compromised [26]. In contrast, Kenney et al reported that two-thirds of parents felt their special needs child had excellent or very good oral health. These parental “perceptions” were compared with the national estimates for caries prevalence for healthy children.
from different age groups. The authors concluded that based on significantly lower percentages of dental disease reported by parents compared to national estimates, parents did not have an accurate perception of the actual state of their CSHCN’s oral health. [13]

In Canada (1986), parents or guardians of 187 children with disabilities were surveyed to estimate their awareness of their child’s oral health [46]. About three-quarters of parents reported that they were satisfied with the appearance of the dentition of their CSHCN. They also reported past experiences of dental pain (17%), tooth extractions (34%) and difficulty chewing (24%). Of course, it is a challenge to compare this 30-year old report of CSHCN to the recent 2009-2010 Canadian Health Measures Survey (CHMS) where, of 6-11 year olds, persistent pain was reported by only 5.4% and avoidance of foods because of problems with teeth by 7.6% of all respondent children [22]. The assumption is that the overall improvement in dental health of Canadian children in the past 30 years is a secular trend that is beneficial to all, including those with special needs.

A retrospective study in France surveyed caregivers regarding their perception of the oral health status of their SCHN and compared the results to the dentist’s perceptions and actual treatment needs of 103 SCHN patients. The study concluded that not only caregivers, but also the examining dentists of SCHN, tended to underestimate the dental treatment needs. The researchers found that caregivers’ misjudged (by underestimating) treatment needs in 99% of the children, whereas the examining dentist failed to identify the treatment needs in 76% of the cases.[47]

To date, no clear conclusions regarding the accuracy of parent’s perceptions of their child’s dental needs are possible [13]. Parents sometimes underestimate need and
in other situations a positive correlation between perceived and actual need for dental treatment has been reported [34]. For a variety of reasons, it is an added challenge for a parent to be able to assess “dental need” in their special needs child.

1.6.5 Dentist’s Willingness to Treat Children with Special Health Care Needs

CSHCN present with a wide range of medical comorbidities. Mild to moderate forms of the most common conditions; i.e. asthma, learning disabilities, autism and ADHD may be perceived as “low risk” for complications to treat in most general dental settings. However, there are several more complex conditions such as cerebral palsy, hemophilia, HIV, epilepsy and cancer that are perceived by dental professionals as “high risk” for complications. The ability to find a dental provider who is willing or able to treat CSHCN with medical conditions such as cerebral palsy may be a common barrier to care experienced by parents. There is some evidence that certain subgroups of CSHCN may be more likely to experience barriers to access dental services since their condition might involve several comorbidities requiring precautions that increase the perception of risk or challenge for treatment in a private setting.[32]

In the US, a telephone survey of 40,840 caregivers of CSHCN determined that these children had access to preventive services. However, a medical condition that was considered severe was an obstacle to both preventive and restorative dental care [33]. Others have found that ‘willingness’ of the dentist to treat was not reported by caregivers as a barrier to obtaining dental care for CSHCN. Rather, factors such as financial limitations, insurance coverage, mother’s educational level and unmet needs for medical care seemed to be strongly associated with the inability to receive dental
treatment. All of the above studies were limited by the response rate of participants and differing definitions of CSHCN. [31, 33, 35].

The AAPD\(^9\) states in their Guideline for Management of Dental Patients with Special Health Care Needs that pediatric dentists graduating from accredited programs are trained to deliver dental care to individuals with SHCN. It also recommends that pediatric dentists should educate other health care professionals, parents and other organizations involved with the management and care of people with SHCN. Therefore, by the nature of their specialty training, it is quite likely that the majority of CSHCN in Canada are referred to and treated by pediatric dentists \([48, 49]\). Thus, the issue of the number of pediatric dentists practising in any given locale might act as a barrier to those CSHCN needing dental care. As of 2013, there were a total of 189 pediatric dentists registered as members of the Canadian Academy of Pediatric Dentistry, of which 46 were registered in the province of BC\(^10\).

Further investigation is warranted to address the issue of the number of pediatric dentists, their training and the factors that enable or prevent them from treating CSHCN in Canada and particularly, in BC.

1.7 Access to Dental Care: Dentist’s Perspective

1.7.1 Degree of Severity of the Medical Condition

The ability of CSHCN to obtain dental care may often be hindered by the complexity of their medical condition. An analysis of the 2001 National Survey of Children with Special Health Care Needs in the US, found that the stability and severity

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of the child’s medical condition affected the willingness of the dentist to treat the child. This reluctance was often translated into treatment not being delivered [31]. A study conducted in New Mexico revealed that if patients had certain medical conditions such as bleeding disorders, severe burns, craniofacial syndromes, cerebral palsy and patients undergoing cancer treatments, dentists were reticent to treat them [24]. The severity or complexity of a child’s behaviour or medical condition may indeed affect a dentist’s disposition to treat CSHCN, particularly medical conditions that are perceived to be more risky or complicated to treat. In these circumstances a referral to a specialist or hospital-based clinic is appropriate to ensure that the CSHCN receives the required care.

1.7.2 Reimbursement

The typical dental practice operates on a “fee for service” basis, with operating costs offset by revenues from fees. The operation and maintenance of a dental practice can be relatively expensive compared to other health care services. Therefore, dental procedures that generate more revenue than they cost to provide and do not require extended “chair time” are desirable from a financial standpoint [50], [51].

There are contradictory points-of-view regarding reimbursement rates as a deterrent for dentists providing care to CSHCN. In the US about 25% of CSHCN have Medicaid coverage, a type of government-funded health benefits. A 2009 study [52] found positive associations between reimbursement and receiving preventive dental care. It was reported that many providers did not accept Medicaid in their practices because of low and/or delayed reimbursement, further complicated by the paperwork necessary to receive the reimbursement. In addition, 34% of CSHCN who had Medicaid
compared to 21% who had a different form of payment did not receive required services. Thus, there was a tendency toward greater delivery of preventive services in states with higher reimbursement rates for preventive services by Medicaid [54]. In other words; dentists were more likely to offer services that were adequately reimbursed. Such an observation is not surprising given the high cost of operating a dental office.

A mail-out survey to general dentists in US, aimed at identifying whether they treated CSHCN and the factors that made them likely to treat or not, found that less than 10% of general dentists treated CSHCN [51]. The researchers hypothesized that low financial reward was linked to the scarce number of dentists willing to provide care for CSHCN. However, due to the overall low response rate from dentists (25% or 1,251 out of 4,970 dentists), caution is urged in making generalizations about this finding.

A similar survey of general and pediatric dentists was conducted in Ontario in 2002 [53]. In this study 88.9% of general dentists and 100% of pediatric dentists reported treating individuals with SHCN. A high percentage of both general dentists and pediatric dentists accepted government-funded insurance in their offices. Pediatric dentists compared to general dentists tended to accept a higher percentage of all government dental benefit programs (90% and 79% respectively). From these findings it appears that a large proportion of Ontario’s general and pediatric dentists provide dental care to individuals with SHCN. However, when both providers were asked what factors, if any, would encourage them to increase care to people with special health care needs (PSHCN), 53% of general dentists and 46% of pediatric dentists mentioned increased compensation. These findings suggest that poor compensation for the extra time typically involved in the treatment of PSHCN is a barrier to a dentist considering
whether to provide treatment for these individuals.

Dentists and especially pediatric dentists in Ontario appear willing to treat PSHCN. Government-funded dental coverage was accepted by most providers. One could speculate that the “willingness” may be related to the apparent “oversupply” of dentists in certain areas of the province. Research on dentists’ perspectives on care for those with special needs from all of Canada’s provinces has yet to be done.

1.7.3 Training

The relationship between the training that dentists receive and their preparedness to treat CSHCN after graduation has been investigated. Krause et al, [54] explored how American and Canadian schools prepared their students to treat those with SHCN. A total of twenty out of sixty-five schools, or 31%, responded to the survey. Approximately 91% of the respondent schools “covered” the topic of CSHCN, but only 65% or two thirds of the schools offered either a didactic or “hands on” course in SHCN. The medical conditions that dental students most likely received “hands on” experience for included Down syndrome, autism, and motor impairments. Fortunately, schools reported that they were developing changes to their curricula; 77% of the schools were preparing to increase both clinical and extramural experiences for students in treating patients with special needs.

A 2005 survey of 500 general dentists with membership in the Michigan Dental Association reported that the majority (60%) of respondents felt the training they received in their dental education did not prepare them adequately to treat PSHCN’s. Only a very small percentage (18%) of the dentists surveyed felt that dental school had
prepared them well or very well to treat SHCNs individuals. Dentists who felt they had received adequate training in treating PSHCNs were more likely to set up practices that were accessible to a wide variety of PSCHN [49]. In contrast, a 2001 study analysed a subset of data from a national survey of general dentists and the investigators concluded that additional training such as postgraduate education in general practice or advanced general dentistry residency appeared to have no effect on willingness to care for the SHCN population [51].

The previously cited survey of Ontario general and pediatric dentists reported that the majority of the responding dentists did in fact treat PSHCNs. About 85% of the general dentists obtained their training in management of the SCHN population in dental school. Pediatric dentists received this training during their specialty programs. Twenty nine per cent of pediatric dentists stated that they had taken further education on this topic. The findings from this study suggest that both pediatric and general dentists received training in their respective programs, enabling them to treat different kinds of PSHCNs. The responses from the general dentists represented only 52% of the total practising general dentists in Ontario, whereas 90% of pediatric dentists were represented in the survey [53].

It is evident that the issue of access to dental services for children with special needs is multifactorial. Barriers such as the “high” cost of dental care, the limited number of dentists able and/or willing to provide treatment, the complexity of medical conditions, the ambiguity of the perceived need for care from the parental perspective, the insufficient reimbursement for the dentists who care for this population and dentist’s lack of training are all implicated to differing degrees in the difficulty or ease with which CSHCN obtain dental care. To date, there is limited knowledge how some or all of
these factors act as barriers to access to dental care in the local context. This project may aid in identifying common themes from the caregiver’s perspective and in guiding the direction of future research.
2 AIMS OF THE STUDY

For children with special health care needs\textsuperscript{11} who are patients of the Dental Department at British Columbia’s Children’s Hospital (DD-BCCH) this pilot study aims to explore:

1. The factors that affect their access to dental care;
2. Parents\textsuperscript{12} perceptions of the oral health status of their child, and
3. Practicality and feasibility of survey research with this patient population.

\textsuperscript{11} The Children with Special Health Care Needs who participated in the study will hereafter be referred to as “children” or “CSHCN.”

\textsuperscript{12} The term “parent” when used in the thesis also includes carers or caregivers who may not be birth parents.
3 METHODS

3.1 Study Design

British Columbia’s Children’s Hospital (BCCH) is a tertiary care pediatric hospital located in Vancouver, Canada. The dental department at BCCH (DD-BCCH) “delivers comprehensive, preventative and therapeutic oral health diagnosis, treatment and consultative expertise for infants, and medically compromised children and adolescents.”13 Children under the age of 18 with medical comorbidities and healthy children under the age of four are accepted by referral from a health care professional. The dental department at BCCH receives approximately 1200 patient referrals per year. Typically, referral sources include community dentists, physicians, and medical specialists within BCCH or other community-based health professionals. Dental care is delivered conventionally in the ambulatory clinic or under general anesthesia in the operating room (OR). About 68% of all children treated at the DD-BCCH meet the definition of CSHCN by virtue of having at least one co-morbid condition in addition to a dental treatment need. Forty-eight per cent of these children were treated under general anesthesia between the years 2009 and 2012 [39].

The dental treatment provided at BCCH is performed by trainees in pediatric dentistry under the supervision of certified specialists in pediatric dentistry and by community pediatric dentists than maintain active privileges at BCCH. The services provided are primarily funded by private dental insurance, government funded dental plans, charity funds or the family’s discretionary income (“out-of pocket”).

This pilot study used a two-phase approach to gather information to answer the

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aims of the study. For part 1 a questionnaire with closed and open-ended questions was administered to caregivers of CSHCN at DD-BCCH. Part 2 consisted of a review of their child’s dental record. This record review was performed to confirm data provided by parents, explore any discrepancies between parents’ reports and clinical findings and to enable comparison of the parent’s perception of the oral health status of the child to the dental needs as identified by the examining dentist (either in the ambulatory clinic or in the OR).

3.2 Study Participants

3.2.1 Recruitment

Ethical approval for the study was granted by The University of British Columbia and Children’s and Women’s Hospital Behavioural Research Ethics Boards (BREB). (Certificate numbers H11-01585/ CW11-0241). (Appendix A)

Participants for this study were parents of “active” patients at DD-BCCH. Initial recruitment was carried out using two methods: posted advertisement (Appendix B) within the dental clinic at BCCH and a mail-out letter of information (Appendix C). These letters of information describing the project and its goals were mailed to parents who had visited the dental department with their child between January 1st and June 30th 2011. To be included in the study, the child had to meet the criteria for special needs as per the AAPD definition and had to be an “active” patient as of January 1st, 2011 at DD-BCCH. Due to the lower than expected recruitment numbers, modifications to the protocol were proposed to the BREB, requesting that on-site recruitment be permitted. Following approval of the amended protocol, recruitment was done by directly approaching the caregivers at the time of their child’s visit at DD-BCCH; In essence,
waiving the 24 hour waiting period required by the Ethics Board to allow parents time to think about consent.

Parents could choose the preferred method of interview, after they expressed interest by either signing a consent form (Appendix D) in the clinic or returning the signed form via regular mail. Participants were informed that their answers and personal information were de-identified and confidential. The initial protocol for the caregiver interview and completion of the questionnaire specified that it take place while the parent was on site with his or her child for a dental appointment either at the dental department or in the OR. However, this approach required modification as it was noted that parents experienced considerable distress when bringing their child for treatment. If the child was being treated under general anesthesia, the parent was all the more anxious.

The initial protocol was for the investigator to administer the survey instrument herself to the parents, but this approach proved to be impractical. Thus, once signed consent was obtained, parents completed the survey on their own by one of two methods: telephone interview or by email. If the caregiver preferred the email method, the survey link was emailed to the caregiver using an electronic data capture tool, REDCap [55]). If a telephone interview was preferred then a convenient time for the caregiver was prearranged. An incentive of 15 dollars, in the form of either pharmacy gift certificate or reimbursement for the parking costs at BCCH, was offered to participants who completed the survey. The recruitment process was active for a period of twelve months (January to December 2011) after which all posted advertisements were removed from DD-BCCH.
### 3.3 Data Collection Instrument

The 33-item survey questionnaire had closed and open-ended questions. It was available only in English. It consisted of items on family demographics, child’s medical diagnosis, child’s past and present experience with dental care and issues related to obtaining dental services, e.g. travel time to DD-BCCH. The questionnaire also included closed and open ended questions to identify common themes around the challenges and enabling factors that caregivers faced in accessing dental care for their child. (Appendix E).

All questions were developed and reviewed by the investigator and her supervisory committee until consensus was achieved. Some of the questions were based on items on the population survey of CSHCN in Massachusetts by Nelson et al. [26]. The questionnaire was pre-tested by a member of the Cerebral Palsy Association of British Columbia who provided her input both as an adult with cerebral palsy and as an advocate for those with CP.

The study data was managed using REDCap electronic data capture tools hosted at the Child and Family Research Institute. REDCap [55] (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies.

### 3.4 Sample Size

Almost no research with the families who attend at DD-BCCH had been done prior to this study. Therefore, this pilot study explored the practicality of a survey study design in the environment of the DD-BCCH, the type of response rate that could be expected in a survey of families, the demographic characteristics of the attending children and families, and barriers to dental care (both at BCCH and in the past) faced
by these children as reported by their parents. The target sample size was 65 subjects, which is well above what is suggested as the ideal sample size for pilot studies (n=30). In pilot studies, a target sample size that truly represents the population to be studied is more important than the number of participants [56].

3.5 Statistical Analysis

Descriptive statistics including means, counts and percentages were calculated for the quantitative data. Qualitative description was used to analyse the responses to the open-ended questions [57-59]. The goal of qualitative description is to provide a comprehensive summary of responses in the “everyday terms” used by the parents. This method is not “highly interpretive”; the responses are presented in “everyday language” in a descriptive summary. The responses to the open-ended questions were sorted into themes that “fit” within the general topic of each question. The investigators classified the responses into broad groupings, first individually and then as a group to obtain consensus.
4 RESULTS

4.1 Quantitative Results

A total of 224 letters of information were mailed. Seventeen consent forms were returned by mail; from these, 13 surveys were completed (5.8% of all letters originally sent). The remaining signed consent forms (n= 54) were obtained through the on-site advertisement and/or by the investigator approaching parents in the dental clinic. Of the total consenting caregivers (n= 71), 50 caregivers completed the survey and one left the survey blank. This participant was unable to be located and it was impossible to contact this caregiver to inquire why this had happened. The majority of caregivers, 70% (n=35/50), used the electronic format to take the survey.

4.1.1 Child’s Demographic and Medical Diagnosis

Table 4.1 shows the demographic characteristics of the participating caregivers, their CSHCN and their families. The sample of CSHCN was evenly distributed amongst males and females with ages ranging from 2 to 21 years old (mean 10.2 years, SD 4.7). The majority of the children were born in Canada (91.8%) and their families spoke English at home. Most of the families resided in urban or metropolitan areas (98%).
Table 4.1 Patient Sociodemographic Information (n=50) <sup>a</sup>

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency(n)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender&lt;sup&gt;b&lt;/sup&gt;</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>25</td>
<td>49.0%</td>
</tr>
<tr>
<td>Female</td>
<td>26</td>
<td>51.1%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>24</td>
<td>47.1%</td>
</tr>
<tr>
<td>Chinese</td>
<td>6</td>
<td>11.8%</td>
</tr>
<tr>
<td>South Asian</td>
<td>3</td>
<td>5.9%</td>
</tr>
<tr>
<td>Other&lt;sup&gt;c&lt;/sup&gt;</td>
<td>18</td>
<td>35.2%</td>
</tr>
<tr>
<td><strong>Country of Birth&lt;sup&gt;d&lt;/sup&gt;</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>45</td>
<td>91.8%</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>8.2%</td>
</tr>
<tr>
<td><strong>Main Language Spoken at Home</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>33</td>
<td>66.0%</td>
</tr>
<tr>
<td>English plus other&lt;sup&gt;e&lt;/sup&gt;</td>
<td>13</td>
<td>26.0%</td>
</tr>
<tr>
<td>&quot;Other&quot; language only</td>
<td>4</td>
<td>8.0%</td>
</tr>
<tr>
<td><strong>Family Income (per annum)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$30,000</td>
<td>14</td>
<td>28.0%</td>
</tr>
<tr>
<td>$30,000 - $45,000</td>
<td>10</td>
<td>20.0%</td>
</tr>
<tr>
<td>$45,000 - $70,000</td>
<td>11</td>
<td>22.0%</td>
</tr>
<tr>
<td>$70,000 and above</td>
<td>15</td>
<td>30.0%</td>
</tr>
</tbody>
</table>

Mean age: 10.2 years, SD: 4.7 years; Age Range: 3-21 years

<sup>a</sup> Only 50 individuals were included in the analysis because one questionnaire was almost blank

<sup>b</sup> 51 persons provided gender data

<sup>c</sup> Other races include West Asian, Japanese, Latin American, Korean, and African American

<sup>d</sup> Parents did not respond to every question (missing data)

<sup>e</sup> Other languages include Chinese, Spanish, Vietnamese, Cantonese, Italian, Japanese, and Persian
Table 4.2 lists the main primary medical diagnoses. Genetic disorders or syndromes followed by developmental delays and impairments such as vision, speech or hearing were the most commonly reported medical conditions.

Table 4.2 Child Health Status

<table>
<thead>
<tr>
<th>Medical Diagnosis</th>
<th>Frequency(n)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generic disorder/syndrome</td>
<td>17</td>
<td>34.0%</td>
</tr>
<tr>
<td>Developmental Delay (neurologic, behavioural, chromosomal)</td>
<td>16</td>
<td>32.0%</td>
</tr>
<tr>
<td>Visual, speech or hearing impairment</td>
<td>14</td>
<td>28.0%</td>
</tr>
<tr>
<td>Autism</td>
<td>12</td>
<td>24.0%</td>
</tr>
<tr>
<td>Seizure Disorder</td>
<td>10</td>
<td>20.0%</td>
</tr>
<tr>
<td>Metabolic, cardiac, renal, immunologic, and hematologic disorders</td>
<td>7</td>
<td>14.0%</td>
</tr>
<tr>
<td>Behavioural, learning disabilities</td>
<td>6</td>
<td>12.0%</td>
</tr>
<tr>
<td>Other(^\text{c})</td>
<td>12</td>
<td>24.0%</td>
</tr>
</tbody>
</table>

\(^\text{a}\) The number of medical conditions exceeds the number of participants because some had multiple comorbidities
\(^\text{b}\) Includes Down syndrome
\(^\text{c}\) Includes cerebral palsy, craniofacial disorders, cancer, prematurity, delayed teeth development, Kawasaki disease, laryngomalasia

4.1.2 Family Demographics and Socio-Economic Status

Most families were two parent families (82.4%), and 71% of the children had one to three siblings. Thirty percent of parents reported earning more than $70,000 (Table 4.1) but 28% of the families were low income\(^\text{14}\). Over three-quarters of parents had post-secondary (college or university) education. About half of the parents had private dental insurance; one-third had public benefits such as the Non-Insured Health Benefits or Healthy Kids; 24% paid for the treatment partially or entirely "out of pocket".

### Table 4.3 Child and Family Dental History

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency(n)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Method of Payment</strong>&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private dental insurance</td>
<td>26</td>
<td>52.0%</td>
</tr>
<tr>
<td>Public benefits</td>
<td>18</td>
<td>36.0%</td>
</tr>
<tr>
<td>Out-of-pocket</td>
<td>12</td>
<td>24.0%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.0%</td>
</tr>
<tr>
<td><strong>Type of Appointment</strong>&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recall or follow up</td>
<td>22</td>
<td>44.0%</td>
</tr>
<tr>
<td>Treatment in Dental Clinic</td>
<td>16</td>
<td>32.0%</td>
</tr>
<tr>
<td>Treatment under general anesthesia</td>
<td>8</td>
<td>16.0%</td>
</tr>
<tr>
<td>Emergency care</td>
<td>2</td>
<td>4.0%</td>
</tr>
<tr>
<td><strong>Age of the First Dental Visit</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>8</td>
<td>16.0%</td>
</tr>
<tr>
<td>2 - 3 years</td>
<td>23</td>
<td>46.0%</td>
</tr>
<tr>
<td>4 - 7 years</td>
<td>15</td>
<td>30.0%</td>
</tr>
<tr>
<td>Don't remember</td>
<td>4</td>
<td>8.0%</td>
</tr>
<tr>
<td><strong>Dental Treatment Received in the Past</strong>&lt;sup&gt;c&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Check ups</td>
<td>40</td>
<td>80.0%</td>
</tr>
<tr>
<td>Preventive care</td>
<td>36</td>
<td>72.0%</td>
</tr>
<tr>
<td>Fillings</td>
<td>29</td>
<td>58.0%</td>
</tr>
<tr>
<td>Stainless steel crowns</td>
<td>22</td>
<td>44.0%</td>
</tr>
<tr>
<td>Extractions</td>
<td>20</td>
<td>40.0%</td>
</tr>
<tr>
<td>Nerve treatment</td>
<td>4</td>
<td>8.0%</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>7</td>
<td>14.0%</td>
</tr>
<tr>
<td><strong>Child's Last Dental Appointment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 6 months</td>
<td>41</td>
<td>82.0%</td>
</tr>
<tr>
<td>6 months - 1 year</td>
<td>4</td>
<td>8.0%</td>
</tr>
<tr>
<td>1 - 2 years</td>
<td>1</td>
<td>2.0%</td>
</tr>
<tr>
<td>&gt; 2 years</td>
<td>2</td>
<td>4.0%</td>
</tr>
<tr>
<td>Does not remember</td>
<td>1</td>
<td>2.0%</td>
</tr>
<tr>
<td>Never Been to a Dentist</td>
<td>1</td>
<td>2.0%</td>
</tr>
</tbody>
</table>

<sup>a</sup> Some caregivers use combined forms of payment

<sup>b</sup> Missing data from two participants

<sup>c</sup> There are more treatments than subjects due to patient reports of multiple dental treatments
4.1.3 History of Dental Care

With respect to the timing of the first dental visit, 16% (n=8) of the children had their first dental visit before one year of age (Table 4.3). However, most children, 48% or (n=24) had their first dental visit between 2 to 3 years of age.

The majority of children (n=40) or 80% had had a previous dental check-up and 72% (n=36) had received preventive dental care (Table 4.3). Indeed, 45/50 or 90% of the children had a dental appointment within the last year. A history of dental extractions was common to 40% (n=20) of the children. However, dental infections that required prescription of antibiotics were reported by only 14% (n=7) of the children.

Over 50% (n=26) of the respondents reported that they had attempted to have their child see a dentist outside of BCCH before being referred. Further, over half or 56% (n=28) of the parents/caregivers reported that a dental office had either refused or been unable to provide dental care for the child. Most parents 74% (n=37) said that their CSHCN had current dental needs.

When parents were asked about the additional direct and indirect costs of bringing their CSHCN for dental care, 57% (n=28) reported having to miss a day of work, 53% (n=26) paying for transportation and 10% (n=4) paying for hotel accommodation. The average travel time of caregivers to BCCH was one hour. However, 18% (n=9) caregivers reported a travel time from 2 to 5 hours.
4.1.4 DD-BCCH Chart Data

The main medical diagnoses recorded in the dental chart were genetic disorder or syndrome (46% or n=23), autism (28% n=14) and developmental delay (16.7% n=9) (Table 4.4). When comparing these medical diagnoses with those reported by the caregivers (Table 4.2), differences in the medical conditions as reported by caregivers were noted in the genetic disorders/syndrome category. A lower percentage of parents 34% (n=17) reported a genetic syndrome than the 46% (n=27) that was recorded in the dental chart.
Table 4.4 Information from Hospital Dental Record

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency(n)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Referral Source</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Specialist (includes pediatricians)</td>
<td>20</td>
<td>40.0%</td>
</tr>
<tr>
<td>Family M.D</td>
<td>5</td>
<td>10.0%</td>
</tr>
<tr>
<td>Dentist (includes pediatric dentist)</td>
<td>13</td>
<td>26.0%</td>
</tr>
<tr>
<td>Other Healthcare Professional</td>
<td>2</td>
<td>4.0%</td>
</tr>
<tr>
<td>Not specified(^a)</td>
<td>10</td>
<td>20.0%</td>
</tr>
<tr>
<td><strong>Medical Status(^b)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic Disorder</td>
<td>27</td>
<td>46.0%</td>
</tr>
<tr>
<td>Autism</td>
<td>14</td>
<td>28.0%</td>
</tr>
<tr>
<td>Developmental Delay (neurologic, behavioural, chromosomal)</td>
<td>9</td>
<td>26.0%</td>
</tr>
<tr>
<td>Seizure Disorder</td>
<td>8</td>
<td>16.0%</td>
</tr>
<tr>
<td>Metabolic, cardiac, real and hematologic disorder</td>
<td>9</td>
<td>18.0%</td>
</tr>
<tr>
<td>Visual, speech or hearing impairment</td>
<td>3</td>
<td>6.0%</td>
</tr>
<tr>
<td>Behavioural/learning disabilities</td>
<td>4</td>
<td>8.0%</td>
</tr>
<tr>
<td>Other(^c)</td>
<td>7</td>
<td>14.0%</td>
</tr>
<tr>
<td><strong>Dental Benefits</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private dental insurance</td>
<td>26</td>
<td>52.0%</td>
</tr>
<tr>
<td>Public benefits</td>
<td>13</td>
<td>26.0%</td>
</tr>
<tr>
<td>Out-of-pocket</td>
<td>9</td>
<td>18.0%</td>
</tr>
<tr>
<td>Other(^d)</td>
<td>4</td>
<td>8.0%</td>
</tr>
<tr>
<td><strong>Dental Treatments Needed/Received(^e)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restorative treatment</td>
<td>40</td>
<td>80.0%</td>
</tr>
<tr>
<td>Extractions due to caries/pulp therapy</td>
<td>36</td>
<td>72.0%</td>
</tr>
<tr>
<td>Preventive care only</td>
<td>29</td>
<td>58.0%</td>
</tr>
<tr>
<td>Eruption guidance</td>
<td>22</td>
<td>44.0%</td>
</tr>
</tbody>
</table>

\(^a\) Unable to establish referral source
\(^b\) Several individuals had more than one comorbidity
\(^c\) Other medical diagnosis include cerebral palsy, craniofacial disorders and cancer
\(^d\) Two children had their fees waived
\(^e\) The total amount of procedures exceeds the number of participants as usually more than one treatment was required and delivered

As noted in Table 4.4, 50% of children were referred by a physician (specialist or family doctor). About one quarter of the children 26 % (n=13) were referred by either a pediatric or general dentist. For 20% (n=10) of children, the parent could not remember the source of the referral.
The types of dental benefits were private dental insurance 52% (n=26), public benefits 26% (n=13) and “out of pocket” payments 18% (n=9). The parents of two of the children benefited from waived fees because of economic hardship. These findings on dental insurance were quite similar to parent self-reports (Table 4.3). However, a difference was noted for public benefits: 26% of parents self-reported public benefits compared to 36% in the dental chart.

Dental treatment required was charted at the dental examination. Thirty-one percent (n=17) of children needed restoration of one to three teeth while 31% (n=17) needed more than three teeth restored. Extraction of primary teeth due to caries was a need of 33% of children (n=18). Only two children required permanent tooth extraction. Periodontal debridement was required for 7 children (13%). Almost one-fifth (18.5%; n=10) of the children had to be examined under general anesthesia.

4.2 Qualitative Results:
4.2.1 Open-Ended Questions

The majority of the 33-items on the survey instrument were closed questions but six of the questions were “open-ended” and allowed parents to talk or write about various issues related to their child’s dental health and dental care. The next section is the analysis of this qualitative data. Supporting quotes from parents and caregivers are provided.

When caregivers were asked “Do you believe this child currently has any dental problems?” 37/50 or 74% stated that their child had problems. The types of problems mentioned “fit” three general categories:
1. Problems related to **tooth cleaning challenges**, such as “severe build-up” on the teeth, received mention by about 11/37 of the parents. Similarly, “impossible to keep clean” was a concern of 6/37 parents. Other poor oral health outcomes related to the challenges of mouth care included “bleeding gums” and “staining”.

2. **Tooth decay** was described as “cavities” by 12/37 or about 1/3 of the parents or “rotten teeth” by 2 other parents.

3. General concerns about the child’s **dental development** were expressed as “crowding” by 8/37 parents; “delayed development of teeth” by 4 parents and “mobile/loose tooth” by another parent.

Those parents whose child had no dental problems mostly said that their child was attending the DD-BCCH for a “regular check-up” or was there in advance of a medical procedure: e.g. “preparation for kidney transplant”

Over half of parents 56% (n=28) said “yes” to the question “**has a dental office ever refused or been unable to provide dental work for your child?**” While the parents were quite aware of the medical and behavioural challenges that their special needs child presented, many caregivers talked about the dentist’s **failure or incapacity to engage their child**:

- “circumstances dentist could not see”
- “dentist wasn’t able to engage”
- “did not feel comfortable’
- “unable to treat”
- “dentist [doesn’t] know how”
- “uneasy dealing with’
“office not specialized”
“normal dentist office do not have people trained
“dentist [doesn’t] know how to deal with someone who doesn’t want to open”

Parent’s acknowledgement of their child’s “complicated” medical condition was obvious from comments like “takes seizure medications”, “his care is very complicated”, “had a cardiac problem”, “child with autism”, or “due to medical condition (seizure disorder)”. Parents made few comments related to the child’s behaviour but some parents did admit “difficult behavior”

The remaining parents whose child had never been refused treatment at a previous dental office had either been directly referred to BCCH from birth “never seen a dentist outside BCCH” or had been referred (directly) to BCCH by another medical or dental professional: “medical specialist referred”, “only way to treat is under general anesthesia”; “for medical reasons”

About one half of the children had seen a dentist prior to the referral to the DD-BCCH. As in the previous question, parents commented on experiences with their “hopeless regular dentist.” The comments that parents made included: “because of her medical condition the dentist didn’t feel comfortable treating my child”, “the dentist didn’t want to treat him. He was afraid of complications and referred us to BCCH”, “regular dentists are hopeless as they do not know what to do with her…”, “not a very good experience…” These comments also extended to specialist pediatric dentists: “our son saw a private pediatric dentist who had no experience with autistic children”; “I went to a pediatric dentist who did check-ups and fluoride (only)….”; “the pediatric dentist was unable to treat my child and referred us to BCCH”; “….when we took our
child to see a pediatric dentist, four people had to restrain him...”; “...I was not impressed with her (pediatric dentist) practice and code of conduct...”; “...had a pediatric dentist who was basically overcharging and giving poor service.....”

The remaining half of the children had received dental care only at DD-BCCH so had no “dental experience” prior to referral. Parents spoke of both the enabling factors in accessing dental care for the child at DD-BCCH and the challenges. Helpful factors included: “For us it has been easy at BCCH. All the services are here, easy to get appointments...”; “special care, tender approach, specialized attention for apprehensive children”; “No challenges. She has only been cared for at BCCH’S dental department”, and “BCCH dental clinic has dramatically improved our son’s health and wellbeing.” Any challenges at BCCH-DD were related to logistical issues: “mostly related to location [of BCCH], coordination of appointments...”; “the waiting time to get in to see a dentist at BCCH”; “trying to get an appointment at BCCH in an emergency, or just a regular check-up, having to wait 5 months after referral, unpleasant receptionist, traveling to Vancouver...”

Of note, is that financial challenges (affordability) were mentioned throughout the comments: “I didn’t have the funds to pay for her dental treatment’; “I prefer BCCH because is less expensive...”; “...due to insurance limitations we can only access BCCH”; “he needed surgery that was going to cost more at the private pediatric dentist than at BCCH”; “he is not covered under MSP for any treatment other than the general anesthetic. Our private insurance is only paying $400 of approximately $2800 worth of dental work”; “me and my husband believe that his treatment should be covered by MSP.”
Perceived treatment need by caregiver in contrast to actual need as determined by examining dentist:

A comparison between perceived need as reported by the caregiver and actual treatment needs determined during examination was obtained for each child. This comparison is provided in detail in (Appendix F) which lists caregiver’ reports and compares them with the actual results as described by the examining dentist either during the GA procedure or in the Dental Department.
5 DISCUSSION

5.1 Study Limitations

This pilot study has limitations which were primarily related to recruitment issues, but also to implementation of the study. Initially, recruitment was based on an expression of interest by a parent returning a signed consent form to the investigator. However, after mailing out a total of 224 letters of information to potential subject-parents with a stamped return envelope the return rate was only 5%. This rate is significantly below return rates for similar studies which report a rate from 40% to 80% of a targeted population [15, 34, 35, 37, 60].

Modifications to recruitment were implemented because of the low response rate. The modifications approved by BREB included the investigator directly approaching parents to inform them about the project while they were in attendance at the dental clinic. When parents expressed interest in participation, informed consent was immediately obtained and a survey link was emailed to allow completion of the survey. This method yielded many more participants. Nevertheless, not all the “interested” parents actually completed the survey even after several electronic reminders were sent. Parents explained not responding to the survey by saying that they were “too busy”, had “changed their mind”, or, “my husband did not want me to”.

Another aspect of recruitment that was modified pertained to interviewing the parents when they accompanied their child to either a dental appointment in the clinic or dental treatment under general anesthesia. In these situations, parents declined to participate or simply provided short, dismissive answers. Likely they were emotionally overwhelmed and/or were worried about the outcome of their child’s concurrent surgery.
It was possible, as well, that these parents had limited time available at the dental clinic as usually they coordinated multiple appointments during a single visit to BCCH and had to rush off to another clinic. Therefore, the sample of parents who participated in the study was not random. Rather, they were ‘volunteers’ who felt encouraged to do so perhaps because they wished to share their stories to either praise or critique the services they had received. Respondents in our study also seemed to be more descriptive and effusive when they needed to “vent” or “complain” about negative experiences. Further, the small financial incentive of the $15 gift card may have encouraged some parents to participate. Finally, some parents had never interacted with dentists outside BCCH and felt that they had never experienced barriers to dental care. Thus, they merely wanted to share their positive appraisal of the services received at the dental department at BCCH.

The study recruitment was also affected by the finding that foster care parents are not authorized to take surveys on behalf of the children in their care. A large number of caregivers of CSHCN who attend at DD-BCCH are foster parents or group home providers. Unfortunately, this important segment of carers for CSHCN is not represented in our study sample.

The “consenting” caregivers generally preferred to take the survey on their own time. Therefore, the electronic format was preferred over telephone or personal interview. Participants reported that the electronic format was user-friendly and allowed them to return to the survey at a later more convenient date if necessary. Generally, caregivers were willing to share their stories and experiences.
Surveys present inherent biases [61]. For example, in our sample, the participants who volunteered to complete the survey may have been those who experienced few barriers to care. One possible explanation is that this sample has a sizeable proportion of highly educated and relatively affluent parents who have private insurance coverage. Such parents are often experienced at advocating for their child and thus obtaining required services. These parents are fully engaged in all the aspects of the medical and dental care of their CSHCN.

In regards to comparing parental perceptions and awareness of the oral health of their child with actual need, unfortunately, the sequencing of the steps of the project did not allow for identification of parents’ perceptions. This problem occurred because most parents answered the survey after their child’s dental examination was completed. A parent’s baseline perception of child’s dental health status before the dental examination was not obtained. Two of the participants were recruited at an “emergency” or “other” type of visit. Even these parents likely completed the survey at home after learning of their child’s dental needs from the clinic visit. Our hope had been to have parents complete the survey in the waiting room before the dental visit, but because this sequence of events did not occur, comparison of actual need with the perceived need was impossible.

5.2 Demographics

Most of the children in the study were from two-parent, well-educated families from middle and upper socioeconomic groups with private dental insurance coverage. This outcome regarding the “nature” of the participants has been reported in other surveys. In a survey based study of CSHCN conducted in Massachusetts [26], married
couples with a college degree or higher and an income of above $100,000 were overrepresented. In another US study that assessed the dental need of children with autism, it was also noted that a high percentage of the caregivers who responded appeared to have been educated beyond high school and earned 200% above the income level measured by the Federal poverty line (FPL).

Most of children in our study were Caucasian, Canadian-born from families who spoke primarily English at home. In contrast, Statistics Canada reports that about one-third of the population of BC were born outside Canada, mainly in Asia (China, Korea, India and the Philippines\textsuperscript{15}). The representation from such ethnic groups in our study was low. The participation of these minorities may have been limited because of language barriers; the survey was not translated into other languages such as Chinese, Tagalog, Hindi, Punjabi and Farsi\textsuperscript{16}.

With respect to place of residence, the majority of the families (n=49) in our study lived in an urban or a metropolitan area. This distribution of place of residence is in agreement with the findings of the report by Mathu-Muju et al [39]. Families who live in isolated, rural or remote communities were simply not represented in our study. For this reason, we gained no additional insight into the challenges that families from rural areas faced accessing dental care for their CSHCN.

In regards to the details of the method of payment for dental services, for parents who had private dental insurance, the self-reported percentage was the same as what was recorded in the dental chart. However, 36% of parents self-reported public benefits compared to only 26% noted in the dental record. Certainly, this discrepancy suggests some misunderstanding on behalf of parents about what “government benefits” they may be entitled to for the dental care for their child. The BC government Medical Services Plan only “covers” the cost of dental general anesthesia at BCCH and any needed extractions. Alternatively, some parents may have thought their child qualified for the government’s Healthy Kids program, but the DD-BCCH inquired and determined that the child was ineligible for these benefits.

The discrepancy in the report of out-of-pocket payments between self-reports and the dental chart record may have been due to misunderstandings or uncertainty about the extra fees that parents often have to pay when the private or public insurance is insufficient to cover the cost of dental treatment. Often, the amount of this extra fee is unclear until the child’s dental treatment is actually completed.

5.3 Medical Diagnosis

The main medical diagnoses for the children in our study were genetic disorders or syndromes, developmental delay, visual/speech/hearing impairment, autism and seizure disorder. These stated medical diagnoses are similar to a previous report from British Columbia Children’s Hospital, where of all CSHCN treated under general anesthesia from 2009 to 2011, developmental delays, autism, intellectual disabilities and seizure disorders were the main medical diagnoses identified during that time period [39]. Because of the modest sample size in our study, correlations between
specific medical conditions and the ease or difficulty in obtaining dental care were not explored. However, an Ontario study [38] reported that patients with certain types of medical conditions faced more difficulty in obtaining dental care than those with other conditions. Similar results have been reported by others [14, 26]; this correlation may be reasonable to explore in future research in BC.

5.4 History of Dental Care

5.4.1 Preventive and Restorative Care

Most CSHCN in our study had a previous examination (80%) and preventive dental care (66%) and most had seen a dentist within the past year. Positive associations between the type of dental coverage and receiving preventive dental care have been previously reported [52]. Given that over half of the CSHCN in our study had private dental insurance, it is not surprising that they were such “positive dental attenders”; cost of care was not a barrier for most. However, restorative care (“fillings” and “caps”) was reported in relatively low proportions by parents in our study (53% and 40%). Some parents complained that their child had received only “check-ups” and “cleanings” prior to coming to DD-BCCH. However, definitive restorative treatment was never attempted or achieved even though there was clinical evidence of caries. Parents were sometimes told to “keep an eye on cavities”. When there was enough evidence of progression of decay, a referral to either a pediatric dentist or BCCH was initiated.

Restorative care has been reported to be a common unmet dental need in the SHCN population, more so than preventive care [33]. This unmet need is possibly due to factors such as the extra time associated with delivering restorative care and the
added risk of complications (aspiration, drug interactions, stress-induced complications, bleeding and even infection). Conditions such as Down syndrome, cerebral palsy, autism and other forms of mental and developmental disabilities are some of the medical conditions that are associated with increased unmet restorative needs for CSHCN who are often limited in their ability to “cooperate” for dental care in an ambulatory setting \[14, 33\]. Not surprisingly, for those who need general anesthesia to enable dental care, current wait lists at DD-BCCH for non-urgent care are 5 to 6 months (K. Campbell, Head, DD-BCCH, personal communication)

5.4.2 Dental Pain and Infection

Caregivers in this sample of CSHCN reported that few children had experienced a dental infection. Furthermore, pain was not frequently reported. This finding is in contrast to reports from the United States and Canada where according to national estimates, 5% of children and 10% of adolescents reported persistent pain anywhere in the mouth. The reported prevalence of pain was even higher (15%) in the CSHCN population \[22, 62\]. One reason for few parental reports of mouth pain is that the great majority of children in our survey had varied degrees of intellectual and/or developmental disabilities. Obviously such disabilities have a direct impact on one’s ability to accurately report pain. As a result, we relied on their caregiver’s “interpretations” of their child’s experiences, which may have been change in behaviour or eating patterns. In addition, the majority of the children in this study were fairly regular attenders at BCCH and had been receiving regular care. Indeed, 90% of the children in our study had attended for a dental appointment within the last year. This
proportion is identical to that reported by the CHMS for 6-11 year old “healthy” Canadian children [22].

5.4.3 History with Dental Providers

Over half of the respondents stated that their CSHCN had been refused care or their dentist had been unable to treat them. This percentage is greater than other reports where 1/3 or 35% of caregivers of children registered with Children’s Rehabilitation Services of Alabama reported difficulty finding a dentist willing to treat their CSHCN, especially when the child had cerebral palsy and epilepsy/seizure disorder.[32]

The caregivers in our study reported that they felt that often their family dentist lacked adequate skills and/or resources to treat their CSHCN. This was true in particular, when the child had difficult behaviour or comorbidity perceived as “high risk” for medical complications. Parents commonly remarked that their child had a “complicated medical condition” or “his care was very complicated”. Parents in our study reported both general and pediatric dentists as unable and/or unwilling to treat CSHCN. Certainly only a small percentage of general dentists have the training, experience or willingness to treat CSHCN with complex medical conditions [51, 63]. Therefore, pediatric dentists, who usually receive specific training in the management of CSHCN are the main dental providers for this patient population [63]. However, in our study some pediatric dentists were perceived as being unable and/or unwilling to treat CSHCN. A possible reason for this perception may be related to the severity of the child’s medical condition necessitating referral to a hospital-based clinic like DD-BCCH.
because of serious concerns about complications from dental treatment. Some of the medical conditions that have been associated to increased risk for complications due to dental interventions are bleeding disorders, cerebral palsy and seizure disorders [53, 63].

Further, dental treatment for CSHCN requires more chair time and staff resources thereby increasing the cost of treatment. However, the majority of government-funded dental plans and even private dental insurance plans do not often compensate for the extra time and resources needed. [52, 53]. If the pediatric dentist determines that the reimbursement for the services provided by the dental insurance or government program is insufficient to cover their costs, then a payment may be requested of the family. Such fees may be a barrier to care for many families. The pediatric dentist may decide that the best place for the child to receive treatment is in a publicly-funded hospital. Additionally, it could be simply that some general and pediatric dentists do not have the training, skills or willingness to treat some of the children within this challenging patient population.

In contrast, studies in other locales have reported few problems with caregivers finding a dentist [64]. The dentists’ ability or willingness to provide dental care to CSHCN was not a common barrier to access dental care cited by caregivers surveyed. Instead reasons such as the high cost of dental care, lack of insurance and the severity of the medical condition were commonly reported [9, 33, 35].

Reasons from the parental perspective that have been commonly associated with dentists being unable or unwilling or to treat CSHCN are diverse [9, 26, 31-33]. A
caregiver in our sample described a dentist as “hopeless”. This comment seemed to relate to their dentist’s lack of knowledge dealing with the behaviour and/or the medical condition of the child. This finding is similar to the results of a large survey study conducted in Massachusetts [26]. About half of the parents in our study reported that the child had difficulty obtaining dental services because the “child does not like to have anything done to his/her mouth”, “cannot behave cooperatively” or “<the child's> medical conditions make dental treatment very complicated.

Financial limitations and insurance coverage issues were reported by parents in our study. Statements such as “I prefer BCCH because it is less expensive…”, “…due to insurance limitations we can only access BCCH” and “<we> believe that the treatment should be covered by MSP…” Challenges with insurance coverage and the cost for dental treatment as barriers to obtaining dental care have been reported in other surveys [9, 14]. The dental services at DD-BCCH tend to be perceived by parents as being free or less costly compared to private dental providers. The reasons for this belief are varied. In special circumstances at BCCH, parents may pay lower fees in comparison to private practices or private surgical facilities because of available charity funds or discounts for hardship. Further, BCCH does not balance bill the government’s Healthy Kids program for those children who are eligible. Also, procedures such as dental emergencies, dental extractions, fees for general anesthesia and hospital fees are billed directly to the Medical Services Plan of British Columbia (MSP)17. Another reason for parents perceiving that dental services are “free” is that the DD-BCCH is a publicly funded facility that adheres to the mandate to treat all children whether or not

they can pay for their services whereas the private dentist may not provide care if the parents lack financial resources\textsuperscript{18}.

Challenges to dental care have been identified in other studies [31]. Results of a cross-sectional survey in Alabama, Georgia and Mississippi, showed that dental insurance coverage was insufficient; about 75% of caregivers had to incur out-of-pocket costs to obtain all the dental care needed by their CSHCN. In another questionnaire-based study in North Carolina, [35], the main problem encountered by the individuals was related to financial constraints. Similar findings have been reported by others [9, 14, 34]. Of course, financial barriers to dental services are common to all vulnerable populations [34].

5.4.4 Sources of Referral

About half of the children who attended the DD-BCCH were referred by a medical professional either a family physician, a pediatrician or another medical specialist either at the BCCH or in the community. These findings are encouraging because they suggest awareness amongst medical providers of the importance of dental care for these medically compromised children. It has been established that dental problems can worsen medical conditions in medically compromised children [11, 30, 60]. One of the caregivers in our study stated that “[they did not seek dental care because] our son was diagnosed with cancer. Dental care was not a priority...” Often other medical conditions, due to their life-threatening nature, will take priority over

elective dental procedures. However, more physicians that care for CSHCN now realize the importance of a healthy mouth in relation to overall wellbeing of the individual. In fact the American Academy of Pediatrics (AAP) and the Canadian Pediatric Society (CPS) have recognized the burden that dental disease places on overall child health and the possible complications of neglecting dental care. Therefore, the AAP and CPS have emphasised the need for pediatricians to assess oral health as an integral part in the examination of any child and in particular those with special needs [65].

5.4.5 Parental Perception of Dental Needs

Our findings from the open-ended questions suggest that about three-quarter of parents believed their CSHCN had a current dental need. Problems most frequently reported by these parents included difficulty to provide oral hygiene which resulted in gingivitis (“bleeding gums”) and staining of the teeth. Dental caries (“cavities”) and developmental problems (“crowding”) were also reported. A US study, which compared parental perceptions of dental needs of CSHCN to that of a group of CWOSN concluded that “cavities”, “broken teeth”, “tooth staining”, “tooth grinding”, “pain” and “crooked teeth” are common complaints for both CSHCN and CWOSN. However, the group of children that appeared to report the worst oral health were the CSHCN that had conditions that affected behavior, speech, learning disabilities, developmental and intellectual disabilities. [9, 13]

Unfortunately, the sequence and process of our study did not allow a valid comparison of perceived need for treatment compared to actual need. Because the majority of parents completed the survey after their child’s visit to the dental department,
their responses were influenced by the information about their child’s dental condition told to them at the visit. However, it is noteworthy that usually the dental needs of CSHCN are grossly underestimated by caregivers and dentists alike [46]. Obviously, the best time to ask parents about their perception of their child’s dental needs would be at their first visit to BCCH-DD prior to the oral examinations.
6 CONCLUSIONS

For children with special health care needs who are patients of the Dental Department at British Columbia’s Children’s Hospital (DD-BCCH)

- The complexity of the child’s medical status, limited ability of dental providers to deliver care and financial obstacles were commonly-reported barriers to access dental care identified by parents.

- The enabling factors for dental care were related to the ease, convenience and for some, cost, of obtaining services at DD-BCCH once a need was recognized by a health care professional. Parents reported that the dental department provided specialized services delivered by personnel who had the skills and the disposition to treat their children.

- Parental perception of the oral health status of the child could not be reliably assessed.

- A mail out survey design to families of record proved not to be a suitable method to obtain information about issues of access from a representative sample of BC families with children who have special needs.
7 RECOMMENDATIONS

A purpose of this pilot study was to test our survey instrument and to assess our study design in anticipation of a larger study to identify barriers to dental care faced by parents of CSHCN in British Columbia. However, with the present study protocol we were unable to recruit a large sample of representative caregivers of the CSHCN who access the DD-BCCH. Therefore, to obtain an enhanced understanding of enabling factors and barriers, a few key screening questions should be added to the intake form for all CSHCN who are new patients of the DD-BCCH. At this first appointment, caregivers may have recent experiences of challenges of access to dental services. Also, this strategy will reliably assess the parent’s perception of the oral health status of their child prior to the oral assessment. Translation of the intake form may also be helpful. Suggestions for items to add to the intake form are:

1. History of the referral: (who referred the child, the reason the referral was made and why and when?).
2. A brief description of the parent’s current perception of the oral health of the child.

In order to survey a broader sample of CSHCN, caregivers of CSHCN that are patients of BCCH but do not receive care at the dental department or are seen by dentists in the community could also be included. Such an approach will include a more diverse group of children from around the province who experience issues of access to dental care. However, given the recruitment challenges experienced in our study with a mail-out survey, a different approach is recommended.
The perception of parents that both general and pediatric dentists were unwilling and/or unable to treat their CSHCN should be addressed with further research, for example, a survey of general and specialists pediatric dentists in BC. Such a survey may help to further clarify the issues that impede and act as barriers to care for CSHCN from the perspective of dental providers. This survey is presently under development in the Division of Pediatric Dentistry at UBC.

From the financial perspective, policies and dental benefit plans should be enhanced. One suggestion is validation of the use of codes such as “unusual time and responsibility”. This practice would increase the dentist’s reimbursement when extra time or effort was involved and would likely enable more CSHCN in British Columbia to receive required dental care. Increasing benefits and reimbursements may increase the number of providers willing to provide care. It could also alleviate the financial barriers to access to care experienced by many families whose children have special health care needs.
BIBLIOGRAPHY


“Access to Dental Services for Children with Special Health Care Needs”

 Volunteers Needed

YOU MAY BE ELIGIBLE IF ………

☐ You are the caregiver of a child with special health care needs (for example, Autism, Cancer, Cerebral Palsy, Down Syndrome, ADHD, Developmental Delay)

☐ Your child is a patient of the DENTAL DEPARTMENT here at BC Children’s

If you are interested please ask reception for a ‘Letter of Information’

Participants will receive Parking costs OR Gift Card $15 VALUE
APPENDIX B: LETTER OF INFORMATION

I would like to announce that Dr. Nancy Vertel, one of our Pediatric Dentistry Graduate Students from UBC is currently conducting a research study in our Dental Department at BC Children Hospital. The study is entitled "Access to Dental Services for Children with Special Health Care Needs: A Pilot Study at BC Children’s Hospital Department of Dentistry". Her research supervisors are Dr. Karen Campbell, Staff Pediatric Dentist and Assistant Professor in Pediatric Dentistry at UBC and Dr. Rosamund Harrison, Professor in Pediatric Dentistry at UBC.

The purpose of Dr. Vertel’s study is to identify the problems that YOU as a caregiver of a special needs child have encountered to get your child’s teeth looked after. As such, the study involves collecting information in two steps:

1. A personal interview with you, the parent or main caregiver of the child;
2. A look through your child’s hospital dental chart.

You and your child’s name and personal information will be kept confidential. Any information used in the study reports will not be identified by name. You have the right to refuse to answer any of the questions or withdraw from the interview process at any time for any reason. This will not affect the care your child receives at BC Children's Hospital.

The interview times will be pre-arranged at your convenience. The interview takes about 45 minutes of your time and as a token of appreciation for your participation the study team offers you to choose from:

- reimbursement for your parking costs while at the hospital during your child’s dental appointment up to a value of $ 15 dollars, OR
- a pharmacy gift card of $ 15 dollar value.

This study, the first of its kind in BC, aims to better understand the dental needs of special needs children in our province. Also, the study will identify things or people that helped or hindered families in their journey to obtain dental care. The study findings will become part of a report that will be shared with you (if you wish), professional dental groups, other researchers and government policy makers. Hopefully, it will lead to recommendations designed to improve things for families seeking dental services for their special needs children.

I encourage you to consider participating in this very important pilot study. If you have further questions about the study, please feel free to contact the study team below.

Kind regards,

Douglas H. Johnston, DDS, MSc, FRCD(C), FCDS(BC)
Head, Pediatric Dentistry, BC Children’s Hospital
Director, Graduate Pediatric Dentistry, UBC

Study Team Contacts:
Principal Investigator:
Dr. Karen Campbell

Co-investigator:
Dr. Nancy Vertel
Title of Research Project: "Access to Dental Services for Children with Special Health Care Needs: A Pilot Study at BC Children’s Hospital Department of Dentistry”.

Principal Investigator: Dr. Karen Campbell
Assistant Professor, Dept. of Oral Health Sciences, UBC
Email:

Co-Investigator: Dr. Nancy Vertel, Graduate Student in Pediatric Dentistry, UBC
Email:

Introduction: We would like to hear from you about your experience getting dental care for your special needs child. From this study, we also hope to learn a bit more in general about the oral health of BC’s children with special needs.

Your participation is entirely voluntary: It is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what this research study involves. This consent form will tell you about the study, why the research is being done, what will happen during the study and the possible benefits and risks.

If you wish to participate, you will be asked to sign this form. If you do decide to take part in this study, you are still free to withdraw at any time and without giving any reasons for your decision.

If you do not wish to participate, you do not have to provide any reason for your decision not to participate nor will you lose the benefit of any dental care to which your child is entitled or is presently receiving. Subjects do not waive any of their legal rights by signing this consent form.

Please take time to read the following information carefully before you decide.

Background to the study: No one has ever done a study of this kind in BC. We often hear from parents that they have difficulty getting dental care for their child with special needs, but no one has ever collected information about it. We also want to know more about the status of oral and dental health of this special group of children in our province.

What is the purpose of the study? By gaining a better understanding of: 1) the scope of oral health needs of children with special health care needs; 2) factors that helped caregivers get dental care for their child, and 3) some of the challenges along the way, we can begin working toward resolving some of the issues to make access to dental services easier.

Who can participate in the study? You may choose to participate if:
- your child has "special health care needs” and is an current patient at the Dental Clinic at BC Children’s hospital;
- you are comfortable communicating in English
What does the study involve: If you agree to participate, we will arrange a personal interview with you to ask you some questions about yourself, your family situation, your child’s medical conditions, past dental history and experiences with past dental care. This 45 minute interview will take place while your child is having treatment at the hospital in the clinic or in the operating room and will be held in a private area. Alternatively, you may wish to have an interview by telephone, set at a mutually-agreeable time. We would also like to review your child’s dental chart to see what dental conditions are present and what type of treatments have been recommended.

Potential Harms, Injuries, Discomforts or Inconvenience: We may ask you to share some personal information (eg., your ethnic background, range of family income). Should you feel uncomfortable about these questions, you have the right to refuse further participation without compromising your child’s future dental care at the clinic. Participation in the study will require about 45 minutes of your time, which rarely may extend beyond the time for your child’s dental visit.

Potential Benefits: As a thank-you for participating you may choose from a $15.00 pharmacy gift card OR reimbursement for public transit/parking up to a $15.00 maximum.

Alternatives to participating in the study: Your child may have their regular dental care as a patient of the clinic even if you do not participate in this research study.

What happens if I decide to withdraw from the study? You do not have to provide any reasons for your decision to withdraw from the study. Your child may continue to have their regular dental care as a patient of the clinic. We will retain any data collected up to the point of your withdrawal from the study.

Confidentiality: Your confidentiality will be respected. No information that discloses you or your child’s identity will be released or published without your specific consent to the disclosure. However, research records and dental records identifying you may be inspected in the presence of the Investigator or his or her designate by representatives of the UBC Research Ethics Board for the purpose of monitoring the research. However, no records which identify you by name or initials will be allowed to leave the Investigators’ offices.

Who do I contact if I have questions about the study during my participation?
The persons who may be contacted about the research are:

   Dr. Karen Campbell      Email:
   Dr. Nancy Vertel       Email:

Who do I contact if I have questions or concerns about my rights as a subject during the study?
If you have any concerns about your/your child’s rights as a research subject or experiences, you may telephone the **Research Subject Information Line** in the UBC Office of Research Services at: or contact by email at:
Title of Research Project: "Access to Dental Services for Children with Special Health Care Needs: A Pilot Study at BC Children’s Hospital Department of Dentistry”.

Subject Consent to participate:

I acknowledge that the purpose of this study has been explained to me and that any questions that I have asked have been answered to my satisfaction.

- I have been informed that I have the right not to participate and the right to withdraw without compromising the dental care of my child. I also understand the benefits (if any) of participating in this survey.
- I know that I may ask now, or in the future, any questions I have about the study or the research procedures.
- I have been assured that records relating to my child and my child’s care will be kept confidential and that no information will be released or printed that would disclose personal identity without my permission unless required by law.
- I also understand that I do not waive any of my legal rights by signing this consent form.
- I am aware that I will receive a signed and dated copy of this consent form.

I ___________________________ (Parent/Caregiver PRINTED NAME) hereby consent to participate as the primary caregiver of _______________________________ (CHILD’S NAME PRINTED).

I wish to be informed about the results of the study  YES  NO  (please circle)

I give my permission for the study team to contact me in future should clarification of any information be necessary  YES  NO  (please circle)

Signature of Parent/Caregiver: ________________________________

Date: _______________________________

Name of Investigator/Designate (PRINTED): ________________________________

Signature of Investigator/Designate: ________________________________
Caregiver Interview - Access to Care for CSHCN: A Pilot Study at BC Children’s Hospital Dental Department

CHILD & FAMILY DEMOGRAPHICS

1. Date of Interview: Day_____ Month_____________ Year____________

2. This interview took place:
   a. At BCCH-DD
   b. During GA procedure
   c. By telephone

3. What is your relationship to this child?
   a. Mother
   b. Father
   c. Foster Parent
   d. Grandparent
   e. Other: _____________

4. Do you live in a:
   a. Rural area (Population less than 20.000 people)
   b. City (More than 20.000 and less than 100.000)
   c. Metropolitan area (More than 100.000 people)

5. Town/City of Current Residence_____________________________________

6. Gender of child: M F

7. Child’s date of birth

   Month: ____  Year: ____
8. Country where the child was born: __________________________

9. How long has the child's family been in Canada? _________________

10. What language is spoken at home with this child? _________________

11. Child’s ethnicity:
   • Caucasian
   • Aboriginal
   • Chinese
   • Filipino
   • South Asian (India, Sri Lanka)
   • South East Asian (Cambodia, Thailand, Vietnamese etc.)
   • West Asian (Iran, Iraq, etc.)
   • Korean
   • Japanese
   • Latin American
   • Other: ______________________

12. Describe the child’s living situation?
   • Two parent family
   • Lone parent
   • Lone parent, plus extended family (grandparent, etc.)
   • Other (please describe): ______________________________

13. How many siblings live in the same home as this child? ________

14. What is the household income (before taxes):
   • <20,000
   • 20,000 to 30,000
   • 31,000 to 45,000
   • 46,000 to 70,000
   • 70,000 & above

15. Please indicate the main caregiver’s highest level of education.
   • Elementary school
   • Secondary (high school)
   • Post-Secondary (College, University)

16. How is this child’s dental treatment paid for? [check all that apply]
   • Out-of-Pocket (You are paying)
   • Private dental insurance (through parent’s employer)
17. **What is the child’s primary medical condition? Indicate all that apply.**

- Autism/pervasive developmental disorder/Asperger’s syndrome
- Cerebral palsy
- Seizure disorder
- Cystic fibrosis
- Impairment
- Metabolic disorder/cardiac/renal/immunologic
- Haemophilia/sickle cell/Von Willebrand disease
- Other: (Please specify)

- Developmental delay (neurologic, behavioral, chromosomal)
- Down syndrome
- Speech, Hearing or Visual
- Craniofacial/cleft lip and palate
- Behavioral/Learning disabilities (ADHD, OCD)
- Cancer
- Genetic Disorder/Syndrome

**CAREGIVER PERCEPTIONS OF ORAL HEALTH STATUS:**

18. **Do you believe this child currently has any dental problems? YES/NO**

a. If, Yes - Describe the problems...

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

b. If, No – Tell us why you are here today...

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

19. **Has the child ever had OR do they now have any of the following (indicate all that apply)?**

- Pain in teeth or mouth
- Facial swelling
- Cavities
- Broken teeth (from a fall or other trauma)
- Abscess (Please explain)
- Gum problems (bleeding gums)
- Tooth/teeth discoloration
- Teeth not coming in when expected
- Frequent mouth sores
- Toothaches
- Crooked teeth
HISTORY OF CARE:

20. At what age did this child have his/her first dental visit? ________

21. When was this child’s last dental appointment?
   - Less than 6 months
   - Btw 6 months and a year
   - Btw 1 and 2 years
   - More than 2 years ago
   - I don’t remember
   - Never been to the dentist

22. Does this child have a family dentist who sees him/her regularly?
   - Yes
   - NO

23. Has a dental office ever refused or been unable to do dental work for the child in the past? YES/NO

a. If, Yes – What were the circumstances?
   ____________________________________________________________________________
   ____________________________________________________________________________
   ____________________________________________________________________________
   ____________________________________________________________________________

f. No – What did you do when you were unable to get treatment?
   ____________________________________________________________________________

24. What have been the main challenges in getting dental care for the child? These challenges may be related to this child and their special needs, the dental office and/or any reason you can think of.
   ____________________________________________________________________________
   ____________________________________________________________________________

25. Tell me about the financial costs to you of seeking dental treatment for this child BCCH-DD?
   - Missed work Yes/No
   - Transport (ferry, flight, cab) Yes/No
   - Hotel Yes/No
   - Parking Yes/No
   - Other Yes/No Please specify___________
26. How many hours did you have to travel to get to this appointment? _________

REFERRAL DETAILS:

27. Who referred your child to BC Children’s Hospital for dental care?
   - Family dentist
   - Pediatric dentist
   - Family Physician
   - Paediatrician
   - Other medical specialist
   - Other (Please specify): ______________________

28. Date of referral: ______________

29. Date of consultation: ______________

30. Date of first treatment booked: ______________

31. Is this appointment a(an):
   - Emergency care
   - First time planned treatment in clinic (fillings, cleaning, sealants)
   - Recall or follow up
   - First time treatment under general anesthesia
   - Second time treatment under general anesthesia
<table>
<thead>
<tr>
<th>PERCEIVED NEED/YES</th>
<th>ACTUAL NEED:</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Bleeding gums, bad breath because he is not brushing properly. He doesn't let me brush his teeth anymore”</td>
<td>2 TO 4 USC, Polish, fluoride</td>
</tr>
<tr>
<td>“Some cavities. Not sure which teeth”</td>
<td>Unable to examine, 1 to 3 teeth need restoration, polish, fluoride</td>
</tr>
<tr>
<td>“She has a hard time brushing, she gets defensive, does not tolerate brushing. I have tried my best but she does not like it”</td>
<td>1 to 3 teeth need restoration, extraction of primary teeth due to caries, sealants, polish, fluoride</td>
</tr>
<tr>
<td>'Decay in her baby teeth. I am concerned about the new teeth because of the staining. I know she needs to have some baby teeth out. I know she has decay in her baby teeth but she does not have pain'</td>
<td>More than 3 teeth need restoration, extraction of primary teeth due to caries, pulp therapy in primary teeth, sealants, polish/fluoride</td>
</tr>
<tr>
<td>'rotten teeth'</td>
<td>More than 3 teeth need restoration, extraction of primary teeth due to caries, pulp therapy, sealants, polish/fluoride</td>
</tr>
<tr>
<td>'her teeth are crowded'</td>
<td>1 to 3 teeth need to be restored, unable to examine, orthodontics, polish/fluoride</td>
</tr>
<tr>
<td>“Cavities”</td>
<td>1 to 3 teeth need restoration, extraction due to caries, scaling, polish/fluoride</td>
</tr>
<tr>
<td>“decay and leaking fillings”</td>
<td>More than 3 teeth need restorations, Unable to examine, polish/fluoride</td>
</tr>
<tr>
<td>“severe grinding and poor oral hygiene due to the difficulty to perform it!”</td>
<td>More than 3 teeth need restoration, extraction of teeth due to caries, Pulp therapy in primary teeth, sealants, polish/fluoride</td>
</tr>
<tr>
<td>“After his Kawasaki disease he had a lot dental problems, rotten teeth. oral infections and a lot tooth aches”</td>
<td>More than 3 teeth need restoration, Extraction of teeth due to caries, Pulp therapy, sealants, polish/fluoride</td>
</tr>
<tr>
<td>“Severe build-up on teeth”</td>
<td>Unable to examine, 2 to 4 units of scaling, polish/fluoride</td>
</tr>
<tr>
<td>“Major cavities”</td>
<td>1 to 3 teeth need restorations, extraction of primary teeth due to caries, polish/fluoride</td>
</tr>
<tr>
<td>“teeth discoloration, cavities, pain in teeth”</td>
<td>More than 3 teeth need restorations, extraction of primary teeth due to caries, pulp therapy, prophylaxis/fluoride</td>
</tr>
<tr>
<td>“no top teeth, loose teeth, etc. Ostegen”</td>
<td>1 to 2 units of scaling</td>
</tr>
<tr>
<td>“improper teeth growth”</td>
<td>Orthodontics</td>
</tr>
<tr>
<td>“Possible orthodontic treatment”</td>
<td>Orthodontics</td>
</tr>
<tr>
<td>on lots of medications, yellow teeth over crowding</td>
<td>Polish/fluoride</td>
</tr>
<tr>
<td>“cavities”</td>
<td>1 to 3 teeth need restorations, polish/fluoride</td>
</tr>
<tr>
<td>“I think the teeth are crooked, the back teeth have decay”</td>
<td>1 to 3 teeth need restoration, extraction of primary teeth due to caries</td>
</tr>
<tr>
<td>PERCEIVED NEED/YES</td>
<td>ACTUAL NEED:</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>“Not anymore. All problems were fixed, and preventative measures were taught”</td>
<td>More than 3 teeth to be restored, unable to examine, prophylaxis/fluoride</td>
</tr>
<tr>
<td>“working on de-sensitization as he still will not tolerate exam or cleaning, etc”</td>
<td>More than 3 teeth to be restored, pulp therapy on primary teeth, Unable to examine, prophylaxis/fluoride</td>
</tr>
<tr>
<td>“due to her condition is almost impossible to keep proper dental hygiene”</td>
<td>Extraction of primary teeth due to caries, more than 3 teeth to be restored, prophylaxis/fluoride</td>
</tr>
<tr>
<td>“Wisdom teeth coming in, no room on bottom Sharp/crooked tooth cutting lip now. know there is still a baby tooth &amp; adult tooth needs to be removed”</td>
<td>Extraction of primary teeth due to crowding, Unable to examine</td>
</tr>
<tr>
<td>“pain in his back teeth”</td>
<td>More than 3 teeth to be restored, prophylaxis/fluoride</td>
</tr>
<tr>
<td>“bleeding, serious teeth malposition, affect his eating, speaking, and language. Lack of some teeth (not come out forever) due to his disability”</td>
<td>Sealants, polish/fluoride</td>
</tr>
<tr>
<td>“She had few cavities and need cleaning”</td>
<td>1 to 2 units of scaling, sealants, prophylaxis/fluoride, 1 to 3 teeth need to be restored</td>
</tr>
<tr>
<td>“Some cavities and teeth spacing. He has had some crowns placed’</td>
<td>Sealants, prophylaxis/fluoride</td>
</tr>
<tr>
<td>“[HE] was on a liquid diet until after 2yrs due to severe GERD. He did not allow us to brush his teeth until approx. 1 year ago. As a result, he has extensive decay and very weak enamel. He may have to have a tooth extracted and have a pulp treatment and it looks like there may be an abscess”</td>
<td>More than 3 teeth to be restored, prophylaxis/fluoride</td>
</tr>
<tr>
<td>Gets cavities squint often</td>
<td>Polish/fluoride</td>
</tr>
<tr>
<td>“Oral Sensory challenges, cannot tolerate brush in mouth, spitting, the taste of toothpaste, anyone helping. He has a very strong gag reflex”</td>
<td>1 to 3 teeth to be restored, prophylaxis/fluoride</td>
</tr>
<tr>
<td>“multiple cavities not enough space for adult teeth to come in overbite and lower jaw issues’</td>
<td>More than 3 teeth to be restored, extraction of primary teeth due to caries, pulp therapy of primary teeth</td>
</tr>
<tr>
<td>“She has a history of grinding so many of her molars are ground down. Weak enamel. Very dry mouth. Inability to clear mouth of food particles after eating. Lots of cavities. Lots of crowns.”</td>
<td>1 to 3 teeth need to be restored, Extraction of primary teeth due to caries, polish/fluoride</td>
</tr>
<tr>
<td>“Delayed development of the teeth. He supposed to have it all now!”</td>
<td>1 to 3 teeth need to be restored, extraction of primary teeth due to caries, polish/fluoride</td>
</tr>
<tr>
<td>“Has not been able to complete 1 successful dental exam - ever. Resulting in numerous dental surgeries etc. Booked now for desensitization program. Dental care is very frightening to my son - however he is very good and immaculate about brushing his teeth”</td>
<td>1 to 3 teeth need to be restored, extraction of primary teeth due to crowding, polish/fluoride</td>
</tr>
<tr>
<td>PERCEIVED NEED/YES</td>
<td>ACTUAL NEED:</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>“He appears to have problems with his enamel. He vomited frequently during chemotherapy and I think that this has damaged his enamel and made his teeth more susceptible to decay”</td>
<td>1 to 3 teeth need to be restored, prophylaxis/fluoride</td>
</tr>
<tr>
<td>“He is missing 11 adult teeth. He never had roots of adult teeth”</td>
<td>Congenitally missing teeth, polish/fluoride</td>
</tr>
<tr>
<td>“No. I thought I was doing all the right things. My child complained of pain sometimes. However, I never checked or thought about his teeth”</td>
<td>More than 3 teeth to be restored, extraction of primary teeth due to crowding, sealants, polish/fluoride</td>
</tr>
<tr>
<td>“I went for his regular exam and I was told he has cavities. Then he was scheduled for his dental surgery”</td>
<td>1 to 3 teeth to be restored, sealants, polish/fluoride</td>
</tr>
<tr>
<td>Cleaning, check-up and filings in preparation for kidney transplant</td>
<td>1 to 3 teeth to be restored, extraction of primary teeth due to caries, sealants, polish fluoride</td>
</tr>
<tr>
<td>“She had problems but is now stable due to the care she received early this year”</td>
<td>1 to 3 teeth need restorations, extraction of primary teeth due to caries, unable to examine, prophylaxis/fluoride</td>
</tr>
<tr>
<td>“ to check on our child's dental condition at regular intervals, at a dental clinic capable of examining children with special needs such as our child's.”</td>
<td>No treatment needed</td>
</tr>
<tr>
<td>“She’s very sensitive mouth and wouldn’t let the dentist to clean her teeth so she's on a special program so that she will get use to the cleaning procedures”</td>
<td>Extraction of primary teeth due to crowding, polish/fluoride</td>
</tr>
<tr>
<td>“Cavities were fixed at a private office”</td>
<td>1 to 3 teeth to be restored, prophylaxis/fluoride</td>
</tr>
<tr>
<td>“ortho consult”</td>
<td>Polish/fluoride</td>
</tr>
<tr>
<td>“A letter was mailed to us as my son has special needs and has been seen at the dental department at children's over the past two years”</td>
<td>Extraction of primary teeth due to caries</td>
</tr>
<tr>
<td>“Follow up exam for dental work done earlier”</td>
<td>Prophylaxis/fluoride</td>
</tr>
<tr>
<td>“Getting a dentist who will work with her is hard- I had a pediatric dentist who basically was overcharging and giving poor service when I decided to try children’s some other dentists I contacted wouldn't work with her period”</td>
<td>Polish/fluoride 1 to 3 teeth to be restored, Unable to examine</td>
</tr>
</tbody>
</table>