

Access to Dental Services for Children with Special Health Care Needs: A Pilot Study at the Dental Department of BC Children's Hospital

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Abstract

Objectives: This pilot study at the dentistry department of BC Children's Hospital (DD-BCCH) in Vancouver, British Columbia, Canada, aimed to explore issues of access to dental services for children with special health care needs (CSHCN).

Methods: Caregivers of CSHCN, who were patients of record at DD-BCCH, were recruited to participate in this study. We collected sociodemographic characteristics, insurance coverage and medical diagnosis, and information on caregivers' perceptions of enabling factors and barriers to dental services using a pretested survey instrument with 33 closed and open-ended questions. We also obtained referral source, insurance coverage and medical diagnosis from the child's dental record. We analyzed quantitative data descriptively and qualitative comments from caregivers thematically.

Results: Common medical diagnoses among this sample of CSHCN ($n = 50$) were: genetic disorder/syndrome, developmental delay, sensory impairments and autism. Half of the children were referred by a medical professional; most (90%) had had a dental appointment within the last year that included preventive treatment. Although most caregivers reported some available dental benefits, affordability of dental services was a concern. Lack of dentist's training or comfort treating CSHCN, because of the complexity of the child's medical condition or behavioural challenges was also a reported barrier.

Conclusions: The complexity of the child's medical status, the limited ability of dentists to provide care and financial obstacles were commonly reported barriers to care. Current efforts may best be focused on encouraging the province's health professionals, including dentists, to facilitate early referral to tertiary-level care for CSHCN whom they consider medically or behaviourally complex beyond their skill or comfort level.

Access to dental services for children with special health care needs (CSHCN) is a multidimensional issue. These children often have complex medical conditions requiring a range of services provided by multiple health care providers, typically in tertiary care centres. Chronic illness may predispose these children to poor oral health outcomes, further complicated by the impact of frequent exposure to sugary medications, less than ideal dietary behaviours, ineffective oral hygiene practices, behavioural challenges and social disadvantage.¹

A number of factors reportedly influence the difficulty or ease with which CSHCN are able to access dental services. These include geographic barriers²; complexity of the child's medical diagnoses³; "high" cost of dental care⁴⁻⁷; limited number of appropriately trained dentists/dental specialists⁸ who are willing^{9,10} and able to provide care; and inadequate reimbursement for the dentists who do provide such care.¹¹ Also, how caregivers perceive the oral health needs of their CSHCN may not always align with the actual state of disease.¹² To date, our understanding of how these factors, singly or combined, act as barriers to dental care for this population is limited, in both British Columbia and across Canada.

BC Children's Hospital (BCCH), located in Vancouver, British Columbia, Canada, is the sole tertiary-care pediatric centre in the province. CSHCN represent about two-thirds of the patient population cared for by the dental department (DD-BCCH). The aims of this pilot study were to explore the factors that influence access to dental services by CSHCN at DD-BCCH and to survey their caregivers' perspectives on their "journey" to secure these dental services.

Methods

For this pilot study, caregivers of CSHCN, who were patients at DD-BCCH as of 1 Jan. 2011, were recruited by letter, posted advertisement or direct request. A 33-item survey of closed and open-ended questions was developed, pretested and administered to the caregiver according to their preference: in person, by telephone or through a secure online platform. After completing the survey, we reviewed the child's dental record to verify caregivers' responses related to some key sociodemographic items, such as medical diagnosis and form of payment for dental treatment.

We analyzed quantitative data descriptively, using means, counts and percentages. We used qualitative description to analyze open-ended survey responses.¹³⁻¹⁵

Ethical approval for this study was granted by the Behavioural Research Ethics Boards of the University of British Columbia and Children's and Women's Hospital.

Results

Quantitative Results

Of the 71 caregivers who consented to participate, 50 completed the entire survey; 70% chose to complete the survey electronically. Our sample was evenly distributed among boys ($n = 25$) and girls ($n = 25$); the age range was 2–21 years (mean 10.2 years, standard deviation 4.7). Most families spoke English at home (Table 1) and (92%) of the children were Canadian-born.

Table 1: Sociodemographic characteristics of children with special health care needs as reported by caregivers using BC Children's Hospital ($n = 50$).

Characteristic	Frequency	
	No.	%
Ethnicity		
Caucasian	24	48.0
Chinese	6	12.0
South Asian	3	6.0
Other	17	34.0
Main language spoken at home		
English	33	66.0
English plus other	13	26.0
"Other" language only	4	8.0
Family income (\$/year)		
< 30 000	14	28.0
30 000–45 000	10	20.0
45 001–70 000	11	22.0
> 70 000	15	30.0

Two-parent families were in the majority (82%), and more than 75% of caregivers had postsecondary education. Annual income for 30% of caregivers was over \$70 000, but 48% of families earned less than \$45 000 and, thus, would be considered low income.¹⁶ About half of the caregivers (52%, $n = 26$) reported having private dental insurance; 36% ($n = 18$) reported public (government-sponsored) dental benefits and 24% ($n = 12$) paid partly or entirely "out of pocket" (Table 2).

Most of the children in our sample had received a previous dental check-up, had a dental appointment within the last year and had a history of preventive dental care (Table 2). Most (62%, $n = 31$) had their first dental visit before the age of 3 years. A history of a dental infection requiring antibiotics was reported by only 14% ($n = 7$). When asked about the out-of-pocket expense of bringing their child for dental care, 57% ($n = 28$) of caregivers reported having to miss a

Table 2: Dental related characteristics of children with special health care needs as reported by caregivers using BC Children's Hospital (n = 50).

Characteristic	Frequency	
	No.	%
Method of payment*		
Private dental insurance	26	52.0
Publicly funded benefits	18	36.0
Out-of-pocket	12	24.0
Other	1	2.0
Type of appointment†		
Recall or follow up	22	44.0
Treatment in dental clinic	16	32.0
Treatment under general anesthesia	8	16.0
Emergency care	2	4.0
Age at the first dental visit		
< 1 year	8	16.0
1–3 years	23	46.0
4–7 years	15	30.0
Don't remember	4	8.0
Dental treatment previously received‡		
Check ups	40	80.0
Preventive care	36	72.0
Fillings	29	58.0
Stainless steel crowns	22	44.0
Extractions	20	40.0
Nerve treatment	4	8.0
Antibiotics	7	14.0
Time since child's last dental appointment		
< 6 months	41	82.0
6 months–1 year	4	8.0
> 1 year	3	6.0
Does not remember/never been	2	4.0

*Some caregivers combined forms of payment

†Data from 2 participants is missing.

‡Caregivers may have reported multiple dental treatments.

day of work for their child's clinic visit.

Caregivers most commonly reported their child's medical condition to be a genetic disorder or syndrome (34%, n = 17), followed by developmental delay (32%, n = 16), impairment, such as vision, speech or hearing (28%, n = 14) and autism (24%, n = 12; **Table 3**). However, the main conditions recorded in the dental chart by a clinician were

Table 3: Health condition of children with special health care needs as reported by caregivers using BC Children's Hospital (n = 50).

Medical diagnosis	Frequency*	
	No.	%
Genetic disorder/syndrome	17	34.0
Developmental delay (neurologic, behavioural, chromosomal)	16	32.0
Visual, speech or hearing impairment	14	28.0
Autism	12	24.0
Seizure disorder	10	20.0
Metabolic, cardiac, renal, immunologic, and hematologic disorders	7	14.0
Behavioural, learning disabilities	6	12.0
Other†	12	24.0

*The number of medical conditions exceeds the number of participants because some had multiple comorbidities.

†Includes cerebral palsy, craniofacial disorders, cancer, prematurity, delayed tooth development, Kawasaki disease, laryngomalacia.

genetic disorder or syndrome (46%, n = 23), autism (28%, n = 14) and developmental delay (26.0%, n = 13 (**Table 4**). Of interest, a lower percentage of caregivers reported a genetic disorder than was recorded by clinicians in the dental chart (34% vs 46%).

About a quarter of the children, 26% (n = 13) were referred by a dentist (pediatric specialist or general dentist). According to the dental charts, 50% of children were referred to DD-BCCH by a physician (specialist or family doctor) (**Table 4**). The remaining 24% were either referred by another health care professional (e.g., health authority staff) or the referral information could not be recalled by the caregiver and could not be determined from the dental chart.

Similar to caregiver self-reports (**Table 2**), dental charts revealed that 52% (n = 26) of caregivers had private dental insurance (**Table 4**). "Out of pocket" payments were made by 18% (n = 9) according to record, but 24% of caregivers reported this method of payment. However, for public benefits, 36% (n = 18) of caregivers self-reported public benefits compared with 26% (n = 13) recorded in the dental chart, indicating that dental staff had subsequently determined their ineligibility for public benefits when care was delivered.

Qualitative Results

The 6 open-ended survey items allowed caregivers to expound on issues related to their child's experience of dental health and dental care. When caregivers were asked, "Do you believe this child currently has any dental

Table 4: Information obtained from BC Children's Hospital dental records of children with special health care needs ($n = 50$).

Characteristics	Frequency	
	No.	%
Referral source		
Medical specialist (includes pediatricians)	20	40.0
Dentist (includes pediatric dentist)	13	26.0
Family doctor	5	10.0
Other health care professional	2	4.0
Not specified	10	20.0
Medical status^a		
Genetic disorder	27	46.0
Autism	14	28.0
Developmental delay (neurologic, behavioural, chromosomal)	9	18.0
Metabolic, cardiac, renal and hematologic disorder	9	18.0
Seizure disorder	8	16.0
Visual, speech or hearing impairment	3	6.0
Behavioural/learning disabilities	4	8.0
Other†	7	14.0
Dental benefits^b		
Private dental insurance	26	52.0
Publicly funded benefits	13	26.0
Out-of-pocket	9	18.0
Other‡	4	8.0

^aThe number of medical conditions exceeds the number of participants because some had multiple comorbidities.

^bSome caregivers used more than one method of payment, so may not coincide with n value.

† Includes cerebral palsy, craniofacial disorders and cancer.

‡ For 2 children, fees were waived.

problems?" 74% ($n = 37$) stated that their child had problems. The types of problems mentioned fell into 3 general categories: tooth cleaning challenges ("severe build-up," "impossible to keep clean"), tooth decay ("cavities," "rotten teeth") and general concerns about the child's dental development ("crowding," "delayed development of teeth"). Caregivers whose child had no dental problems usually said that their child was attending DD-BCCH for a "regular check-up" or was there in advance of a medical procedure ("preparation for kidney transplant").

Over half of caregivers 56% ($n = 28$) said "yes" to the

question "Has a dental office ever refused or been unable to provide dental work for your child?" Over half of the respondents ($n = 26$) also reported that they had attempted to have their child see a dentist outside of BCCH before being referred. Although caregivers well understood the medical and behavioural challenges their special needs child presented ("child with autism," "his care is very complicated"), many caregivers talked about their perceptions of the dentist's failure or incapacity to engage their child ("normal dentist office do not have people trained," "dentist [doesn't] know how") or commented on experiences with their "hopeless regular dentist." These perceptions extended to specialist pediatric dentists as well ("our son saw a private pediatric dentist who had no experience with autistic children," "had a pediatric dentist who was basically overcharging and giving poor service").

The remaining children had received dental care only at DD-BCCH, so had no other experience of dentistry before referral. Caregivers spoke of both the enabling factors in accessing dental care for their child at DD-BCCH and also 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"; and "BCCH dental clinic has dramatically improved our son's health and wellbeing." Any difficulties at DD-BCCH were practical issues: "mostly related to location [of BCCH], coordination of appointments"; "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...."

Notably, financial challenges (affordability) were mentioned throughout: "I didn't have the funds to pay for her dental treatment"; "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 [government-funded Medical Services Plan] 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."

Discussion

This pilot study is the first of its kind to investigate the challenges that caregivers in British Columbia encounter when accessing dental services for their CSHCN. Our sample consisted largely of English-speaking, well-educated, mid-to-lower-income caregivers. Although many had access to some form of dental benefits for their child, most expressed concern about the affordability of dental services. All of the children had medical diagnoses that could compromise oral and overall health outcomes in the

absence of dental supervision. However, it was encouraging to learn that many of the children had a history of preventive care and had been spared from more serious dental complications, such as infection. Of the families that had only attended DD-BCCH, most were quite satisfied with the level of care they received. Caregivers who attended DD-BCCH only after being referred by their physician or dentist expressed frustration because their child had previously been unable to receive care at all or not in the manner they had hoped for. Oral hygiene challenges, tooth decay and issues with their child's dental development represented the common dental concerns of the caregivers surveyed.

This project is not without limitations. Recruiting caregivers to obtain an adequate number of complete surveys was an ongoing challenge. Recruitment was hindered by many factors, including a low response to the initial recruitment letter and the limited time that interested, but busy, caregivers had to complete the survey in any format. We suspect that our "BCCH families" may also have experienced "research fatigue," as they may have been previously approached repeatedly to participate in other projects at BCCH. Also, many caregivers of CSHCN who attend DD-BCCH are foster parents or from group homes and, therefore, are not authorized to complete surveys on behalf of the children in their care. Perhaps the caregivers who agreed to participate wished to share specific stories and experiences, both positive and negative, with the researchers. Thus, the limitation of this response bias must be recognized.

It is unlikely that the final sample in our study was representative of British Columbia families with CSHCN, as most were 2-parent families, English-speaking, well-educated with dental benefits. For instance, with respect to ethnicity, Statistics Canada reports that about a third of the province's population was born outside Canada, mainly in Asia.¹⁷ Although we did not explore the specific challenges that newly immigrated families face in this endeavour, we were nevertheless able to gain interesting and unique insight into the journey to care for longer-term resident families with CSHCN.

One discrepancy between caregivers' self-reported information and that revealed in the child's dental record was related to dental benefits. Over one-third reported public benefits compared with about a quarter in the dental record. This discrepancy suggests some misunderstanding on the part of caregivers about what "government benefits" they may be entitled to for the dental care of their child in a public hospital. British Columbia's MSP¹⁸ covers only the cost of dental general anesthesia at BCCH and any medically necessary extractions. Some parents may have mistakenly thought that MSP would pay for all of their child's care. Alternatively, they may have believed that their child qualified for the provincial government's Healthy Kids program for

low-income children, but may have been ineligible for these benefits and, thus, government benefits were not recorded in the hospital dental chart.

Over half of the respondents stated that their CSHCN had been refused care or their previous dentist had been unable to undertake any treatment. The caregivers in our study often felt that their family dentist lacked the necessary skills and resources to treat their CSHCN. This was true, in particular, when the child had difficult behaviour or comorbidity that was perceived as "high risk" for medical complications. Parents commonly remarked that their child had a "complicated medical condition" or "his care was very complicated." They reported both general and pediatric dentists as unable or unwilling to treat CSHCN. Certainly, only a small percentage of general dentists have the training and experience needed to treat CSHCN; thus, understandably, many may be hesitant to provide invasive dental care.

Pediatric dentists, who have usually received specific training in the management of CSHCN, are often the main dental providers for this patient population.¹⁹ However, in our study, caregivers perceived even pediatric dentists to be unable or unwilling to treat CSHCN. A possible reason for this perception may be that the pediatric dentist appreciated the potential for complications from dental treatment for the child, but may not have clearly articulated their rationale for referral to the caregiver.

Further, dental treatment for CSHCN requires more chair time and staff resources, which increase the cost. Most government-funded and private dental insurance plans do not compensate for these factors.^{11,20} If the pediatric dentist determines that reimbursement is insufficient to cover the costs, then further payment may be requested, and such fees may be a barrier for many families. The pediatric dentist may correctly decide that the best place for the child to receive treatment is in a publicly funded hospital.

Dental services at DD-BCCH are often perceived by caregivers as free or less costly compared with private dental providers. The reasons for this belief are varied. In special circumstances, caregivers may gain access to hospital-based charity funds or pay less overall because DD-BCCH does not "extra-bill" the caregiver for fees not covered by the government-sponsored children's dental benefit program. Also, dental emergency care, dental extractions, fees for general anesthesia and hospital fees are billed directly to MSP.¹⁸ Another reason for caregivers perceiving that dental services are free is that DD-BCCH is a publicly funded facility that adheres to the mandate to treat all eligible children regardless of whether they can pay for services,²¹ whereas the private dentist may decline to provide care if the caregivers lack financial resources.

About half of the children who attended DD-BCCH were referred by a medical professional: a family physician, a pediatrician or another medical specialist. These findings

are encouraging because they suggest awareness among medical providers of the importance of dental care for these medically compromised children. More physicians who care for CSHCN now realize the importance of a healthy mouth in relation to overall well-being. In fact, the American Academy of Pediatrics and the Canadian Pediatric Society have recognized the burden that dental disease places on overall child health and the possible complications of neglecting dental care.²²⁻²⁴ Both organizations have emphasized 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.

Conclusions

Caregivers of CSHCN who are patients of DD-BCCH identified the complexity of the child's medical status, the limited ability of dental providers to deliver care and financial obstacles as barriers to accessing dental care. Enabling factors were related to ease, convenience and for some, the lower cost, of services at DD-BCCH once a need was recognized by a health care professional.

Based on the findings in this local context, caregivers perceive publicly funded tertiary-care facilities, such as DD-BCCH, as better equipped to provide specialized services for CSHCN. This caregiver perception was affirmed by the actions of the referring health care professionals. Further, caregivers felt that the care was delivered by personnel who had the skills and disposition to treat their child. The mandate of these institutions to deliver care regardless of a family's ability to pay may actually shield families from some of the burden of extra associated costs. Therefore, future efforts to improve access to dental care for CSHCN in the community setting may be best focused on improving their dental benefits. An example of this would be validation of the "unusual time and responsibility" code to enhance the dentist's reimbursement when extra time or effort is required. Increased remuneration to dentists for publicly funded dental services may increase the number of already suitably skilled providers willing to engage in caring for these patients and, at the same time, alleviate some of the financial barriers for families.

In the interim, our pilot findings suggest that British Columbia dentists should provide early referral to tertiary-level care for medically or behaviourally complex CSHCN whose treatment they feel is beyond their skill or comfort level. It would be beneficial to conduct parallel studies across Canada to determine whether similarities exist in other provinces.

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