Scientific Article

Unmet Dental Needs and Barriers to Care for Children with Significant Special Health Care Needs

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Abstract: ***Purpose:*** *The purpose of this study was to conduct the first known large scale survey of parents of children with special health care needs (CSHCN) to determine their child's: oral health status; access to dental care; perceived barriers (environmental/system and nonenvironmental/family); and oral health quality of life, accounting for each child's medical diagnosis and severity of diagnosis.* ***Methods:*** *A 72-item survey was sent to 3760 families of CSHCN throughout urban and rural Massachusetts.* ***Results:*** *The study yielded 1,128 completed surveys. More than 90% of the children had seen a dentist within the past year; 66% saw a pediatric dentist, and 21% needed intense behavioral interventions. Although most families had high education levels, private dental insurance, and above average incomes, 20% of CSHCN had an unmet dental need. Children with craniofacial anomalies had twice as many unmet needs and children with cystic fibrosis had fewer unmet needs. Children with cerebral palsy, autism, developmental delay, and Down syndrome had more aversions to dental treatment, more treatment complications posed by their medical conditions, and more difficulty finding a dentist willing to provide care. Children with cystic fibrosis, metabolic disorders, or hemophilia encountered fewer barriers to care.* ***Conclusions:*** *The data paint a picture of high unmet dental needs with subpopulations of children with special health care needs who are more at risk for system barriers and internal family barriers to care based on their medical diagnoses.*

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Pediatric dentists have long known that dental care is one of the "elephants in the room" for children with special health care needs (**CSHCN**). We have rendered a large portion of this care with professionalism, while at times underwriting the cost of the procedures ourselves because the reimbursement did not cover our costs. The wake-up call for pediatricians to the magnitude of the problem came in 2004, when the CDC published its 2001 National Survey of Children with Special Health Care Needs (**NSCSHCN**). The CDC surveyed by telephone 38,866 families of CSHCN, with 750 of those families residing in Massachusetts. The national survey paints a positive picture of access to health care for this population of children. The service most commonly reported as needed nationally, but not received, however, was preventive dental care: More than 8% of CSHCN needed but did not obtain this service. Furthermore, approximately 78% of CSHCN needed dental care (second only to prescription medicines) as a specific service in the past year.[1] The more recent 2005 national survey data showed the same trend in access to dental care.[2]

McIver described 5 key barriers to dental care for CSHCN: (1) the primary medical care system; (2) the child's parents; (3) the child himself; (4) the dentist; and (5) payment for dental care.[3] Al-Agili et al.'s survey of families of CSHCN in Alabama found that 35% had problems finding dentists willing to treat their children. Significant barriers included: Medicaid insurance; poor oral health or a severe disability such as cerebral palsy; and a shortage of dentists with training in the care of CSHCN.[4]

Cassamassimo et al. analyzed a data subset of a national survey of general dentists conducted in 2001 to determine their overall care of CSHCN. Only approximately 10% of the dentists reported currently seeing CSHCN often or very often in their practices, and only 1 in 4 dentists reported

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having had "hands on" experience with CSHCN during dental school. Furthermore, postgraduate education in general practice or advanced general dentistry residencies had no effect on willingness to care for CSHCN.[5]

In 1994, the Maternal and Child Health Bureau presented the term "children with special health care needs" as a way to recognize that children with many different diagnoses and conditions may have important, common needs. The definition they developed for CSHCN was "...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."[6] In 2004, Palfrey et al. presented a more exclusive definition to evaluate the medical home model for more medically involved CSHCN. This definition for CSHCN was used in the present dental study to examine those CSHCN with the most severe involvement (6% of all children).[7]

The purpose of this study was to conduct the first known large scale survey of parents of children with special health care needs to determine their child's: oral health status; access to dental care; perceived barriers (environmental/system and nonenvironmental/family); and oral health quality of life, accounting for each child's medical diagnosis and severity of diagnosis. This study attempted to cast a wide net within the most severely involved medical diagnoses, drawing from more than 16 medical diagnoses and 24 corresponding medical findings and over 1,000 families.

Methods

The impetus for this cross-sectional study came from a special task force on improving the oral health of CSHCN held by the Office of Oral Health within the Massachusetts Department of Public Health (**DPH**). To assess CSHCN's dental needs, access to care, and barriers to oral care, a convenience sample of 15 Massachusetts pediatric practices were recruited to provide access to those children with the most severe medical or physical involvement. These included: 3 hospital primary care pediatric practices from across the state chosen for their large size (to increase the response rates of families with CSHCN) and geographic location (to increase the representativeness of our sample); 8 hospital pediatric specialty clinics from across the state (to increase the response rates from families with very medically involved children); 2 community private pediatric practices (northern Massachusetts and Cape Cod were chosen for their geographic location); 1 inner city community health center; and 1 neighborhood/university-affiliated pediatric health center.

Additional surveys were completed by: families attending multiple conferences and advocacy meetings for CSHCN; recruitment through bilingual (English and Spanish) newsletters; listservs; and advocacy group Web sites. All study procedures and the survey instrument were approved by the governing institutional review boards of all collaborating clinics or advocacy groups. The data were collected from parents and guardians of CSHCN, who completed surveys by telephone or mail from January through October 2007.

Massachusetts resident parents or guardians who had children born from January 1988 through December 2005 were eligible to participate, provided their child qualified as a CSHCN according to the screener used in the CDC national heath surveys. Parents or guardians had to speak either Spanish or English or have a home interpreter who was literate in both English and Spanish to participate.

The survey was written with guidance from the Massachusetts DPH task force on CSHCN and was reviewed by all physicians involved in the study. The survey consisted of 72 items that tapped the following domains: medical diagnosis or description of condition; dental care status (including unmet needs); dental care access; dental care provision (emergency, general dentistry care, pediatric dental specialty care, other specialty care, and hospitalizations); dental care transition into adulthood; barriers to dental care; quality of life questions; background; and demographics. The survey was translated

Table 1. CHILD AND FAMILY DEMOGRAPHICS

Demographic characteristic	N (total and per category)	% per category
Gender	1,076	
Male	685	64
Female	391	36
Race/ethnicity	1,071	
African American	94	9
Asian	29	3
Caucasian	863	81
Hispanic, Latino, Spanish	89	8
Other	39	4
Language spoken at home	1,071	
English only	860	80
English and Spanish or other	176	17
Spanish or other only	35	3
Insurance	1,073	
Medicaid/Massachusetts Health	490	46
Private medical	842	78
Private dental	716	67
Marital status	1,075	
Married	847	79
Single parent	98	9
Separated, divorced, or widowed	119	11
Other	11	1
Mother's education	1,067	
Grade school	30	3
High school diploma	149	14
Some college	219	20
College degree or higher	669	63
Father's education	967	
Grade school	27	3
High school diploma	199	21
Some college	187	19
College degree or higher	554	57
Income	995	
<$20,000	115	12
$20,000-$40,000	149	15
$40,000-$60,000	145	15
$60,000-$80,000	140	14
$80,000-$100,000	144	14
>$100,000	302	30

from English into Spanish and then reverse translated to validate the translation. Data from all surveys were entered by 2 different data entry staff. The 2 sets of data were compared and differences were mediated by 2 authors.

The questionnaire was validated by comparing surveys (completed by 10 families of CSHCN who were patients at the Department of Dentistry, Children's Hospital Boston, Boston, Mass and not used in the study) to their hospital medical and dental records for paired agreement on responses to medical diagnoses and dental history. There was 94% agreement (range=87-100%) on those questions that could be answered by both the family and the information in the medical and dental charts. The most frequently missed question (incorrect data given by 4 out of 10 families) was that the family forgot they had presented for emergency dental care. In 2002, Gilbert et al. measured the validity of self-reported dental visits from northern Florida residents. Agreement between self-report and the dental record at each half yearly interview ranged from 84% to 91%. Importantly, validity did not differ between persons of any key socioeconomic groups.[8]

Depending upon the preferences of the collaborating clinic or advocacy group or their IRB, families were recruited and surveyed in 1 of 3 ways:

1. recruited by mail and then surveyed by telephone;
2. recruited by mail and then asked to complete and return an enclosed survey; or
3. recruited in person and asked to complete the survey in person.

Each method was specifically requested by at least 1 medical center or advocacy group. Inter-rater reliability was tested as each new interviewer was trained by the primary interviewer. Seven telephone interviews were completed with the primary interviewer and a trainee, both of whom marked responses on the survey. All surveys compared were at least 97% consistent.

Data cleaning and analysis were performed using SPSS v 15.0 (SPSS Inc, Chicago, Ill) and SAS 9.1 (SAS system for Windows, SAS Institute Inc, Cary, NC).

Results

Sample. We attempted to contact 4,374 families. A total of 3,760 families received a survey via mail or in person or at least 1 phone call; 1,128 surveys were completed–236 by phone, 694 by mail, and 198 through conferences. The overall response rate was 30%, as 614 families were ineligible due to incorrect contact information (214 addresses and 400 telephone numbers). The Massachusetts geographic regions represented in the study sample were very similar to the distribution for the general Massachusetts population, with approximately 45% of the sample coming from the Metro Boston area and the remaining 55% distributed fairly evenly across Western Massachusetts, Central Massachusetts, the North Shore, and the South Shore/Cape/Islands.

The children in our sample were an average of 10.1±4.4 years old. Most children were male, which was expected given that many special health care needs exist at higher rates for males (Table 1).[9] The predominant racial/ethnic group was Caucasian, and nearly all the children had been born in the United States. Most children came from English-speaking homes, with parents who were married, highly educated, and earners of above-average incomes. Compared with the general population of Massachusetts, as reported in the 2000 Census, our sample was twice as likely to have private dental insurance and the parents were twice as likely to have a college degree or higher. According to the US Census Bureau's 2004 estimates, approximately 13% of Massachusetts children live below the poverty line ($20,650 for a family of 4) and the median household income is $53,657. While our sample accurately represented the lowest-income families, higher-income families were greatly overrepresented, leaving middle-income families underrepresented. Because oral health status and access to dental care is known to be influenced by insurance type and parents' income and

Table 2. CHILD'S PRIMARY DIAGNOSIS

Diagnosis	% yes (N=1,045)
Autism/pervasive developmental disorder/Aspergers syndrome	32
Cerebral palsy/musculoskeletal/seizure disorder	11
Cystic fibrosis	7
Developmental delay/neurologic/behavioral/chromosomal	15
Down syndrome	24
Speech/hearing/blind	<1
Metabolic/cardiac/renal/immunologic	2
Hemophilia/sickle cell/Von Willebrand disease	6
Craniofacial/cleft lip and palate	3
Other	<1

Table 3. ORAL HEALTH STATUS

Oral health status and unmet needs	N (total and per category)	% per category
Parent report on child's oral health status	1,079	
Excellent/very good	548	51
Good	298	27
Fair/poor	233	22
Child currently has unmet dental needs	1076	
Yes	212	20
No	810	75
Do not know	54	5
Has child ever had:	1081	(% yes)
Pain in teeth or mouth	189	18
Cavities	377	35
Broken teeth	128	12
Crooked teeth	364	34
Tartar buildup needing professional removal	289	27
Gum problems	116	11
Tooth discoloration	202	19
Enamel problems	87	8
Grinding of teeth	361	33
Nerve problems	43	4
Teeth not growing in when expected	215	20
Frequent mouth sores	45	4

education, the data presented here likely represent the "best case scenario" for CSHCN.

The CDC's 2005 NSCSHCN that involved over 38,000 households used the same CSHCN screener to identify participants. Compared to the CDC's national data, our sample was 3 times more likely to need extra medical care and mental health or educational services (93% vs 39%) and 4 times more likely to have functional limitations (83% vs 21%) or need special therapies (87% vs 18%)[10]. Our intent was to target the more involved CSHCN, and these comparative proportions suggest we succeeded.

The most common primary diagnoses represented in our sample were: autism spectrum disorders; Down syndrome; developmental delay/neurological disorders; cerebral palsy; and cystic fibrosis (Table 2). The children also had a variety of additional medical conditions, including: various feeding difficulties; seizures; behavioral or emotional issues; and health or physical limitations.

Dental care history and oral health status. Nearly all children in the sample (94%) saw a dentist at least once per year; 69% had received a checkup or cleaning only, and 30% had received both checkups and emergency or restorative services. Most (66%) saw a pediatric dentist and received care in either a private dental office (77%) or hospital dental service (21%). Twenty-six percent of children required special accommodations to receive treatment, and 21% required intense behavioral intervention (restraint or sedation).

Despite their frequent use of dental services, only 51% of parents reported their child's oral health status as being "excellent" or "very good," and 22% rated it as "fair" or "poor" (Table 3). In the CDC's 2003 National Survey of Children's Health, approximately 66% of Massachusetts parents of CSHCN reported that their children's overall oral health was "excellent" or "very good" and only approximately 11% of parents of CSHCN rated their child's oral health as "fair" or "poor."[10]

Of additional concern, nearly 20% of children in our sample currently had unmet dental needs. The 2001 NSCSHCN found that only approximately 8% of parents reported that their child had unmet dental needs in the past year, which is less than half the rate found in our sample.[11] For Massachusetts CSHCN, the rate of unmet dental need was only 6% on the same survey. One likely reason for the discrepancies between our sample and these other samples is that the national surveys targeted the broader population of CSHCN, which represents 12% to 15% of all children. We specifically targeted the more involved subsample of this population–representing approximately 6% of all children–and their greater medical complexity may have created additional barriers to care and, therefore, worse overall dental health and greater unmet needs.

Table 4. POTENTIAL BARRIERS TO CARE

Potential barriers to care	Yes (N)	Yes (%)	If yes, how often does this prevent parent from taking child to the dentist?*		
			Often (%)	Sometimes (%)	Never (%)
Environmental barriers					
Hard to take time off from work to bring child to the dentist	130	12	28	36	36
Hard to find dentist willing to treat child because of his/her medical condition	211	20	44	31	24
Dental care is too expensive	227	21	30	28	42
Hard to find a dentist for child nearby	202	19	44	17	39
Hard to travel to the dental office	98	9	34	34	33
Can't get convenient appointment times	126	12	22	53	25
Can't find a dentist who will accept child's dental insurance	167	16	46	21	33
Dental staff are anxious or nervous about treating child	180	17	34	35	30
Hard to find a dentist's office that is handicapped accessible	93	9	37	26	37
Nonenvironmental barriers					
Child is afraid of the dentist	412	39	24	30	46
Child does not like to have anything done to his/her mouth	545	51	25	29	46
Child cannot behave cooperatively at the dentist	377	36	28	37	35
Child's medical conditions make dental treatment very complicated	364	34	32	25	44
Child is too young to see a dentist	30	3	56	6	38
Parent is afraid of going to the dentist	223	21	20	24	57
Child only has baby teeth that will just fall out	172	16	9	7	84
Child has other, more urgent health care needs	274	26	19	33	48

* Percentage distribution for the cases where the barrier was endorsed.

The most common dental problems reported as having ever occurred were cavities, crooked teeth, grinding of teeth, and tartar build-up. Compared to recent national data for CSHCN, this study's children had less caries, fewer broken teeth, and a similar report of crooked teeth, but more perceived pain and grinding.[12] Compared to the caries rate from National Health and Nutrition Examination Survey data from 1999 to 2002–41% for the primary teeth (2- to 11-year-olds) and 42% for permanent teeth (6- to 19-year-olds)–our population has a slightly lower caries rate (35%) than the general population.[13] In typical US neighborhoods, approximately 35% of adolescents are perceived by parents and peers as requiring orthodontics,[14] similar to the parental perceptions in this study (34%).

Barriers to care. Parents were asked whether they had experienced any of a list of potential barriers to care. The list contained both "environmental" barriers, which originate in the dental care system (cost of care, getting appointments, accessibility, etc), and "nonenvironmental" barriers, which originate

Table 5. ENVIRONMENTAL AND NONENVIRONMENTAL BARRIERS BY PRIMARY DIAGNOSIS*

Barriers	Autism/ developmental delay/ Down syndrome N=712 (%)	Cerebral palsy N=114 (%)	Cystic fibrosis/ metabolic/ hemophilia N=150 (%)	Craniofacial N=33 (%)	*P*-value
Environmental					
It is hard to find a dentist willing to treat my child	125 (18)	24 (21)	5 (3)	8 (24)	<.001
It is hard for me to find a dentist for my child near my home	105 (15)	23 (20)	3 (2)	5 (15)	<.001
I can't get convenient appointment times	62 (9)	13 (11)	8 (5)	12 (36)	<.001
I can't find a dentist who will accept my child's dental insurance	74 (10)	17 (15)	12 (8)	8 (24)	.01
Dental staff are anxious or nervous about treating my child	92 (13)	17 (16)	4 (3)	7 (21)	<.001
It is hard to find a dentist's office that is handicapped accessible	31 (5)	26 (24)	2 (1)	5 (15)	<.001
Nonenvironmental					
My child is afraid of the dentist	185 (26)	20 (18)	8 (5)	7 (21)	<.001
My child does not like to have anything done to his/her mouth	249 (35)	34 (30)	10 (7)	11 (32)	<.001
My child cannot behave cooperatively at the dentist	211 (30)	22 (20)	3 (2)	9 (27)	<.001
My child's medical conditions make dental treatment very complicated	158 (22)	40 (36)	9 (6)	11 (32)	<.001
My child has other health care needs that are more urgent than dental care	94 (13)	30 (27)	21 (14)	14 (42)	<.001
Total (mean±SD)					
Environmental barriers	1.0±1.7	1.3±2.0	0.5±1.1	1.9±2.3	<.001
Nonenvironmental barriers	1.4±1.7	1.4±1.6	0.4±0.9	1.7±1.8	<.001

* Specific diagnoses were combined to create larger cell sizes for analyses. Combinations were based on similarities in children's challenges, such as behavioral challenges or certain physical challenges. Only children where the parent endorsed the barrier and reported that it often or sometimes prevented them from taking their child to the dentist were included in these analyses. Only barriers that differed significantly by diagnosis are included in the Table.

with the child and family (child's behavior, fear of dentist, competing demands, etc). If parents endorsed a barrier, they were asked to rate how often that barrier prevented them from taking their child to the dentist.

We considered a barrier to have "high frequency" if it was endorsed by at least 20% of parents. Only one environmental barrier (dental care too expensive) met these criteria, but "hard to find a dentist willing to treat child" was close to these criteria (Table 4). Nearly all nonenvironmental barriers met the 20% criteria.

A barrier was considered to have "high impact" if it was reported by at least 30% of the parents as "often" preventing the parent from taking their child to the dentist. While the majority of environmental barriers met these criteria, most of the nonenvironmental barriers did not. Only 3 barriers met criteria for both high-frequency and high-impact: (1) "dental care is too expensive," (2) "hard to find a dentist willing to treat child"; and (3) "child's medical conditions make dental treatment very complicated."

Some barriers impacted children with certain diagnoses at significantly higher rates (Table 5). Overall, children with craniofacial disorders and cerebral palsy tended to be impacted by more barriers, both environmental and nonenvironmental, and children with cystic fibrosis, metabolic disorders, or hemophilia were impacted the least. Children with autism, developmental delay,

Table 6. AVERAGE NUMBER OF BARRIERS BY DEMOGRAPHIC CHARACTERISTICS

Demographic characteristic	Environmental barriers		Nonenvironmental barriers	
	Mean±(SD)	*P*-value for chi-square	Mean±(SD)	*P*-value for chi-square
Year of birth				
1988-1994	0.9±1.6	.82	0.9±1.4	<.001
1995-2001	1.0±1.8		1.3±1.7	
2002-2005	1.0±1.5		1.5±1.7	
Language				
English	1.0±1.7	.07	1.2±1.6	.03
No English	1.5±1.8		1.9±1.9	
Income				
<$20,000	1.7±2.2	<.001	1.7±1.7	<.001
$20,000-$40,000	1.6±2.2		1.4±1.7	
$40,000-$60,000	1.2±1.9		1.3±1.7	
$60,000-$80,000	0.8±1.6		1.0±1.4	
$80,000-$100,000	0.9±1.7		1.3±1.7	
>$100,000	0.5±1.0		1.0±1.5	
Region				
Cape and Islands	0.9±1.5	<.001	1.2±1.7	<.01
West	1.7±2.0		1.5±1.7	
Southeast	0.9±1.6		1.1±1.6	
North Shore	0.8±1.6		1.1±1.5	
East	0.7±1.5		1.1±1.6	
Urban	1.4±1.9		1.7±1.7	
Central	1.1±1.8		1.0±1.5	

or Down syndrome were impacted more frequently by nonenvironmental barriers.

The number of barriers experienced also was influenced by certain demographic characteristics (Table 6). Children from non-English-speaking households and from the more rural western part of the state tended to experience more environmental and nonenvironmental barriers. Children from within the urban Boston area also tended to experience more barriers, although this may have been influenced by income, which strongly influenced number of barriers. For environmental barriers in particular, the number of barriers reported increased as household income decreased.

Unmet needs. Twenty percent of children overall had current unmet dental needs. Hispanic children and children from Spanish-speaking families had significantly more unmet needs than expected, as did children from lower-income families and children with Medicaid/Mass Health (Table 7). For most diagnoses, the rate of unmet needs was approximately 20%, as expected. Children with cystic fibrosis, however, had significantly fewer unmet needs than expected while children with craniofacial anomalies had significantly more (Table 8).

We used generalized estimating equations to determine which factors were the best predictors of unmet needs. The analyses included demographic variables as well as environmental and nonenvironmental barriers to care. The first analysis included barriers as "number of barriers" categorized as none, 1 to 2 barriers, and 3 or more. The second analysis included the individual barriers.

Table 9 provides the univariate and multivariate odds ratios for all significant multivariate predictors of unmet needs. Children living in the western and central parts of the state fared the worst with a 3- and 4-fold greater risk, respectively, of having unmet needs. Both the number of environmental barriers, as well as some particular barriers themselves, were associated with unmet needs, particularly finding a dentist who was willing to treat the child and to accept the child's insurance. There were no nonenvironmental barriers associated with unmet needs after adjusting for the other variables.

Table 7. MET VS UNMET NEED BY DEMOGRAPHIC CHARACTERISTICS

Demographic characteristic	Overall (N)	Overall (%)	No unmet needs (%)	Unmet needs (%)	*P*-value for chi-square
Gender					
Girl	391	36	37	37	.96
Boy	685	64	63	64	
Year of birth					
1988-1994	325	30	29	34	<.20
1995-2001	577	54	54	53	
2002-2005	174	16	17	13	
Language*					
English	1,036	97	98	94	.001
Spanish	88	8	6	14	<.001
Other	132	12	11	11	<.90
Income					
<$20,000	115	12	10	17	.02
$20,000-$40,000	149	15	15	16	
$40,000-$60,000	145	15	15	15	
$60,000-$80,000	140	14	15	11	
$80,000-$100,000	144	15	14	18	
>$100,000	302	30	33	24	
Race and ethnicity*					
African-American	94	9	8	11	.15
Caucasian	863	81	84	72	<.001
Hispanic, Latino, Spanish	89	8	6	14	<.001
Asian	29	3	2	4	.08
Other	38	4	3	5	.09
Insurance*					
Medicaid/Massachusetts Health	490	46	43	51	.04
Private health insurance	842	79	81	72	<.01
Private dental insurance	716	67	69	61	.02

*For language, race, ethnicity, and insurance, respondents could choose all that applied. Therefore the categories within those domains are not mutually exclusive and the percentages do not add up to 100% within the columns, as they do for gender, year of birth, and income.

Discussion

Maintaining good oral health is a particular challenge for CSHCN because of increased medically based oral health risks, limitations on access to care, and competing demands. These challenges have been documented for the general CSHCN population–according to the CDC national survey, 8% of CSHCN nationally have unmet dental needs. It was only suspected, however, that the challenges were even greater for the more medically complex children.

Our survey targeted the more involved subpopulation of CSHCN in Massachusetts to characterize access to dental care, dental needs, and barriers to care and to define those with met and unmet dental care needs, including an analysis of barriers to dental care. The data paint an interesting picture. As often happens in survey studies, our sample tended to be more advantaged in terms of parents' education and income and children's insurance status. While our sample represented the lowest-income families well, higher-income families were greatly over-represented, leaving middle-income families underrepresented. Because oral health status and access to dental care is known to be influenced by insurance type and parents' income and education, the data presented here likely represent the "best case scenario" for CSHCN.

In addition, most in our sample received regular dental care. Despite this, our sample reported more than twice the rate of unmet needs (20%) than the general population of CSHCN. In addition, twice as many parents in our study rated their child's oral health status as "fair" or "poor" compared to the CDC's national survey of CSHCN parents. Though the presence of unmet needs was, as expected, disproportionately greater for children from minority populations and from low-income families, as well as for children who received less regular dental care, the fact that unmet needs existed at higher than national levels across all demographic strata bears further investigation.

In addition to poor oral health conditions, parents in our study reported many barriers to care, particularly environmental barriers. Using the 2000 US Census data, Waldman and Perlman estimated that to treat the Massachusetts population of CSHCN, each of the pediatric dentists would have to treat 400 children with disabilities in his/her practice.[15] It is no surprise, then, that access to care was a major barrier and cause of unmet needs even in our sample of high-resource families, particularly for children who were more geographically isolated.

In our study, children with cerebral palsy and craniofacial anomalies experienced the greatest number of barriers to care. We purposely did not select sites with a very strong pediatric dental presence. Al-Agili et al. also found that children with cerebral palsy were the most at risk for problems accessing dental care. Unlike our sample, however, they found that children with cleft lip and/or palate had the fewest perceived problems accessing care. The fact that families who were recruited for the Al-Agili study came from a multidisciplinary cleft lip and/or palate team that included a dentist may explain the discrepancy in findings.[2]

In summary, 1 in 5 children in our sample had unmet dental needs. This translates to a national estimate of nearly 1 million of the children with significant special health care needs suffering because of limitations in the dental care system, the majority of whom are treated by pediatric dentists. While this report identifies some subpopulations which are more at risk, both demographically and geographically, improving their access to care likely will require large systems-level changes.

Table 8. MET VS UNMET NEED BY PRIMARY DIAGNOSIS

Primary diagnosis	No unmet needs N (%)	Unmet needs N (%)	*P*-value
Autism/pervasive developmental delay/Aspergers disorder	237 (77)	69 (23)	.35
Cerebral palsy/musculoskeletal/seizure disorder	84 (78)	24 (22)	.69
Cystic fibrosis	63 (95)	3 (5)	<.001
Developmental delay/neurologic/severe behavioral/ chromosomal anomalies	106 (77)	31 (23)	.56
Down syndrome	186 (79)	50 (21)	.85
Metabolic/cardiac/renal/immunologic	18 (86)	3 (14)	.59
Hemophilia/sickle cell/Von Willebrand's disease	52 (88)	7 (12)	.08
Craniofacial/cleft lip and palate	19 (59)	13 (41)	<.01

Table 9. EFFECT OF DEMOGRAPHIC VARIABLES AND BARRIERS ON UNMET DENTAL NEEDS

	Univariate				Multivariate			
Demographic variable	Odds ratio	95% confidence interval		*P*-value	Odds ratio	95% confidence interval		*P*-value
Year of birth								
1988-1994	1.6	0.9	2.8	.11	2.3	1.3	4.0	<.01
Primary diagnosis category								
Autism/developmental delay/Down syndrome	2.9	1.4	6.1	<.01	3.6	1.7	7.7	.001
Craniofacial	6.7	2.6	17.8	<.001	5.3	1.6	18.0	<.01
Caucasian	0.5	0.3	0.8	.001	0.5	0.3	0.9	.01
Region								
West	3.6	1.8	7.4	<.001	3.1	1.2	8.0	.02
Southeast	1.6	1.1	2.5	.03	1.9	1.0	3.5	.05
East	1.6	1.1	2.5	.02	2.0	1.2	3.6	.02
Central	3.3	2.1	5.3	<.001	4.1	2.2	7.7	<.001
No. of environmental barriers								
1-2	2.8	2.1	3.6	<.001	2.4	1.4	4.1	.001
≥3	6.0	3.8	9.5	<.001	3.9	1.9	7.9	<.001
Environmental barriers								
It is hard to find a dentist willing to treat my child because of his or her medical condition	5.5	4.0	7.6	<.001	2.7	2.0	3.6	<.001
I can't find a dentist who will accept my child's dental insurance	3.9	2.6	6.0	<.001	3.1	1.1	8.9	.03
Dental staff are anxious or nervous about treating my child	5.6	4.0	7.8	<.001	2.5	1.5	4.3	.001

Conclusions

Based on this study's results, the following conclusions can be made:

1. The subpopulation of children with special health care needs (CSHCN) who are more involved or medically complex have more dental care concerns than the general CSHCN population.
2. Despite having private insurance and parents with higher-than-average incomes and education levels, 20% of the children in our study had unmet dental needs.
3. Environmental barriers to care were greater for families who were more geographically isolated and those who faced linguistic and economic barriers.

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