

ORIGINAL RESEARCH

Unmet dental and orthodontic need of children with special healthcare needs in West Virginia

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ABSTRACT

Introduction: Of children aged 0–17 years in the USA, an estimated 11 203 616 (15.1%; 95% CI: 14.8, 15.3) are Children with Special Health Care Needs (CSHCN). The state of West Virginia, the heart of Appalachia, has a land mass which is 97.65% rural with previously identified high overall dental need and oral health disparities. It is home to an estimated 70 609 CSHCN, or 18.5% (95% CI: 17.0, 19.9) of the state's children in 2009–2010. The purpose of this study was to determine the parent/guardian's perceived unmet dental care need of CSHCN in West Virginia.

Methods: Data from the National Survey of Children with Special Health Care Needs was used to determine prevalence. A telephone survey of 59 941 parents/guardians of CSHCN (1149 from West Virginia) for the dental interview was conducted in 2009–2010.

Results: Nationwide, 26.7% (25.9, 27.5) of parents/guardians reported their CSHCN had dental care or orthodontia needs other than preventive care. In West Virginia, the perceived dental care or orthodontia needs other than preventive dental care need was 26.5% (22.2, 30.0). Unmet national dental care need other than preventive dental care was 5.4% (5.0, 5.9) and in West Virginia 5.0% (2.4, 7.5).

Conclusions: CSHCN have significant unmet dental needs. Parents/guardians in West Virginia reported similar unmet need compared with national reporting. Policies to address the health care of CSHCN should include dental needs. The clinical



implications are that CSHCN have a variety of needs, including orthodontia. The benefits of orthodontic referrals should be considered in treatment planning options for CSHCN.

Key words: Children with Special Health Care Needs, unmet dental need, USA, West Virginia.

Introduction

Children with Special Health Care Needs (CSHCN) have an illness or condition requiring additional health care and support on any one, or a combination of physical, intellectual, developmental, behavioral or emotional means of support or care¹. Examples of CSHCN are children with cerebral palsy, muscular dystrophy, asthma, sickle cell anemia, diabetes, heart conditions, depression, conduct disorders, and attention deficit hyperactivity disorder¹. Children with Special Health Care Needs rely upon parents and guardians to learn about their conditions and find the resources available to meet their needs. Many parents and guardians do not recognize all of their child's needs nor have they learned how to access the resources for their child's benefit. They face many obstacles in the process of securing assistance.

Government and non-government agencies providing services, insurance and healthcare plans, and healthcare providers also need to identify and monitor CSHCN's needs and quality of care to ensure the proper provision of critical services². Children with Special Health Care Needs comprise a significant group which is the target of many governmental programs and policies³. For example, having information about the special needs of extremely low-birthweight infants is necessary to plan their future medical and educational services needs⁴. Children with Special Health Care Needs have increased risks of needing health care, special education, and incurring associated financial burdens. They also have increased numbers of bed days and school absence days³. Previous studies have addressed the importance of health insurance to help CSHCN in surmounting the barriers to access and utilization of needed services⁵.

Families with CSHCN are more likely to require Medicaid insurance and less likely to have parents with full-time employment⁶. Many advances were made with healthcare coverage in expanded Children's Health Insurance Programs and other federal and state programs⁷. Once such advancement was the conceptualization of the 'medical home' for the provision of continuous, comprehensive pediatric care from infancy to young adulthood⁷. This concept is of particular value to CSHCN who have many healthcare needs. A recent review indicated that there was moderate support of the hypothesis that medical homes provide improved health-related outcomes for CSHCN⁸. Having a regular physician or nurse in a medical home seems protective of unmet needs, particularly unmet dental needs, in that comprehensive, coordinated care, even with the limitations of poverty and disability, helps to decrease unmet healthcare needs⁹. Another support-based approach is the concept of family-centered care for CSHCN. Evidence indicates a positive association of the family-centered care approach and improved health, satisfaction, access, communication, more improved use of healthcare services and cost¹⁰.

Just as significant is the concept of unmet need for health care, or the extent that needed health services are not received¹¹. There are few studies addressing the unmet healthcare needs of CSHCN^{5,12-14}. Of those that exist, there are many similarities of needs with the different health conditions¹³⁻¹⁵. Unmet need has been described as a critical indicator of access problems¹⁶. Dental care is the most prevalent unmet need of CSHCN^{9,16}.

The US state of West Virginia is the heart of Appalachia. It is located entirely within the Appalachian region and is 97.66% rural by land mass, and 38.95% rural by population¹⁷. In 2010, the median income in the state was \$38,241, and the



unemployment rate was 9.1%¹⁸. West Virginia is primarily White (93.9%) with 3.4% Black, 1.2% Hispanic or Latino, 0.7% Asian, and 0.2% American Indian and Alaska Native¹⁹. As in much of the rest of rural Appalachia, the dental health of the citizens of West Virginia has continued to be poor, despite efforts to address it. Water fluoridation is available in 91.7% of the public water serving households in West Virginia²⁰; mobile dental units were funded for use in schools, Head Start and other locations; West Virginia Office of Public Health sponsored Oral Health Forums; and there was an expansion of the state Children's Health Insurance Program²¹. Nevertheless, dental need remains high. West Virginia Office of Maternal and Child Health issued a report which indicated 65.6% of West Virginia children had caries by age 8 years (compared with the national caries prevalence of 22%)²². In 2010, West Virginia led the nation in the number of adults aged 65 and older who had all their natural teeth extracted (36% vs 17% nationally); and was in the bottom 3 states for the number of people visiting a dentist or dental clinic within the past year for any reason²³. The consequences of unmet dental need range from discomfort and poor oral quality of life to the potential of mortality. For children, and CSHCN in particular, primary prevention includes the parent and/or guardian 'lifting the lip and looking', as well as supervising brushing and flossing, and routine dental visits.

This descriptive study sought to provide surveillance data concerning CSHCN in terms of the perceived unmet dental needs reported by parents or guardians for the nation and for West Virginia. West Virginia was of particular interest due to the lack of current data about CSHCN and the known, overall high rate of dental caries in children in West Virginia.

Methods

Data used in this study were obtained from the 2009–2010 US National Survey of Children's Health (NS-CSHCN), the details of which are available elsewhere²⁴. The data were collected with participant consent and an assurance of confidentiality, with Centers for Disease Control and

Prevention's National Center for Health Statistics oversight. As the data were public access with identifiers removed, IRB approval was not required for this study.

In summary, approximately 3850 households with children per state were contacted by random digit dialing, including cell phones (196 159 households). All of the children in the households were screened for special healthcare needs (372 698 children). The data were collected by the State and Local Area Integrated Telephone Survey Program (SLAITS) for the Maternal and Child Health Bureau and the Department of Health and Human Services. If the participant was contacted using a cell phone, he or she was asked if he or she had a landline. If no landline existed or it was unlikely that the participant would answer it, the survey continued with the cell phone. Nationwide 40 242 CSHCN interviews were completed in full, with 59 941 responding to the question, 'How many children/youth have special health care needs'. In West Virginia, the sample size was 1149.

The outcomes of interest were the dichotomous yes/no responses of parents or guardians to the interview questions:

- During the past 12 months was there any time when [child's name] needed the following service: preventive dental care?²⁵
- During the past 12 months/Since [his/her] birth, was there any time when [child's name] needed any other dental care or orthodontia?
- Did [child's name] receive all the preventive dental care that he/she needed?
- Did [child's name] receive all the other dental care that he/she needed?²⁶.

The Data Resources Center for Child and Adolescent Health provides the data with an online, interactive software tool based in SPSS® and SAS®. The Child and Adolescent Health Measurement Initiative is responsible for online analysis with Taylor linearization methods to calculate variance estimated for proportions used to construct 95% confidence intervals using standard statistical formula in limited multivariate data analysis. The site was queried for responses to the



aforementioned questions for the state of West Virginia and the USA, nationally.

Results

The demographics of the national and West Virginia study populations²⁵ is presented (Table 1). The state and nation are homogenous in the distribution of CSHCN by age and sex. As previously mentioned, the state of West Virginia is primarily White and the White West Virginia sample is significantly higher than the national white sample of CSHCN.

The perceived need or receipt of preventive dental care within the previous 12 months²⁵, is described (Table 2). It indicates a recognition on the part of the parent or guardian of a need with the potential of acting upon the need. West Virginia CSHCN had greater need or receipt of preventive dental care than national CSHCN overall, within all age groups, both sexes, and by race/ethnicity; however, the 95% confidence intervals are contained within the national confidence intervals, indicating the differences may be due to chance. In West Virginia, the overall need or receipt of preventive dental care was 91.8%, whereas the national percentage was 89.6%. A greater perceived need or receipt of preventive dental care occurred for ages 12–17 years (West Virginia 96.8%, and national 95.7%). Nationally, parents/guardians of males reported a need for or receipt of preventive dental care at 89.5%, while in West Virginia it was 91.8%. The percentages for females were 89.8% and 91.7%, respectively. Considering race and ethnicity, nationally the perceived need or receipt of preventive dental care was 87.7% for Hispanic, 90.6% for White, 87.9% for Black, and 89.6% for other, while in West Virginia these were 94.7%, 91.5%, 95.4%, and 96.5%, respectively. The sample by race/ethnicity for West Virginia had fewer than 50 respondents in non-White categories.

The perceived need for other dental care or orthodontia²⁵ is described (Table 3). The results were mixed. Overall, on a national basis, 26.7% of respondents reported CSHCN need for other dental care or orthodontia, while in West Virginia

this was 26.5%. West Virginia CSHCN had greater need for other dental care or orthodontia than national CSHCN in age groups 0–5 years (10.2% vs 8.3%), and 6–11 years (27.4% vs 24.4%), in males (28.0% vs 25.1%), in Blacks (25.9% vs 20.0%), and in others (33.4% vs 24.2%); whereas, the national CSHCN had greater need in the ‘other’ categories. The age group 12–17 years had a nationally reported need for other dental care or orthodontia of 38.5%, and in West Virginia this was 33.5%; females had a nationally reported need of 29.0%, and in West Virginia 24.6%; and the national reported need of Whites was 29.6%, whereas in West Virginia it was 26.3%. However, West Virginia and national confidence intervals overlapped in all analyses. The samples by age 0–5 years, and race/ethnicity in the non-White categories had fewer than 50 respondents.

Unmet dental need for the previous 12 months is presented (Table 4)²⁵. West Virginia respondents indicated 84.2% received all needed preventive dental care, and 8.1% had no perceived need for preventive dental care. Nationally, 80.7% indicated receiving all needed preventive dental care and 10.4% indicated no perceived need for preventive dental care.

Unmet preventive dental care need in West Virginia and the USA were 7.7% and 8.9%, respectively. West Virginia and national confidence intervals overlapped in the analysis.

West Virginia respondents indicated 21.5% of CSHCN received all other needed dental care or orthodontia and 73.6% indicated no unmet other dental care or orthodontia need. Nationally, 21.3% parent/guardian respondents indicated their CSHCN received all other dental care or orthodontia needs, and 73.3% indicated no unmet other dental care or orthodontia needs.

Unmet national dental care need other than preventive dental care was 5.4% (5.0, 5.9) and in West Virginia 5.0% (2.4, 7.5). West Virginia and national confidence intervals overlapped in the analysis. The sample of unmet needs for other dental care or orthodontia in West Virginia had fewer than 50 respondents.



Table 1: Demographics of the Sample of Children with Special Health Care Needs (Dental Needs) 2009–2010 (data source²⁶)

Characteristic	Location - n (%)	
	National	West Virginia
CSHCN sample	59 941	1149
Age (years)		
0-5	10 775 (20.8)	207 (19.7)
6-11	24 085 (38.7)	490 (39.4)
12-17	25 081 (40.5)	452 (40.9)
Sex		
Male	35 622 (59.3)	683 (59.6)
Female	24 189 (40.7)	464 (40.4)
Race/ethnicity		
Hispanic	4 383 (11.1)	17 (2.2)
Non-Hispanic White	27 528 (69.6)	675 (89.2)
Non-Hispanic Black	3 936 (10.0)	20 (2.6)
Other	3 682 (9.3)	45 (5.9)

CSHCN, Children with Special Health Care Needs.

Table 2: Parent/guardian perceived need or receipt of at least one preventive dental visit within the previous 12 months for CSHCN, 2009–2010 (data source²⁶)

Perceived need/receipt	Location - % (95% CI)	
	National	West Virginia
Need/receipt (overall)	89.6 (89.1, 90.2)	91.8 (89.5, 94.1)
Age (years)		
0-5	65.4 (63.4, 67.3)	72.5 (63.6, 81.3)
6-11	96.3 (95.7, 96.9)	96.4 (93.9, 98.9)
12-17	95.7 (95.2, 96.3)	96.8 (94.7, 99.0)
Sex		
Male	89.5 (88.8, 90.3)	91.8 (88.9, 94.8)
Female	89.8 (88.8, 90.7)	91.7 (88.0, 95.5)
By race/ethnic group		
Hispanic	87.7 (85.9, 89.6)	94.7 (84.4, 100)†
White	90.6 (90.0, 91.3)	91.5 (89.9, 94.0)
Black	87.9 (86.2, 89.6)	95.4 (88.4, 100)†
Other	89.6 (87.6, 91.6)	96.5 (91.4, 100)†

†Estimates based on sample sizes <50, use caution in interpretation.



Table 3: Parent/guardian perceived dental need of other dental care within the previous 12 months for CSHCN, 2009–2010 (data source²⁶)

Perceived need	Location - % (95% CI)	
	National	West Virginia
Need (overall)	26.7 (25.9, 27.50)	26.5 (22.2 ,30.0)
Age (years)		
0-5	8.3 (7.1, 9.5)	10.2 (3.4, 17.1)§†
6-11	24.4 (23.2, 25.6)	27.4 (21.0, 33.8)
12-17	38.5 (37.2, 39.8)	33.5 (26.0, 41.1)
Sex		
Male	25.1 (24.1, 26.1)	28.0 (22.2, 33.7)
Female	29.0 (27.8, 30.3)	24.6 (18.1, 31.1)
By race/ethnic group		
Hispanic	24.7 (22.3, 27.1)	21.8 (0-48.8)§
White	29.6 (28.6, 30.5)	26.3 (21.7, 31.0)
Black	20.0 (18.0, 22.1)	25.9 (4, 47.9)§†
Other	24.2 (21.4, 26.9)	33.4 (15.1, 51.7)†

†Estimates based on sample sizes <50, use caution in interpretation.

§Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30%.

Table 4: Parent/guardian perceived unmet dental need within the previous 12 months for CSHCN, 2009–2010 (data source²⁶)

Unmet need	Location - % (95% CI)	
	National	West Virginia
Preventive		
No unmet need	10.4 (9.8, 10.9)	8.1 (5.8, 10.4)
Received all needs	80.7 (80.0, 81.5)	84.2 (80.7, 87.6)
Unmet needs	8.9 (8.4, 9.5)	7.7 (4.9, 10.6)
Other dental care		
No unmet need	73.3 (72.5, 74.1)	73.6 (69.2, 77.9)
Received all needs	21.3 (20.6, 22.0)	21.5 (17.6, 25.4)
Unmet needs	5.4 (5.0, 5.9)	5.0 (2.4, 7.5)†

†Estimates based on sample sizes <50, use caution in interpretation.

Discussion

Using a nationally representative sample of the USA, national and West Virginia CSHCN dental care needs were similar, as were the unmet dental care needs in both preventive dental care and other dental care or orthodontia. Overall, the national need or receipt of preventive dental care was 89.6%,

and for West Virginia it was 91.8%. The overall other dental care or orthodontia needs were 26.7% nationally and 26.5% for West Virginia. Of the needs, nationally 80.7% indicated they received all needed preventive dental care, 10.4% indicated that they had no needed preventive dental care, 21.3% indicated they received all needed other dental care or orthodontia, and 73.3% indicated they had no unmet other dental care need or orthodontia. Similarly in West Virginia,



84.2% indicated they received all needed preventive dental care, 8.1% indicated that they had no needed preventive dental care, 21.5% indicated they received all needed other dental care or orthodontia, and 73.6% indicated no unmet other dental care or orthodontia needs. Unmet preventive dental care need was 8.9% in the USA and 7.7% in West Virginia. Unmet other dental care or orthodontia needs were 5.4% in the USA and 5.0% in West Virginia. The other unmet other dental care or orthodontia needs were based on a sample of 30. The confidence intervals of all areas of report overlapped, so the differences may be due to chance.

The 2009–2010 National Survey of Children with Special Health Care Needs contained dental related questions restructured from the previous 2005–2006 survey. The questions relating to preventive dental care cannot be compared across survey years. This is a limitation of the study in trend evaluation. The 2005–2006 question for other dental care was 'During the past 12 months, was there any time when [child's name] needed other dental care?'²⁵. In 2009–2010, the question had 'or orthodontia' added. This also impacts any comparisons of various survey years. For example, the percent of CSHCN in 2005–2006 who had unmet other dental care needs was 2.6% (2.3, 2.8) nationwide and 1.9% (0.9, 2.9) in West Virginia²⁵. A comparison with 2009–2010 may indicate a statistically significant increase in unmet need, or it may indicate that parents or guardians were not considering orthodontic need in 2005–2006.

Few studies exist concerning CSHCN and dental care, and there are particularly few which address orthodontic needs. This study adds to the literature in that a large national survey was used and specific state data were also available to evaluate dental needs and particularly unmet dental need, including the orthodontic component. The study is limited by self-report with the potential of recall bias, although this should result in a tendency toward the null. Misclassification bias is a possibility because parents or guardians may be unaware of a child's preventive, orthodontic, or other dental need.

A major concern is that parental or guardian reporting does not correspond with a clinical appraisal of dental need. West Virginia has a high DMFS (decayed, missing and filled surfaces) in children overall, well above the national average and it would be expected that the pattern would exist with West Virginia CSHCN. Future research is needed to determine if the perceptions of parents or guardians of CSHCN correspond with clinical evaluations of dental need.

Conclusion

West Virginia is similar to the rest of the USA with approximately 5% of CSHCN having unmet other dental or orthodontia needs. The dental needs of CSHCN remain a concern and the increase in unmet care since 2005–2006, though potentially explained by a change in the survey question, is troubling. Future research is needed to determine the correspondence of parent or guardian perceived needs for dental care and the results of an oral evaluation.

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