Barriers to Dental Care for Children in Virginia With Autism Spectrum Disorders

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ABSTRACT

Purpose: The purposes of this study were to examine the reported use of dental services for families of children with autistic spectrum disorders and identify barriers that affect their access to dental care.

Methods: Participants were caregivers of at least 1 child with an autism spectrum disorder. Caregivers completed a questionnaire that assessed access and barriers to dental services. Descriptive, bivariate, and multivariate regression analyses were conducted to examine dental care access issues in relation to individual factors.

Results: Each respondent's household income and child's history of difficult behavior in the dental office were significantly related to the ability to receive care when needed and whether the child had a regular dental provider. An inability to find a dentist with the skills or willingness to work with people with disabilities was the most frequent reason cited for not having a regular dental provider.

Conclusions: Children with autism spectrum disorders who display difficult behavior are less likely to have a dentist for routine car, have longer intervals between dental appointments, and receive care when needed.

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In the United States, there are nearly a million children younger than 6 years old who have disabilities and nearly 4.5 million 6- to 16-year-olds with disabilities.^{1,2} It is estimated that approximately 8 percent of disabled children had unmet dental needs in 1994 and 1995.^{3,4} Several studies based on parental reports found that between 13 percent and 75 percent had problems obtaining dental care for their special needs children.^{1,5-8} Some of the barriers reported by parents include: the child's difficulty with communication; excessive patient fear of unfamiliar people or settings; awkwardness of staff in dealing with disabled children; financial disincentives; a need for sedation to complete dental care; having a severe disability; dentists not accepting Medicaid; and dentists' lack of knowledge and training with special needs populations.

Increased understanding of the barriers to dental services for special needs children has shown that access to dental services is more limited—and their needs greater —than for those without disabilities. One study found that 40 percent of caretakers experienced difficulty in locating a dentist willing to treat special needs patients,

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despite the fact that 75 percent of these individuals were cooperative enough to undergo dental treatment in a traditional dental setting.⁶ A lack of access to dental care directly affects overall health and quality of life, and the consequences of oral disease can be a long-term burden.

Children with autism spectrum disorders (ASDs) present a unique challenge for the dental community. ASDs impact the brain's normal development and are accompanied by significant impairments in social interaction and communication, which can range from mild to severe. ASD children often have deficits in language and social interaction and display a lack of eve contact, repetitive behavior, and the need for a rigid routine.9 In pediatric dentistry, communication is the key to behavior management. Therefore, the inability to communicate with an autistic patient makes it difficult for practitioners to provide comprehensive care in a traditional manner. Kamen et al has said that autistic patients are probably the most difficult for any dentist to treat. Repetitive body motions (ritualism), echolalia (repetition or echoing of verbal utterance), hyperactivity, and low frustration thresholds are some of the challenges practitioners face in treating this population.9 To minimize potential anxiety, practitioners may need to make special accommodations for some of their autistic patients.¹⁰ Furthermore, autistic patients are often unresponsive or disinterested in demonstrations of dental procedures and will resist efforts to establish rapport with the dental personnel.11

Increased understanding of this population's utilization of dental care and the barriers that prevent access to dental services is important in identifying opportunities for improving the oral health of autistic children. Furthermore, by determining the obstacles families face in obtaining dental care for their autistic children, health care professionals can work to minimize the difficulties they encounter. This study's purposes were to analyze the utilization of dental services among families of autistic children and identify barriers that affect their access to dental care.

METHODS

For this study's purposes, a modified version of a questionnaire previously developed by Al-Agili et al. was used.¹² This questionnaire was shortened from the previous version and focused on barriers to accessing dental care for ASD children and socioeconomic factors, including parent's/guardian's education and income level. The 5 dental care access measure questions were:

- 1. When was your child's last visit?
- 2. Does your child have a dentist for periodic oral health care?
- 3. Is your child currently scheduled for a checkup within the next 12 months?
- 4. Within the past year, was there a time when you needed dental care but were unable to get it?

5. Has your child ever been refused treatment?

Additional questions inquired about difficulty in finding a dentist, type of dental provider visited, and travel distance to the provider.

The questionnaire was mailed to all families in the state of Virginia who were registered with The Autism Program of Virginia (TAPVA) and cares for at least 1 ASD child. This state registry contained a total of 200 families who were contacted via mail. Included with the questionnaire was a cover letter explaining this study's purpose and a stamped, self-addressed return envelope. After 2 weeks, those who had not responded were mailed a postcard encouraging them to reply. At 4 weeks, an additional cover letter, questionnaire, and return envelope were resent. A deadline for receipt of questionnaires was set at 6 weeks after the initial mailing. This study was approved for human subjects by the Institutional Review Board of Virginia Commonwealth University, Richmond, Va.

Bivariate correlations (P<.10) between individual factors and dental care access issues were considered significant and further examined using multivariate regression. A final multivariate regression analysis was completed for each of the five dental care access measures. Factors found to have P<.05 in the multiple regression analysis were considered significant.

RESULTS

DESCRIPTIVE

A descriptive analysis of univariate distributions was obtained for each of the 20 questionnaire items. Since not all respondents answered each question, the denominator used to calculate the proportions was the total number of non-missing values. The overall sample size of the study was reduced from N=200 to N=188 due to 12 undeliverable surveys, resulting in an overall response rate of 29 percent (N=55). Descriptive characteristics of the sample have been presented in Table 1 with descriptive characteristics of the 5 dental care access issues presented in Table 2.

BIVARIATE RESULTS

Bivariate analyses (Pearson's chi-square/Fisher's exact tests) were used to examine the relationships between the child's: ASD diagnosis; socioeconomic factors; past behavior in a dental office; insurance type; and 5 dental care access measures. Due to sample size and response distributions across categories some categorical levels were combined for analysis. These included age, income, education, behavior, ease of locating a dentist, and time since last visit.

As noted in Table 3, respondent's education as well as child's age, race, and history of behavior in the dental office were significantly related to "time since last dental visit." Respondents' education, income, and insurance coverage and child's history of behavior in the dental office were significantly related to having a dentist for periodic dental care. There were no respondent characteristics significantly associated with whether a child was "scheduled for a checkup in the next 12 months." Insurance coverage, household income, and child's age and history of behavior in the dental office were significantly related to whether a child was "unable to receive dental care when needed in the last year when needed."

Table 1. Descriptive Characteristics of Diagnosis,Socioeconomic, and Behavioral Factors

	N	Percent
Diagnosis	55	100
Autism	36	65
Asperger's syndrome	13	24
Pervasive developmental disorder.	6	11
not otherwise specified (PDD-NOS)		
Insurance coverage	55	100
Private	43	78
Medicaid	12	22
No health insurance	0	0
Age (ys)	55	100
3-5	19	34
6-11	19	35
≥ 12	17	31
Sex	55	100
Male	39	71
Female	16	29
Race	55	100
Caucasian	43	78
African American	8	15
Asian	1	2
Hispanic	2	3
Other	1	2
Education	55	100
≤ High school diploma	19	34
Some college	17	31
Associate's degree	17	31
Bachelor's degree	2	4
Household income	54	100
< \$20,000	4	8
\$20,000-\$49,999	18	33
≥ \$50,000	32	59
History of child's behavior in dental office	49	100
Cooperative	20	41
Somewhat uncooperative	13	26
Extremely uncooperative	16	33

Table 2. Descriptive Characteristics of DentalCare Access Measures

Access Characteristics	N	Percent*
Time since last visit	55	100
Have never visited a dentist	8	15
≤1 year	39	71
≥1 year	8	15
Has a dentist for periodic care	55	100
Yes	42	76
No	13	24
Currently scheduled for checkup in the next 12 months	55	100
Yes	38	69
No	17	31
Reasons why not scheduled for a checkup	*	
Cannot find a dentist who treats special needs kids	9	16
No services available	2	11
No dental insurance	0	0
No Medicaid-participating dentist in area	2	4
No transportation	0	0
Other	6	31
Child was unable to receive care when needed within past year	54	100
Yes	10	19
No	44	81
Ever refused treatment	52	100
Yes	13	25
No	39	75
Provider type	46	100
General dentist	16	35
Pediatric dentist	28	61
Oral surgeon	1	2
Don't know	1	2
Travel time	45	100
< 30 mins	34	75
30 mins to 1 hr	7	16
1-2 hr	4	9
Difficulty in locating a dentist	52	100
Very difficult or cannot locate one	8	15
Somewhat difficult	19	37
Somewhat easy to easy	25	48

* Those surveyed could check as many as applied; therefore, totals do not equal 100 percent.

Table 3. Bivariate Correlation of Individual Factors and Dental Care Access Measures

Time since last visit	Has dentist for periodic care	Currently scheduled for a checkup	In the past year, unable to get care	Ever refused treatment
.71	.87	.67	.35	.24
.45	.10*	.36	.002*	.01*
.10*	.36	.28	.02*	.18
.05*	.30	.27	.25	.71
.05*	.003*	.20	.18	.37
.42	.04*	.32	.06*	.06*
.06*	.005*	.21	.006*	.29
	Time since last visit .71 .45 .10* .05* .05* .42 .06*	Time since last visit Has dentist for periodic care .71 .87 .45 .10* .10* .36 .05* .003* .42 .04* .06* .005*	Time since last visit Has dentist for periodic care Currently scheduled for a checkup .71 .87 .67 .45 .10* .36 .10* .36 .28 .05* .30 .27 .05* .003* .20 .42 .04* .32	Time since last visit Has dentist for periodic care Currently scheduled for a checkup In the past year, unable to get care .71 .87 .67 .35 .45 .10* .36 .002* .10* .36 .28 .02* .05* .003* .20 .18 .42 .04* .32 .06*

* P<. 10 was threshold of significance for consideration in multivariate regression.

MULTIVARIATE RESULTS

A multivariate regression analysis was completed for each of the 5 dental care access measures. Factors found to have P<.10 in the multiple regression analysis were considered independently significant in terms of a child's ability to access care. According to the multivariate regression (Table 4), the child's history of behavior in the dental office and household income were the only individual factors that remained significant for 2 dental care access measures. The first related to having a dentist for periodic oral health care (P<.001 and P<.01 respectively), where those who displayed "extremely uncooperative" behavior and had an income between \$20,000 and \$49,000 were less likely to have a regular dentist.

Child's history of behavior in the dental office and household income were also significantly related to being "unable to get care in the last year when needed" (P<.001 and P<.02 respectively). Children who displayed "extremely uncooperative" behavior and whose family's income was in the \$20,000 to \$49,000 bracket were less likely to get care when needed. There were no significant multivariate regression results found for the remaining dental care access issue questions, which included: When was your child's last dental visit, is your child currently scheduled for a checkup within the next 12 months, and has your child ever been refused treatment?

DISCUSSION

The purposes of this study were to assess the utilization of dental services among autistic children and identify barriers that affect their access to dental care. ASD children in the state of Virginia face many barriers to oral health care. Children whose parents reported a history of uncooperative behavior were significantly less likely to have a dentist for periodic care and to receive care when needed and significantly more likely to have longer gaps between dental appointments. Those who did not have a regular provider or were not been previously seen were younger children or those with uncooperative behavior.

Respondents reported that 30 percent of ASD children had never visited a dentist or had not visited one within the past year (Table 2). This is useful information, as frequency of visits to a health care provider has been used in national surveys as an indicator of unmet dental health needs.¹ The American Academy of Pediatric Dentistry recommends routine care at intervals no longer than 1 year, which means that 30 percent of ASD children in the state of Virginia have unmet dental needs.¹³ This is very close to the percentage (27 percent) of special needs children in Alabama found to have unmet health care needs and significantly higher than the percentage (6-7 percent) of children in the general population reported by the 1993 National Health Insurance Survey to have unmet dental care needs.^{12,14}

Dentists have limited opportunities to treat special needs children during their formal education and training, which may contribute to a lack of confidence among practitioners when it comes to working with or accepting special needs patients. More than 50 percent of US and Canadian dental schools offer fewer than 5 hours in didactic instruction regarding special needs populations, and 73 percent of schools devoted less than 5 percent of students' clinical time to the dental care of disabled children.^{10-11,15,16} These factors may negatively impact access to dental services for this population. Increased clinical opportunities, as well as continuing education courses that address the treatment of disabled patients, would improve dental students' competence in working with special needs patients.

Parents' perceptions of dental care access were analyzed based on report of their ability to locate a dentist, having been refused care, and being able to receive care when needed. Prior research has found that 35 percent to 75 percent of parents experience difficulty in finding

		Does your child have a dentist for periodic oral health care?	Within the last year, was there a time when your child needed dental care but was unable to get it?
History of past dental behaviors*	Household income*	Yes (percent)	Yes (percent)
Cooperative	\$20,000 - \$49,999	75	0
Cooperative	≥ \$50,000	100	0
Cooperative		100	9
Somewhat uncooperative	< \$20,000	100	33
Somewhat uncooperative	\$20,000 - \$49,999	100	0
Somewhat uncooperative	≥ \$50,000	100	0
Extremely uncooperative	< \$20,000	100	100
Extremely uncooperative	\$20,000 - \$49,999	20	80
Extremely uncooperative	≥ \$50,000	70	20
	\$20,000 - \$49,999	0	100
	≥ \$50,000	50	0
*Regression results	P-value	<i>P</i> -value	
History of past dental behavior	.001	.001	
Household income	.01	.02	

Table 4. Multivariate Regression Results of Dental Care Access Factors

dentists willing to treat their child, and 23 percent were unable to receive care when needed.^{5,7,14-15} This study found that 15 percent of children had never been to the dentist, 19 percent were unable to receive care when needed, and 25 percent had been refused treatment (Table 2). These problems could be ameliorated through improved training opportunities for dentists, and by increasing parents' awareness of the need for early oral health intervention.

Income was found to significantly predict whether a child had a dentist for periodic oral health care. Those in the \$20,000 to \$49,000 income bracket were less likely to have a regular dentist (Table 3). Individuals in this income range tend to be enrolled in private insurance policies that are less comprehensive than Medicaid, and may not be able to pay out-of-pocket for dental services. Of those who earned less than \$20,000, 100 percent had a periodic oral health care provider (Table 3). This access to dental services may be due to being the likelihood of being enrolled in public health insurance programs such as Medicaid with an income of less then \$20,000. State Medicaid programs are mandated to provide a comprehensive set of dental benefits according to EPSDT standards. Children with special health care needs who are publicly insured may or may not have

improved access to dental services depending on the quality of the individual state's dental Medicaid program.

STUDY LIMITATIONS

The response rate (29 percent) may be a limitation of this study, though this rate is in the normal range for surveys.¹² It was assumed that families experiencing problems accessing services for their special needs child would be eager to participate in a study that could ultimately help them better access these services. Relatively low response may be due to the survey's length, although the cover letter stated that it would only take 10 to 15 minutes to complete the survey, its appearance (eg, number of pages) may have conveyed a greater time commitment.

The Autism Program of Virginia's (TAPVA) mailing list may be skewed towards those of higher socioeconomic status (SES). An individual must seek out this organization to be included on this list; those of higher SES tend to be more active in utilizing these types of resources. Therefore, it was not surprising that most children came from families with above average incomes. Given the high SES of this sample, barriers to dental care for the general population of ASD children may be underestimated. These results may not be generalizable to those with a lower SES.

CONCLUSIONS

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

- 1. Children with autism spectrum disorders who displayed difficult behavior were significantly less likely to have a dentist for routine care and less likely to receive care when needed.
- 2. Children from a household income in the \$20,000 to \$49,000 bracket were significantly less likely to have a regular dental provider and access care when needed.
- 3. Twenty-four percent of the ASD children did not have a dentist for periodic oral health care. The most frequent reason for not being scheduled for a dental appointment was an inability to find a dentist with special skills or a willingness to work with disabled patients.

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