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ABSTRACT

Background. Without guidelines or policies in dentistry for transitioning adolescents with special heath care needs from pediatric to adult oral health care, little is known about traditional support services. The authors surveyed pediatric dentists about their transition of adolescent patients with and without special health care needs (SHCNs) to adult care.

Methods. In 2009, the authors e-mailed a pilot-tested survey modified from a survey used for U.S. pediatricians to 4,000 pediatric dentists. The survey included demographic questions and questions regarding services and barriers associated with the transition of patients to adult care.

Results. Responses were obtained from 1,686 (42.2 percent response) pediatric dentists who were mostly in group or solo private practices and were younger, in that most had completed their education in the preceding 15 years. More than one-half practiced in suburban settings, and most worked with both dental hygienists and dental assistants. Most assisted patients with SHCNs with their transitions to adult care, and the predominant barrier to transitioning to adult care was availability of general dentists and specialists who were willing to accept these new patients. Pediatric dentists' answers paralleled those of pediatricians for the most part in terms of services provided and barriers to transition.

Conclusions. Most responding dentists helped adolescents with and without SHCNs make the transition into adult care, but the major barrier was the availability of general dentists and specialists.

Clinical Implications. With an office protocol in place that includes trained staff members, transitioning patients (especially those with SHCNs) to adult care can be facilitated to provide the appropriate oral health and support services.

Key Words. Special needs; dentistry; adolescents; oral health care; transitioning.

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The U.S. Department of Health and Human Services' Maternal and Child Health Bureau defined children with special health care needs (SHCNs) as children who have or are at increased risk of developing a chronic physical, developmental, behavioral or emotional condition and who require health-related services of a type or amount beyond that required by children generally.[1]

Estimates suggest that 9.5 to 12.5 million children and adolescents in the United States meet the definition of having SHCNs.[2] Across the last three decades, the life expectancy of children with SHCNs has increased, so that more than 90 percent survive beyond their 20th birthdays. Today, most adolescents with SHCNs achieve some degree of independence and have productive adult lives.

Transitioning from a pediatric health care system to an adult-centered health care system can be challenging for young adults with SHCNs and their families. The transition, however, frequently does not occur. If it does, it often is poorly organized and does not meet the goals of a collaborative and coordinated transfer of patients from one practitioner to another.

Transitions in health care for young adults with SHCNs are lifelong processes that meet their indi-

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vidual needs as they move from childhood to adulthood.[3] One of the goals of Healthy People 2010 is for young people with SHCNs to receive the services needed to make the necessary transitions to all aspects of adult life, including health care, work, recreation and independent living.[4]

The goal of transitions in health care for young adults with SHCNs is to help them reach their maximum potential through developmentally appropriate health care services that continue uninterrupted from adolescence to adulthood. The services should be comprehensive, responsive, continuous, coordinated, family centered and culturally competent.

In 2002, the American Academy of Pediatrics (AAP), American Academy of Family Physicians, American College of Physicians and the American Society of Internal Medicine issued a joint policy statement titled "A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs."[5] These organizations' goal was that by 2010, all physicians who provide health care to young people with SHCNs will understand the rationale for the transition; have the knowledge and skills to facilitate the process; and know if, how and when the transition is indicated.

Although a consensus exists among a number of medical organizations, the results of The National Survey of Children With Special Health Care Needs showed that fewer than one-half of parents who were caring for an adolescent with SHCNs had had discussions with their child's physician about meeting the child's health care needs into adulthood.[6] There have been a few studies (with small sample sizes) regarding how pediatricians incorporate transition support.[7-10] No nationally representative study regarding how pediatricians incorporate transition support was published until the National Alliance to Advance Adolescent Health issued a report in October 2008.[11] This report's authors used data from AAP's Periodic Survey of Fellows[12] to obtain information about pediatricians' perspectives regarding the age at which planning for transitioning should take place and the range of services that should be offered. The report stated that most pediatricians do not routinely offer transitioning support, and most pediatricians said that transitioning should begin between the ages 18 and 20 years for patients with and without SHCNs. Only 11 percent of pediatricians had a staff member dedicated to coordinating transitional planning. Other findings in this report included lack of educational materials, lack of a portable medical summary and lack of referrals to adult physicians.

Little is known about whether dentists provide transitional support for adolescents with SHCNs. In 2004, Casamassimo and colleagues[7] surveyed general dentists and found that less than one in 10 dentists saw children with SHCNs. Additionally, the report stated that only one in four general dentists had educational experiences with patients with SHCNs. In 2002, Nowak[8] reported the findings of a survey of a national sample of pediatric dentists; almost 95 percent of these pediatric dentists routinely scheduled appointments with children with SHCNs, and 71 percent continued to follow children with SHCNs after these patients turned 21 years of age.

There are no guidelines or policies in dentistry that offer dentists guidance for transitioning adolescents to adult oral health care providers. On the basis of a literature search, we determined that pediatric dentists treat most children with SHCNs.[7,8,13-17] Anecdotal evidence indicates that many pediatric dentists are frustrated about how to care for the continuing needs of these patients as they become young adults. The Commission on Dental Accreditation standard 2-26 for predoctoral dental education states, "Graduates must be competent in assessing the treatment needs of patients with special needs."[18] Implementation is required by July 1, 2013. The results of an earlier study[19] showed that 42 percent of dental education programs provided hands-on educational experiences with patients with SHCNs, but only 36 percent of students had an actual encounter with a patient with SHCNs. It is too early to report what effect this standard's change will have on dentists and their treating special patients. For now, the pediatric dentistry community remains the primary source of oral health care for pediatric patients with SHCNs, as well as many patients older than 21 years who have SHCNs.

We conducted a study to survey pediatric dentists on their transition of adolescents to adult oral health care providers with an emphasis on adolescents with SHCNs, the transition-related services provided and the barriers encountered in

ABBREVIATION KEY. AAP: American Academy of Pediatrics. **AAPD:** American Academy of Pediatric Dentistry. **SHCNs:** Special health care needs.

moving patients from pediatric to adult oral health care.

METHODS

We used a used a cross-sectional survey design. The institutional review board of the University of Iowa approved the study. We administered the study electronically in the fall of 2009.

Sample. In 2009, we obtained a representative sample of 4,000 practicing and academic pediatric dentists who were listed as active or life members in the American Academy of Pediatric Dentistry's (AAPD's) membership database.

Questionnaire and study procedures. We modified a questionnaire used to survey a random sample of AAP members regarding transition of patients with SHCNs into adult practices.[12] We modified the questions to apply to dental services as needed. The first part of the questionnaire requested demographic information about the respondent and his or her practice. The second part asked respondents about transition of patients with and without SHCNs and to identify whether they provided transition services for all or most patients, some or not at all. We pilot-tested a draft questionnaire with 10 pediatric dentists and incorporated their comments and suggestions into the final survey instrument. We converted the final instrument into an electronic format and sent it out via the Internet.

We collected data electronically and report them as percentages of respondents.

RESULTS

Demographics. Of 4,000 active and life members of the AAPD we surveyed, we obtained responses from 1,686, for a response rate of 42.2 percent. Most were men (57.7 percent), 46.4 percent were 30 to 39 years of age, and 58.2 percent had completed training since 1995 (Table 1).

Most respondents practiced in suburban settings (57.5 percent), followed by 18.9 percent in urban settings (within a city) and 13.1 percent in inner-city locations (city centers). Only 9.3 percent reported practicing in a rural setting. The predominant practice types were solo (38.6 percent) and group (36.2 percent) practices. A total of 14.6 percent of respondents practiced in an institutional setting (hospital, 8.7 percent; dental school as a faculty member, 3.5 percent; and community health center, 2.4 percent).

About one in 12 respondents (8.3 percent) reported that a general dentist was affiliated with their practice. Having auxiliary personnel in the practice, which is important in supporting patients with SHCNs during treatment, was common among respondents. A total of 45.4 percent of respondents had two or three dental hygienists, 20.7 percent had four to six dental hygienists, and 9.7 percent had more than six dental hygienists. A total of 34.9 percent of respondents had two or three dental assistants, 29.2 percent had four or five dental assistants, and 31.2 percent had six or more dental assistants. Only a few respondents reported having a designated dental health educator (1.2 percent) or

TABLE 1

Demographic variables of pediatric dentist respondents (n = 1,686).

VARIABLE	PERCENTAGE
Sex*	
Male	57.7
Female	42.3
Type of Practice*	
Solo	38.6
Group	36.2
Hospital	8.7
Dental school faculty	3.5
Community health center	2.4
No response	10.6
Ages of Respondents (Years)*	
30-39	46.4
40-49	18.2
50-59	22.4
60-69	14.1
Year Education Completed*	
1965-1979	16.5
1980-1994	26.1
1995-March 2010	58.2
Location†	
Urban	18.9
Inner city	13.1
Suburban	57.5
Rural	9.3
No. of Dental Hygienists in Practice*	
1	24.3
2-3	45.4
4-6	20.7
More than 6	9.7
No. of Dental Assistants in Practice*	
1	4.7
2-3	34.9
4-5	29.2
6 or more	31.2

* Owing to rounding, not all of the totals for the variable categories are 100 percent.
† The percentages in this category do not total 100 percent, as some participants did not respond.

TABLE 2

Services provided by pediatricians (n = 628) and pediatric dentists (n = 1,686) to support transition to adult care for adolescent patients with special health care needs.

SERVICE PROVIDED	PEDIATRICIANS (%)*		PEDIATRIC DENTISTS (%)†		
	All or Most	Some	All or Most	Some	None
Educational Handout	11	14	17	8	75
Discuss Consent and Confidentiality Issues	33	27	39	13	48
Assist in Creating a (Dental)‡ Health History or Summary	27	26	58	16	27
Create Individual (Oral)‡ Health Transition Plan	12	26	26	19	55
Assist in Referral to General Practitioner (Dentist)‡	47	33	54	26	20
Assist in Referral to Specialist (Dentist)‡	45	32	53	27	20
Support General Practitioner With Education and Consultation	23	30	37	29	33
Assist With (Dental)‡ Documentation for Program Eligibility (Supplemental Security Income, Vocational Rehabilitation, College)	32	34	21	25	54
Assist in Identifying Options to Maintain (Dental)‡ Insurance	19	22	23	21	56

* Source: McManus and colleagues.[11]
† Owing to rounding, not all of the totals for the service provided categories are 100 percent.
‡ Wording used to modify the questions on the American Academy of Pediatrics survey[12] to make them applicable to dental services.

a staff member designated as a care coordinator (1.6 percent) in the practice.

Transitioning of patients. A total of 92.8 percent of respondents reported that less than 10 percent of patients were 15 to 21 years old—an age range during which transition would likely occur for many patients. Transition might occur at an earlier age, as only 14.9 percent of respondents stated that more than 15 percent of their patients were 10 to 14 years old. A total of 44.8 percent of respondents reported that most of their patients were 9 years old or younger.

We asked respondents about various ages for transition of children who were older than 12 years. The predominant transition age for patients with SHCNs was between 18 and 20 years (49.2 percent); for patients without SHCNs, it was between 15 and 20 years of age (37.8 percent). A total of 21.2 percent of respondents said they had expanded their transition efforts in the last five years, but only about 12.5 percent had staff members dedicated to this effort for patients either with (13.0 percent) or without (12.0 percent) SHCNs.

Barriers to and services in support of transition. We gave the respondents a list of services that they could provide patients with SHCNs to assist in transition. We modified the list from the AAP's survey used to query physicians.[12] The findings from our survey and those from the AAP survey are shown in Table 2. More than one-half of the respondents to our survey provided assistance in referring the patient to a general dentist or specialist dentist and created a dental history and care summary for all their patients with SHCNs. When the percentages of respondents who provided services for the "some" or "all or most" categories were combined, more than one-half of respondents provided five of the services in the list, but up to one-half or more of respondents did not provide four of the services in the list for patients with SHCNs.

We then asked respondents to indicate their barriers to transitioning adolescents with SHCNs and to classify them as to impact (Table 3). Two-thirds or more of respondents said that availability of general dentists (70 percent) and specialists (66 percent) was the major barrier to transitioning adolescents with SHCNs. About one-third of respondents said that insurance

TABLE 3

Barriers for pediatricians (n = 628) and pediatric dentists (n = 1,686) to transitioning adolescents with special health care needs from pediatric to adult care.

BARRIER DESCRIPTION	PEDIATRICIANS (%)*		PEDIATRIC DENTISTS†		
	Major	Small	Major	Small	Not at All
Available General or Family Practice (Dentists)‡	41	39	70	24	6
Available Specialists	40	38	66	27	7
Bond With Pediatric (Dentists)‡ Difficult to Break	32	58	35	57	8
Ability to Self-Advocate at (Dental)‡ Visits	19	65	24	55	21
Staff Lacks Sufficient Time to Provide Transition Services	36	45	13	38	50
Staff Lacks Skills in Transition Planning	33	46	11	40	49
Lack of Insurance Reimbursement for Transition Planning	38	38	36	35	30
Lack of Knowledge About Community Resources That Support Young Adults With Special Health Care Needs	39	49	29	49	22

* Source: McManus and colleagues.[11]
† Owing to rounding, not all of the totals for the barrier descriptions are 100 percent.
‡ Wording used to modify the questions on the American Academy of Pediatrics survey[12] to make them applicable to dental services.

issues (36 percent) and the difficulty of breaking the bond with the pediatric dentist (35 percent) were major barriers. Pediatricians' responses to the same questions on their survey[11] for major barriers are included in Table 3 for comparison.

DISCUSSION

Our findings indicate that pediatric dentists are transitioning adolescent patients from their practices at an early age. Almost 93 percent of respondents reported that less than 10 percent of their patients were between 15 and 21 years of age, which is the usual age range in which the transition to adult oral health care occurs. Although we did not ask about it in our survey, we speculate that practices are overwhelmed with younger patients (45 percent of respondents said that more than one-half of their patients were between birth and 9 years of age) or that parents are transferring the children from a pediatric practice to an adult practice. The responses to the question about services provided by pediatric dentists to support the transition to adult oral health care were varied. Just more than one-half of respondents said they assisted in a referral of patients to general dentists (54 percent) and provided a history and summary for the patient (58 percent). Only a few respondents discussed consent and confidentiality issues (39 percent), provided educational handouts (17 percent), created an individualized oral health transition plan (26 percent) or helped identify options to maintain dental insurance (23 percent).

As with the AAP survey, the major barriers to transitioning patients in our survey were the availability of general dentists (70 percent) and specialists (66 percent) and lack of reimbursement (36 percent) and staff time for transitioning services (13 percent). Breaking the bond between adolescents with SHCNs and pediatric care providers was cited by 32 percent of pediatricians and by 35 percent of pediatric dentists as a major barrier. Whereas pediatricians reported lack of staff skills (33 percent) and staff time (36 percent) as major barriers, fewer pediatric dentists reported that lack of staff skills (11 percent) and staff time (13 percent) were major barriers and 49 and 50 percent, respectively, reported they were not barriers. These findings may reflect the complexity of the medical issues surrounding a medical care transition as compared with the complexity of oral health issues in a dental care transition.

The size of the problem of transitioning adolescents with SHCNs to adult oral health care is difficult to quantify. Estimates put the number of adolescents with SHCNs reaching adulthood at about 750,000 per year.[20] These adolescents have varying dental, economic, medical and behavioral needs. The pediatric dental community can provide the full range of dental and management services required for most children and adolescents. Whether the general practice dental community can manage adult-onset dental problems, compounded by progressive effects of disabilities and medical problems, remains to be seen. Significant changes in predoctoral and specialty education, reimbursement and behavior management techniques may be required to help the adult oral health care community be receptive to the transition of patients with SHCNs.

CONCLUSIONS

To our knowledge, ours is the first study to report on the transitioning of adolescent patients with SHCNs from pediatric to adult oral health care. Many of our findings were similar to those of an AAP survey other than the small number of adolescent patients in pediatric dentists' offices and clinics. Breaking the bond between practitioner and patients in pediatric practices frequently is reported as a major barrier, but most pediatric dentists did not report this.

It would be helpful if transition policies and guidelines were developed by pediatric dentistry in collaboration with general dentistry, as well as physicians in pediatric and family and internal medicine practices. Educational programs offered in dental school and through specialty and continuing education should include transitioning strategies, protocols and experiences, so that adolescent patients with SHCNs can be transitioned effectively and appropriately to adult oral health care. ■

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