Scientific Article

Oral Care for Special Needs Patients: A Survey of Nebraska General Dentists

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Abstract: ***Purpose:*** *The purpose of this survey was to assess the attitudes, behavior, and demographics of general dentists in Nebraska regarding their providing oral health care to patients with special health care needs (PSHCN).* ***Methods:*** *A 14-item questionnaire and accompanying cover letter were sent to 800 licensed general dentists in Nebraska. The survey asked for the dentists' demographic information and questions about their PSCHN. Responses to the questionnaire were tabulated, and percent frequency distributions for responses to each item were computed.* ***Results:*** *Of the 800 surveys sent, 371 (~46%) were returned. Solo practitioners were more likely to report seeing PSCHN (P<.001). Most respondents see all ages, but approximately 10% see only PSCHN over 18-years-old. The most common reasons given to improve the practitioners' ability to care for PSCHN were improved reimbursement (~35%) and more continuing education (~36%).* ***Conclusions:*** *These data indicate that most general dentists surveyed in Nebraska see special needs patients of all ages. The most common reasons for not seeing more special needs patients were the level of the patient's disease, the patient's behavior, and insufficient training/experience. (Pediatr Dent 2011;33:409-14) Received February 21, 2010 / Last Revision January 9, 2011 / Accepted January 10, 2011*

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In 1995, the Maternal and Child Health Bureau defined children with special needs as all children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that generally required by children.[1]

This definition was published in 1998 and was subsequently followed by a definition from The American Academy of Pediatric Dentistry's Council on Clinical Affairs in 2004. They described patients with special health care needs (**PSHCN**) as individuals having a physical, developmental, mental, sensory, behavioral, cognitive, or emotional impairment or limiting condition that requires medical management, health care intervention, and/or use of specialized services or programs.[2,3]

Disabilities may be developmental (manifesting prior to age 22-years-old) or acquired (injury or disease after 22-years-old) in nature and cause limitations in performing daily self-maintenance activities and substantial limitations in a major life activity. Health care for PSHCN is beyond routine and requires specialized knowledge, increased awareness, attention, and accommodation.[3]

It is estimated that 13.9 percent of U.S. children have special health care needs, and 21.8 percent of households with children include at least one child with a special health care need (**CSHCN**).[4] These children are disproportionately poor and socially disadvantaged and face significant barriers to health care.[5] The US Surgeon General's report on Oral Health has identified CSHCN as being among those groups who are experiencing the greatest level of difficulty in gaining access to dental care.[6]

The Surgeon General's report is validated by the findings of Newacheck et al., who reported that dental care access was a major concern among parents of CSHCN.[7] Stiefel et al., studied persons with disabilities and reported that, as a population, they had significantly poorer hygiene than individuals without disabilities.[8] The study also noted that presence of a physical disability or other illness may also limit access to services, as these individuals typically: have unique oral and systemic conditions; have difficulty in physically accessing care; and are often confronted by providers unable to meet their complex needs.[8]

The quality of oral health care for persons with intellectual disabilities has been reported in the literature to be less than that of their normal peers, and the presence of an involved, interested party is critical to the improvement of their oral hygiene.[9] Collectively, PSHCN are among the most underserved in our society; they have more dental disease, missing teeth, and difficulty in obtaining dental care than any other segment of the population.[10] Massachusetts and New York census data on children with disabilities indicated that there are numerous difficulties associated with the delivery of dental care to youngsters with special needs.[11,12] New York data indicated that, if willing, each provider would only need to see 12 PSHCN patients to improve access in the state.[12]

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The lack of willingness to treat PSHCN is likely attributable to provider-based barriers that include, but are not limited to: inadequate reimbursement for dental services; uncooperative behavior during dental treatment; a belief that special equipment is required to provide care; inability to afford the time necessary to treat PSHCN given the relatively high activity of the practice; and lack of practitioner training in special needs care.[13-18] The latter is noted as a significant reason for the dental neglect of disabled persons.[13]

Historically, given their training and background, pediatric dentists have been the mainstay in providing care for PSHCN. Even though pediatric dentistry is an age-defined field of practice, care for PSHCN has often been provided by the specialty, regardless of the patient's age.[19] Beyond this central core of dental providers, the dental profession as a whole was overwhelmed regarding its level of special needs competency by the deinstitutionalization movement in the late 1950s and 1960s—creating access limitations and provider skill/knowledge deficiencies for PSHCN that still linger today.[19-21]

At the time, recognition of this growing public health problem stimulated change within the academic environment.[20,21] Unfortunately, well-intentioned efforts by federal legislators, the Robert Wood Johnson Foundation, the Department of Health Education and Welfare, and the Commission on Dental Accreditation in the 1970s and 1980s to improve the training of dental students failed to significantly improve provider competency and access for the population.[22,23]

The Surgeon General's report in 2000 renewed interest in special needs care, prompting new accreditation standards for the nation's dental schools in 2004.[22] Concomitantly to these efforts, additional factors had been evolving which further inhibit the improvement of PSHCN access, including: dental admission reductions; aging of the workforce; changing workforce distribution/population ratios; student indebtedness; and third party economics that have adversely impacted special care reimbursement.[21] Moreover, there has been a growing awareness and concern over patients aging out of care, thereby creating additional pressure to address transition issues between pediatric and adult environments.[24,25] Studies indicate that more than 90% of children with disabilities now survive into adulthood.[26]

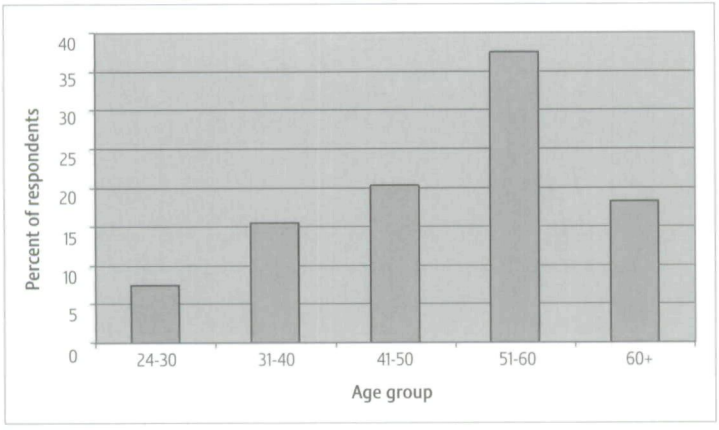

Figure 1. Distribution of participants' ages in years (N=368).

As these individuals make that transition, they often leave a patient/family centered pediatric health care environment and enter an adult environment which is more centered on individual responsibility.[24,25] Furthermore, pediatric providers become stretched beyond their skill sets as they are asked to deal with adult conditions and treatments. To be effective, transition must seek to focus on maximizing lifelong function and potential through the provision of high quality and developmentally appropriate health care services.[24,25]

Improving access, treatment, and quality of care of PSHCN is a critical public health issue for the profession that requires joint efforts by pediatric specialists and their generalist counterparts. Relatively few studies have revealed the attitudes and practices of general dentists regarding a child's first visit, prenatal oral health counseling, and management of PSHCN—issues which require calibration and coordination between the 2 provider groups.

Therefore, the primary purpose of this survey was to expand that knowledge base by assessing the attitudes, behavior, and demographics of general dentists in a rural state like Nebraska with regards to patients with special health care needs.

Methods

This research project and survey/cover letter were developed and approved by the Institutional Review Board of the University of Nebraska Medical Center (**UNMC**), Omaha, Neb. A list of all general dentists licensed in the state of Nebraska was obtained from the UNMC Health Professions Tracking Center, which plays a key data management role by collecting, maintaining, and disseminating primary source health care provider information. The rationale for selecting general dentists was made because they: constitute the largest number of primary care dentists providing potential access points for PSHCN within the state; see the same group of patients within their practice on a regular recall basis; and display the attitudes and behaviors the study seeks to evaluate.

The survey was conducted in 2008 anonymously with no response tracking system. A 14-item questionnaire and accompanying cover letter were sent to 800 licensed general dentists in Nebraska in February 2008. The survey asked for demographic information, such as the: gender; age; number of years practicing dentistry; type of practice (solo, partnership, public health, faculty practice, other); practice location by county or counties; population size of the community served, if additional training had been completed (General Practice Residency [**GPR**], Advanced Education in General Dentistry [**AEGD**]); and payer status of the patient base (insurance, self-pay, Medicaid). The survey also asked questions about the: percentage of PSHCN seen in the office; age range of PSHCN treated within the practice; type of dental services provided to PSHCN; utilized behavior management techniques for PSHCN; major reason(s) for not treating any or more PSHCN; and ability to improve care for PSHCN.

A postage-paid, preaddressed envelope was provided for returning questionnaire responses, which were tabulated. Percent frequency distributions for responses to each item were computed. Descriptive statistics and chi-square tests were

conducted using SPSS 17 (SPSS Inc, Chicago, Ill) to analyze data. All tests utilized a .05 level of statistical significance.

Results

Of the 800 surveys sent, 371 (~46%) were returned and 317 (~85%) of the respondents were male and 53 (~14%) were female (1 respondent did not specify gender). All ages were well represented; approximately 8% (28) of the respondents were between 24 and 30-years-old, 16% (58) were 31- to 40-years-old, 20% (75) were 41- to 50-years-old, 38% (139) were 51- to 60-years-old, and 18% (68) were more than 60-years-old (Figure 1). Three respondents (~1%) left this question blank. Most respondents (249; ~67%) reported being solo practitioners, but approximately 23% (86) were reportedly in a partnership. Public health, faculty practice, and "other" represented only approximately 1% (4), 3% (10), and 5% (20), respectively. Two respondents (~1%) left this question blank.

Surveys were returned from 60 of the 93 counties in Nebraska; approximately 24% (90) of the surveys returned were from Douglas County, and approximately 17% (62) were from Lancaster County. All other counties each represented less than 4% of the surveys returned. Following this, almost half (~46%) of the respondents were from communities with a population greater than 50,000. The following percentages reported serving communities of the following sizes: 20,000 to 49,999 (~18%); 10,000 to 19,999 (~7%); 5,000 to 9,999 (~10%); and fewer than 5,000 (~19%).

Most respondents had not completed any advanced training beyond their doctorate (307; ~83%), but approximately 12% (46) had completed a GPR and 4.0% (15) had completed an AEGD program. There was no significant correlation between additional training completed and percentage of PSHCN. However, general dentists with additional training are more likely to see PSHCN, but this statistic was not significant ($P<.10$). The following numbers of respondents had been in practice for the following years: more than 20 years (249; ~64%); fewer than 5 years (31; ~8%); 6 to 10 years (39; ~11%) 11 to 15 years (24; ~7%); and 16 to 20 years (34; ~9%). Nearly all survey respondents reported seeing patients with private insurance (361; ~97%) and self-pay patients (357; ~96%); however, only approximately 74% (276) reported seeing Medicaid patients.

Most practitioners (80%) who responded to this survey reported that: less than 5% of their patients were PSHCN; 12% treated 6% to 10% PSHCN; and only approximately 3% treated no PSHCN. Solo practitioners were more likely to report seeing PSHCN ($P<.001$). There were no correlations between seeing PSHCN and age, gender, or size of community. Of the practitioners who see PSHCN, most see all ages, but approximately 10% see only PSHCN over 18-years-old. Practitioners who reported seeing a greater number of PSHCN were more likely to also report seeing all ages of PSHCN ($P<.001$).

General dentists were asked to check all that apply for the question: What do you use for behavior management of PSHCN? When selecting behavior management techniques for PSHCN, approximately 28% of Nebraska general dentists provide oral sedation, and 42% report using nitrous oxide (Figure 2). Only approximately 9% provide care under general anesthesia, and even fewer use IV sedation (~2%) and immobilization devices (~4%). Many respondents (~13%) listed something under the "other" category, such as "TLC," "patience," and "positive reinforcement." Sixty-nine percent of Nebraska dentists who responded to this survey, however, stated they provide comprehensive care for their PSHCN, with referrals as needed, 38% see PSHCN only for simple restorative and preventive care, and only approximately 16% provide comprehensive care for their PSHCN.

The most common answer given for not seeing more PSHCN was the "level of the patient's disease" (~49%; Figure 3). "Patient's behavior" and "insufficient training/experience"

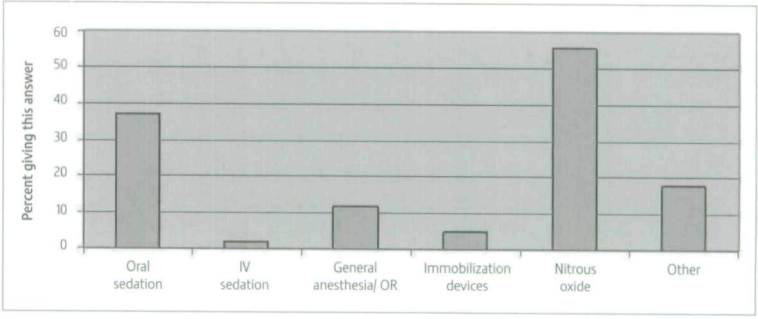

Figure 2. Response to the question: "What do you use for behavior management of special needs patients?" (N=278)

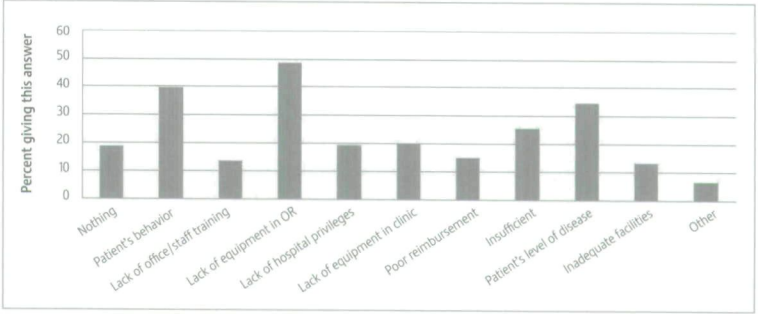

Figure 3. Response to the question: "What are the major reasons you do not see more special needs patients?" (N=353)

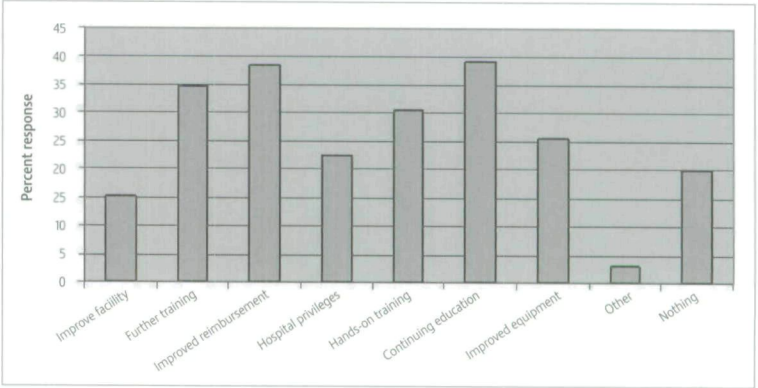

Figure 4. Response to the question: "What would improve your ability to care for special needs patients?" (N=339)

were the second (~40%) and third (~35%) most common reasons given. About a quarter (~25%) of respondents listed "poor reimbursement" as a reason they do not see more PSHCN. Less common reasons included "lack of office/staff training," "lack of equipment in clinic," and "inadequate facilities," all of which were cited by less than 15% of respondents. Under the category of "other" responses given, reasons given included: "my practice is already very busy"; "liability of sedation"; "there are not many PSHCN in my area"; and "not interested at this stage of my career." Others stated "obtaining hospital privileges" or "not having a hospital in the town where they practice." Nearly 20% (~19%) said there were no reasons why they would not see more PSHCN and would happily include more in their practices.

A wide variety of answers were given for what would improve the practitioners' ability to care for PSHCN (Figure 4). The most common answers given were "improved reimbursement" (~35%) and "more continuing education" (~36%). Between 20% and 30% of respondents gave other answers, including "further training," "hospital privileges," "hands-on training," and "improved equipment." Only 14% said an improved facility would help them see more PSHCN, and approximately 18% said nothing would encourage them to see more PSHCN. Under the "other" category, respondents listed "need more patients/referrals" or "a lift to move patients from wheelchair to dental chair."

Discussion

The dental literature appears to identify 2 certainties:

1. The involvement of generalists is critical to the expanding access for PSHCN.
2. Given the generalists' limited experience with the patient population, education and training in special needs care continues to be needed.[22,27-29]

The combination of the special care knowledge gap among generalists and the aforementioned access barrier factors has created a very dynamic and complex problem with no straightforward comprehensive strategy to effect resolution. To understand the impact of these factors in a rural state, the present study sought out attitudes of practitioners regarding current access and expanding access issues for PSHCN in their offices. Regarding the current level of access to their practices, the study obtained information concerning perceived or real barriers, patient management strategies, and the spectrum of care available to the population—an indirect indicator of the impact of these barriers. Expanding access issues centered upon willingness to see additional patients and how to eliminate barriers.

Consistent with study objectives, the survey captured responses from greater than 46% of dentists who were sent questionnaires. The respondents reported that special needs care comprised less than 5% of patient care activity within their offices and that care was generally being provided to a full age range of patients. Interestingly, practitioners who reported seeing a greater number of PSHCN were more likely to also report seeing PSHCN of all ages. This agreed with findings by Dao et al.,[20] that the better educated and experienced one was treating PSHCN, the more likely they were to treat them. Such supportive attitudes are critical in rural states like Nebraska, where the number and distribution of pediatric dentists is low and concentrated within urban settings.

General dentists were asked to check all that apply for the question: "What do you use for behavior management of specialty health care needs patients?" Therefore, regarding patient behavioral management practices, practitioners showed a predilection for the use of: (1) nitrous oxide; (2) oral sedation; (3) a mixture of psychological management strategies (positive reinforcement, TLC, extended time with the appointment); (4) general anesthesia; (5) immobilization devices; and (6) IV sedation. This survey did not ask a question to address the most common technique used or whether it is dependent on the patient's needs. Making definitive statements regarding the distribution of management strategies and the spectrum of care that dentists provide without knowledge of the patient's functional level must be considered cautiously.

The data, however, appear to suggest that there is greater reliance upon nitrous oxide and oral sedation vs psychological management strategies and immobilization devices. This may reflect the expediency of inhalation and pharmacological agents to achieve patient compliance and/or a lack of familiarity in the application or knowledge of other behavioral management techniques. In a related finding, most generalists reported providing comprehensive care with a referral as needed or seeing patients for simple restorative and preventive care.

These tendencies among providers are subsequently reinforced by responses noting that the patient's level of disease, the patient's behavior, and insufficient training/experiences were major barriers to providing care. Collectively, the data suggests that generalists manage the patient within the traditional flow of the practice and, as the complexity of patient behavior, systemic health, and dental need increases, they reach a point where they are extended beyond their skill set and are making referrals. Unfortunately for the patient population, such complexities lead to further oral decline, as access to more advanced levels of dental care are restricted geographically. Collectively, these responses define a consistent message within study data that is overtly confirmed by respondents themselves. They note that improving access for patients basically centers upon 2 core issues: (1) education; and (2) improving reimbursement. Casamassimo et al's.,[23] study of generalists and access for children with special needs found a similar spectrum of provider perceptions. They noted that patient's behavior and levels of disease, and training were the key barriers to providing care.

To address the oral health needs of the special care population, educational initiatives must be employed at 3 levels: (1) predoctoral; (2) postdoctoral; and (3) private sector continuing education.[22] As noted, accreditation standards have been implemented to bolster predoctoral curriculums, and postgraduate general dentistry programs have a long-standing history of focusing on PSHCN.[20,22,28] A number of academic institutions have established special needs clinics, and creating a special needs specialty has also been proposed. Such a

specialty has been questioned regarding how effective it would be. Generalists are a required component to the solution, and the, may reduce their role by increasing referrals to a limited number of special needs providers, creating a reliance on such providers in a manner not unlike what occurred with pediatric dentists.[27] While these academic efforts need to be continually reinforced and supported by the profession, advocates and federal legislation, increased focus on continuing education programs, and other knowledge-sharing mechanisms can aid those already in practice. A study by Doa et al.,[20] demonstrated that the better prepared dentists are regarding knowledge and skills in special needs care, the greater the likelihood that they would: treat a more diverse population (including pediatrics); set up their practices for special needs care; be more confident in staff skill levels; and be more positive and confident in their own abilities. Building upon the sentinel call for an improved educational effort, a number of academic institutions sponsor mini-residencies or have developed operating room training programs for practicing generalists.[22,30]

Organization of academic institutions with special needs dental clinics into an affiliation of regional centers of excellence under a national umbrella could potentially serve as a stronger nidus for regional and local education/training initiatives. As is true for other national training programs (eg, the AIDS Education and Training Centers), an infusion of federal funding will be necessary for initiating and sustaining the effort, as well as ongoing commitment from the profession itself. Other states have mandated a specific number of hours in special needs care for licensure renewal.[22,31] At a more local grassroots level, special needs study clubs could be emphasized that foster relationship building and information sharing among providers. Including both pediatric and adult providers in such study clubs would also be beneficial. Additionally, in rural states the use of HIPAA-compliant teleconferencing or Internet information-sharing software technologies to bring geographically dispersed provider groups together could be encouraged.

Even though dentists within the current study noted that education is desired, the literature shows that providing such opportunities does not necessarily translate into improved access. Casamassimo et al.,[23] cautioned that educational efforts may simply reinforce the efforts of those practitioners who already provide care without stimulating an expansion in the number of willing providers. In like fashion, Theirer[22] noted that, while education may improve sensitivity to the needs of the population, such awareness is ineffective unless coupled with action on the part of providers to see patients. Such willingness may be tempered by reimbursement issues that plague the population.[20,21,28]

While pediatric care is a mandated part of Medicaid, adult Medicaid is optional and at continual risk for benefit reductions or elimination. As a profession, advocating for the inclusion of Medicaid dental benefits and other third party reimbursement mechanisms for adult PSHCN is a critical cofactor in improving access.

This study's findings need to be considered in the context of its limitations. The results of this study are limited by the design's nature and sample's size. There was less than a 50% response rate, which may not be ideal. At the same time, however, it may be appropriate and considered to be in the normal range for surveys, considering that the survey was anonymous with no response tracking system. Additionally, all data collected in this study was via self-reporting, so it was subject to recall bias, which included intentional deception, poor memory, and misunderstanding questions. Participants may or may not have honestly answered questions about their perception and knowledge practices and oral health. The findings were based on the perceptions of responding rather than on objective patient data. The variation in backgrounds of the participants may have played a role in this study.

Conclusions

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

1. Most general practitioners see PSHCN of all ages, but with varied percentages.
2. For behavior guidance, Nebraska general dentists rely on the use of nitrous oxide and oral sedation techniques, while only a small percentage provides care under general anesthesia or use more time-intensive behavior guidance techniques.
3. General dentists' willingness to see PSHCN was based upon the level of the patient's disease, patient's behavior, and provider training/experience.
4. The most common reasons given to improve the practitioners' ability to care for PSCHN were improved reimbursement, more continuing education and further training.

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