

# Scientific Article



## Parental Attitudes Regarding Behavior Guidance of Dental Patients with Autism

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**Abstract:** ***Purposes:** The purposes of this study were to evaluate: (1) parents' ability to predict dental treatment cooperation by their autistic child; (2) behavior guidance techniques (BGTs) used during treatment; and (3) parental attitudes regarding basic and advanced BGTs. **Methods:** Data were collected from 85 parent/autistic child pairs and their dentists using surveys and treatment records. **Results:** Parents most accurately predicted if their child would permit an examination in the dental chair ( $\geq 88\%$ ) and would cooperate for radiographs ( $\geq 84\%$ ). BGTs utilized most often ( $>50\%$ ) were positive verbal reinforcement (PVR), tell-show-do (TSD), mouthprops, and rewards. In general, basic BGTs were more acceptable ( $>81\%$ ) than advanced BGTs ( $>54\%$ ). The most acceptable techniques ( $>90\%$ ) in order were: PVR, TSD, distraction, rewards, general anesthesia, hand-holding by parent, and mouthprops. When parents evaluated only BGTs used for their child, all BGTs, including a stabilization device, were highly acceptable ( $>91\%$ ), except for staff restraint (74%). **Conclusions:** Parents were accurate in predicting cooperation for some procedures. The most acceptable and efficacious BGTs in order were: PVR, TSD, distraction, rewards, and hand-holding by parent. Parental perceptions of BGTs were influenced by whether or not they had been used for their child. (Pediatr Dent 2008;30:400-7) Received June 22, 2007 | Last Revision October 10, 2007 | Revision Accepted October 15, 2007*

KEYWORDS: PEDIATRIC DENTISTRY, BEHAVIOR GUIDANCE, PARENTAL ATTITUDES, AUTISM

The focus of behavior guidance techniques (BGTs) as recognized by the American Academy of Pediatric Dentistry (AAPD) involves interaction between the dentist and dental team, the patient, and the parent that is directed toward communication and education.<sup>1</sup> Parental attitudes towards BGTs have been the subject of several reports.<sup>2-8</sup> Parental acceptance is a key consideration in selecting a BGT, as most parents prefer involvement rather than leaving the decision solely to the dentist.<sup>1,9</sup> Some parents are more accepting of advanced BGTs (eg, protective stabilization, sedation) when provided detailed explanations of the techniques, while others are not.<sup>4-7,10,11</sup> Parental influences, the legal environment, and societal changes are moving dentists towards BGTs that are considered less aversive by parents.<sup>8,12-14</sup>

Selection of BGTs for healthy, uncooperative children is different than for fearful patients or those with intellectual disabilities. There has been minimal research, however, exploring attitudes of parents of children with special health care needs (CSHCN).<sup>1</sup> One study found that parents of CSHCN were significantly more accepting of protective stabilization

for simple dental procedures, but did not differ from parents of healthy children in opinions of other BGTs.<sup>7</sup>

Autism is a complex neurobehavioral disorder. As currently defined by the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition - Text Revision (DSM-IV-TR), diagnostic criteria are: (1) impairments in social functioning; (2) deficits in communication; and (3) restricted interests.<sup>15</sup> Common comorbidities include: motor deficits, sensory abnormalities, cognitive deficits, medical conditions such as epilepsy, and psychiatric diagnoses such as attention deficit/hyperactivity disorder and mood disorders. Children with autism are a heterogeneous group with variable ability to cooperate in the dental setting.<sup>16-18</sup>

Some of the defining characteristics of autism may negatively impact acceptance of dental treatment. Resistance to change may make it difficult for the autistic child to respond positively in unfamiliar environments. Atypical sensory responses, such as heightened perceptions of touch, smell, and sound and visual stimuli may overwhelm the child's capacity to cope.<sup>19</sup> Receptive and expressive language deficits and impaired interpretation of nonverbal communication may undermine BGTs based on communication. Social limitations, such as deficits in pretend play and imitation, and an inability to focus on a joint endeavor with another person may make BGTs such as tell-show-do (TSD) unproductive.<sup>20,21</sup> Dentists who treat autistic patients are challenged to find safe, acceptable, and effective BGTs. Among dental patients with special health care needs, autism is one of the most frequent indications for providing dental care under general anesthesia (GA).<sup>22,23</sup>

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Parental attitudes regarding BGTs for children with autism have not been described. The purposes of this study were: (1) to evaluate parents' ability to predict cooperation for dental treatment by their autistic child; (2) record BGTs used during treatment; and (3) assess parental attitudes regarding basic and advanced BGTs.

**Methods**

Children with autism and their parents/legal guardians were recruited from a hospital, a dental school, and 9 private pediatric dental practices as subjects in this institutionally approved study. Between August 2003 and February 2004, all were invited by the dentist to participate on the day of the child's dental appointment. Inclusion criteria were:

1. children with a diagnosis of autism from the DSM-IV-TR<sup>15</sup> or equivalent assigned by a pediatrician, medical specialist, and/or psychologist;
2. children up to age 19 years;
3. written consent from the child's parent(s) or legal guardian(s).

No incentives were given for participation. Those with a diagnosis of pervasive developmental disorder, other than autistic disorder, were not included. Participating dentists and staff were trained to use the research instruments via a 2-hour training session with the lead investigator.

Data were collected from parental interviews, dentist treatment notes, and parental surveys. BGTs were evaluated for acceptability, efficacy, success or failure, and parental attitudes towards the techniques after observing their child during the dental visit. BGTs were classified according to current AAPD guidelines: basic behavior guidance (communication and communicative guidance, TSD, voice control, nonverbal communication, positive verbal reinforcement (PVR), distraction, parental presence/absence, nitrous oxide/oxygen) and advanced behavior guidance (protective stabilization, sedation, general anesthetic (GA)).<sup>1</sup>

Patient demographics (gender, age, ethnicity, payer), residence, appointment type, treatment location (hospital, school, private practice), local anesthetic use, and initial vs return visit were documented in the treatment records. Dentist notes included treatment attempted and accomplished, utilization and success/failure of BGTs, the calming effect of the stabilization device (if used), and assistant usage.

Prior to treatment, parents were asked to predict what treatment could be accomplished (eg, examination in the dental chair, dental prophylaxis, fluoride treatment, radiographs, restorations, extractions). Parents also predicted whether certain structure or coping strategies (eg, time of day, writing board, headphones) would help their child during the dental visit.

A post-appointment survey included questions concerning BGTs illustrated by brief descriptions or photographs. Questions included whether a particular strategy would work for their child (yes, no, or uncertain) and if the approach was acceptable. Parents were asked to rate all BGTs, regardless of

whether or not it was used for their child. They were asked about structure and coping strategies. The parents rated their own anxiety at the dentist using the 4-question Corah dental anxiety scale (4-20 point range)<sup>24</sup> and reported education level. Parents were encouraged to complete the post-appointment survey prior to leaving the office; when immediate completion was not possible, it was returned by mail.

**Data analysis.** Descriptive statistics were calculated for all variables, including mean and standard deviation ( $\pm$ SD) for quantitative variables and frequencies and percentages for categorical variables. McNemar's test was used to compare:

1. parental predictions of child cooperation and actual treatment accomplished; and
2. parental pre- and post-appointment opinion on coping structures and strategies.

Table 1. DEMOGRAPHIC CHARACTERISTICS OF AUTISTIC PATIENTS AND THEIR PARENTS

Demographic characteristics	% (N)
<b>Patient gender</b>	
Males	78 (66)
Females	22 (19)
<b>Patient age (ys)</b>	
<4	5 (4)
4-7	22 (19)
>7	73 (62)
<b>Patient ethnicity</b>	
Caucasian	74 (63)
Asian	17 (14)
African American	7 (6)
Native American	2 (2)
<b>Patient residence</b>	
Home	93 (79)
Special school	4 (3)
Foster care	2 (2)
Care facility	1 (1)
<b>Parental education level</b>	
College	82 (70)
High school	14 (12)
Unknown	4 (3)
<b>Insurance</b>	
Medicaid	57 (48)
Private insurance	41 (35)
None	2 (2)

Table 2. PARENTAL PREDICTION OF COOPERATION AND ACTUAL TREATMENT ACCOMPLISHED FOR AUTISTIC CHILDREN

Procedure	No. of parents responding	Pre-appointment prediction (%)	Actual treatment performed (%)	Agreement (%)	P-value*
<b>Exam in chair</b>					
Initial visit	24	88	100	88	.25
Return visit	56	95	96	95	1.0
All patients	80	93	98	93	.22
<b>Prophylaxis</b>					
Initial visit	22	77	68	54	.75
Return visit	50	88	88	80	1.0
All patients	72	85	82	72	.82
<b>Fluoride application</b>					
Initial visit	20	55	70	45	.55
Return visit	46	78	89	76	.23
All patients	66	71	83	67	.13
<b>Radiographs</b>					
Initial visit	18	11	0	89	.50
Return visit	31	29	13	84	.06
All patients	49	22	8	86	.02

\* McNemar's test.

The chi-square test was used to compare parental acceptability for each BGT by whether or not the technique was used on the child. The statistical significance of the tests was computed using exact methods due to small sample sizes for several of the comparisons (SAS v. 9.1, SAS Institute, Inc, Cary, NC). Additional analyses were performed to assess if the results differed by type of visit (initial or return), parent education level (high school or college education), and location where patient was seen.

**Results**

Data were analyzed from 85 children with autism and their parents/legal guardians. The mean age (±SD) of the children was 9.6 years (±3.7), with a range of 2.7 to 19 years. There were 66 males and 19 females. Ethnicity of the subjects reflected surrounding county demographics.<sup>25</sup> The payer was Medicaid (57%), private insurance (41%), or no insurance (2%). Participating parents/guardians were 84% mothers and 16% fathers. Most parents were educated past high school (Table 1). The mean dental anxiety score (±SD) was 7.9 (±3.1) for the parent completing the survey, compared to the reported median 8.0.<sup>24,26</sup>

Fifty-nine percent of the patients were treated by 7 dentists at the hospital, 21% by 9 private practice dentists, and 20% by 4 pediatric dentistry residents at the dental school. Twenty-nine percent were seen for an initial visit, and 71% were returning patients. Appointment types were: preventive recall (56%); initial examination (27%); emergency care (8%); operative treatment (4%); and other treatment (5%),

including space maintenance, GA, and orthodontic recall). Four children (5%) received local anesthesia: 2 during operative care, and 2 during emergency appointments. Some children seen for emergency care also were first-time patients.

**Parental predictions.** Table 2 depicts the accuracy of parental predictions of their child's ability to accept varied treatments. Parents accurately predicted when their child could have an examination in the dental chair (≥88% agreement). Parents also predicted fairly well if their child would cooperate for radiographs (≥84% agreement), but tended to overestimate their child's willingness to cooperate. Parents were less accurate regarding prophylaxis and fluoride application, particularly if the child was being

seen for the first time (≤54% agreement). Restorations and extractions were not done often enough for analysis.

Parents did not differ on efficacy of structure and coping strategies before or after the dental visit, regardless of whether the child was an initial or returning patient. The most helpful parameters (≥82%) were the: same dentist; parent staying with the child; and same dental staff (Table 3). All parameters had an 80% or greater agreement (data not shown).

**Parental rating of BGT acceptability and BGTs utilized.**

Figure 1 illustrates parental rating of BGT acceptability and BGT frequency of use. All BGTs were rated as acceptable by ≥ 54% of parents. In general, basic BGTs were more acceptable than advanced BGTs. The most acceptable techniques (>90%) in declining order were: PVR; TSD; distraction; rewards; GA; hand-holding by a parent; and mouthprops. Acceptability for varying methods of protective stabilization was: parental restraint (84%); staff restraint (63%); and stabilization device (54%).

Four techniques were used more than 50% of the time: PVR; TSD; mouthprops; and rewards. Nitrous oxide, oral sedation, and GA were used least frequently, and negative verbal reinforcement (NVR) was not used at all (Figure 1). Dentist ratings of success were: distraction (86%); frequent breaks (81%); rewards (80%); nitrous oxide (67%); TSD (65%); PVR (60%); and oral sedation (33%). The stabilization device was used for 25 children, with a dentist-reported calming effect noted for 5 (20%). Most children were treated by 1 assistant (73%), although 27% needed 2 or more assistants.

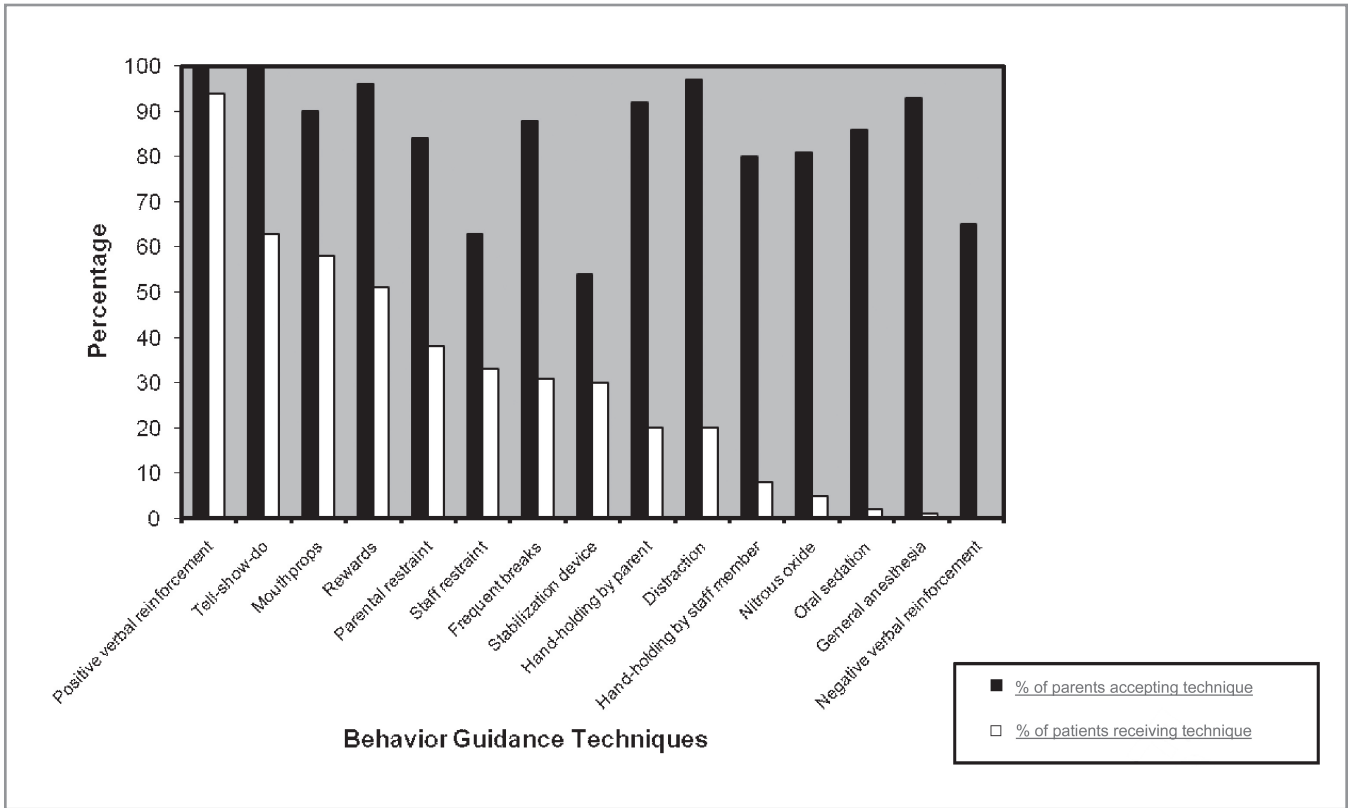


Figure 1. Post-appointment parental acceptance of behavior guidance techniques (BGTs) and frequency of BGT use among autistic patients (N=85).

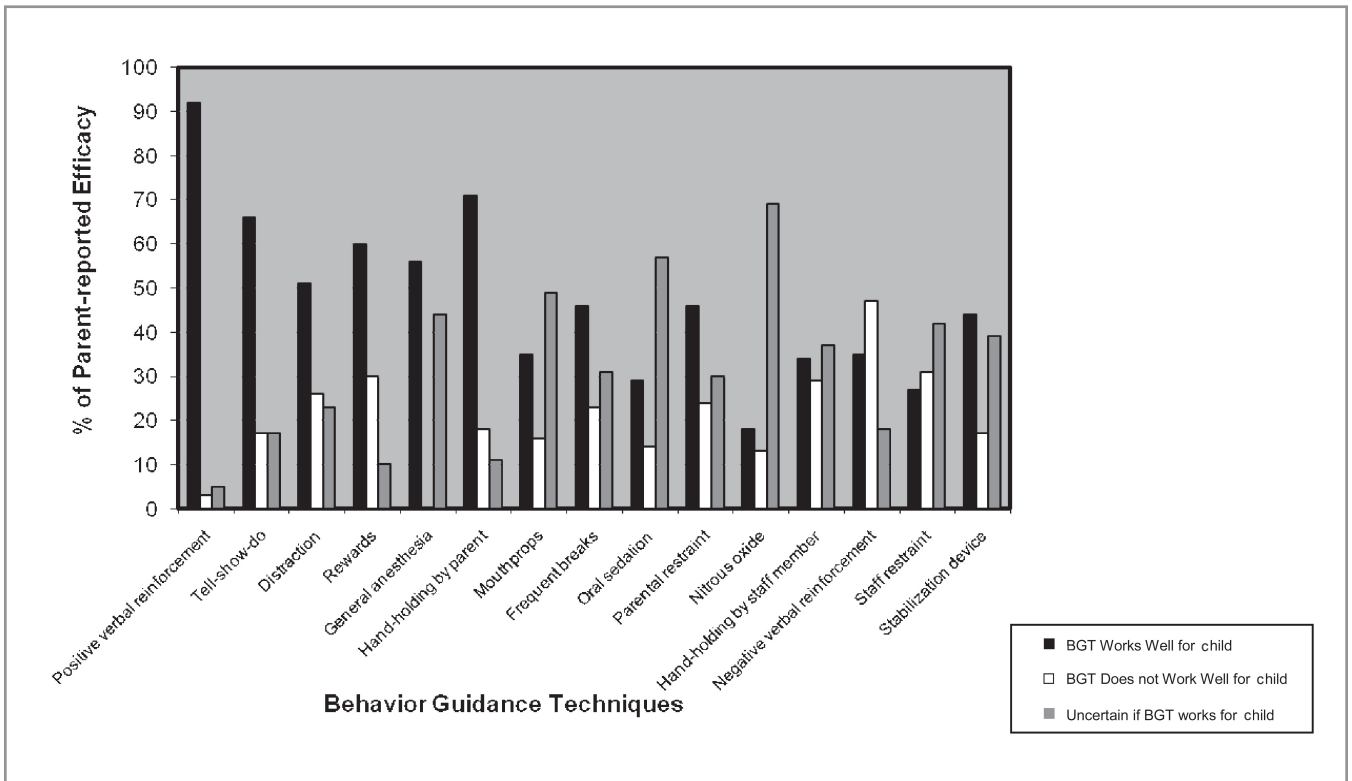


Figure 2. Post-appointment parental opinion of behavior guidance techniques (BGTs) efficacy among autistic children (N=85).

Table 3. PARENTAL OPINION ON STRUCTURE AND STRATEGIES THAT HELP THEIR AUTISTIC CHILDREN COPE IN THE DENTAL OFFICE\*

Structure and strategies	No. of parents responding	Pre-appointment	Post-appointment
		% believing helpful	% believing helpful
<b>Rehearsal at home</b>			
Initial visit	24	46	42
Return visit	59	49	51
All patients	83	48	48
<b>Personal coping mechanism</b>			
Initial visit	24	38	46
Return visit	57	56	51
All patients	81	51	49
<b>Staying with child</b>			
Initial visit	23	78	87
Return visit	58	86	85
All patients	81	84	85
<b>Same dentist</b>			
Initial visit	24	83	92
Return visit	58	88	88
All patients	82	87	89
<b>Same dental staff</b>			
Initial visit	23	87	87
Return visit	56	80	82
All patients	79	82	84
<b>Same operatory</b>			
Initial visit	23	57	52
Return visit	56	70	71
All patients	79	66	66
<b>Appointment at the same time of day</b>			
Initial visit	24	25	21
Return visit	54	31	28
All patients	78	29	26

\* McNemar's test; P-values for preappointment vs post-appointment comparisons were all nonsignificant ( $P \geq .45$ ).

**Parental rating of BGT acceptability and efficacy.** When parents rated acceptability and efficacy for each BGT, there were no differences between initial and returning patients, parents with a high school vs college education, or the location in which the patient was seen (data not shown). All BGTs were rated as more acceptable than efficacious. As strategies became less effective, parents ranked them as more unpredictable. Only PVR had an efficacy rating by parents of greater than 90%. Hand-holding by a parent, TSD, rewards, GA, and distraction were 51% or greater. Efficacy for varying methods of protective stabilization was: parental restraint (46%); stabilization device (44%); and staff restraint (27%). Parents were most uncertain of the efficacy of nitrous oxide and oral sedation (Figure 2).

When BGTs were used, greater acceptability and efficacy were noted. Table 4 stratifies BGT acceptability by whether or not a technique was used for a child. Parents' acceptance of a stabilization device used on their children was 95%, significantly higher than the 40% acceptability reported by

parents of children who were not treated with that device ( $P < .001$ ). BGTs were rated at 91% or greater acceptability, with the exception of staff restraint (74%), when the technique had been used.

Parental opinion on efficacy was significantly greater for those children receiving TSD, mouthprops, rewards, frequent breaks, nitrous oxide, parental restraint, stabilization devices, and hand-holding by a staff member ( $P < .05$ ). Only mouthprops (48%) and staff restraint (35%) were rated lower than 50% when the technique had been used (Table 5).

### Discussion

The defining characteristics of autistic disorder present a range of challenges and a lifetime of situational stresses to children with autism and their parents.<sup>27</sup> A dental appointment is among the routine activities where the autistic child may exhibit misbehavior. The dental environment is not a "good fit" with the capabilities, characteristics, and style of behavior of autistic children, as it presents the patient with sensory stimulating activities, possible discomfort, and loss of control in an unfamiliar environment.<sup>28</sup> The poor fit of dentistry with the qualities of autism can hinder guiding patient behavior towards positive outcomes.

As with any child, strategies for behavior guidance of patients with autism start with the parents. Their inclusion in BGT selection is part of the informed consent process.<sup>1,14</sup> Parental ability to predict their child's response in the dental setting may influence acceptance/rejection of BGTs. Parents of uncooperative children are more accepting of advanced BGTs than parents of cooperative children.<sup>9,11</sup> In this study, parents recognized that their children would be unable to cooperate for radiographs.

Parents of returning patients more accurately predicted accomplishment of prophylaxis and fluoride application. Parental opinions regarding structure and coping strategies were consistent pre- and post-appointment.

Parental acceptance of BGTs has been correlated with education about and rationale for BGTs.<sup>6,10,29</sup> Other studies demonstrated that parental acceptance increases when BGTs are used for the child.<sup>5,8,9</sup> Parental dental fear has been shown to influence both dental fear and cooperation of healthy children.<sup>30</sup> This study's parents were well educated, represented a wide range of socioeconomic status, and had dental anxiety scores below the reported population median value. Regarding dental care acceptance, an autistic child may be less likely to imitate their parent than a nonaffected sibling, making parents' dental anxiety status less influential.

This study's design differed from other reports evaluating parental attitudes and is not directly comparable to other results. All parents had a child with autism and were with



their child during treatment, the survey presented BGTs without a rationale explaining their use, and parental acceptance was assessed as either acceptable or not without using a visual analogue scale. The most important difference may be that the parents had already consented to using BGTs and had seen them used for their child prior to rating acceptance. Seeing a BGT in use may alter parental perception. Parents were most familiar with the BGT employed for their child and would be

expected to favorably perceive a BGT well presented by their child's dentist and used effectively.

Based on opinions of this group of parents of autistic children, the following basic approaches are likely to be perceived both as acceptable and working well (>50% success): PVR; TSD; distraction; rewards; and hand-holding by a parent. Other beneficial factors included: parents remaining with their children; treatment provided consistently by the same dentist/dental staff; and using a coping object (eg, stuffed toy, headphones, writing board).

Communication-based principles are a part of all basic BGTs. Although children with autism may be expected to obtain less benefit from communication-based BGTs, dentists use them frequently. Dentists in this study did not have a standardized way to rate "success" of BGTs. TSD success was defined as any participation by the child in TSD. Nitrous oxide was infrequently used in this study, primarily due to the nature of treatment provided (eg, preventive recall). The communication-based BGTs dentists use with nitrous oxide are expected to be less effective with autistic patients. This provides another reason why nitrous oxide was seldom used by the dentists in this study.

Dentists recommending advanced BGTs should plan to present a complete rationale to the parents. Parents of healthy children have become less accepting of physical behavior guidance strategies while becoming more accepting of sedation and GA.<sup>8,29</sup> Parents were more accepting of active restraint when they were directly involved. Restraint by dental staff was rated as more acceptable and effective when limited to holding a patient's hands than holding the arms, torso, or legs.

Reports of parental acceptance for the use of passive restraint have varied.<sup>2,3,5,31</sup> Parental acceptance of the stabilization device used with conscious sedation depended on the way it was presented by the dentist; positive explanations

Table 4. PARENT-RATED ACCEPTABILITY FOR BEHAVIOR GUIDANCE TECHNIQUES (BGT) FOR AUTISTIC CHILDREN

BGT	Technique used		Technique not used		P-value*
	No. of parents responding	% acceptable	No. of parents responding	% acceptable	
<b>Basic behavior guidance</b>					
Positive verbal reinforcement	71	100	4	100	1.0
Tell-show-do	47	100	25	100	1.0
Mouthprops	41	95	28	79	.06
Rewards	40	100	33	91	.10
Frequent breaks	22	91	52	87	.72
Distraction	13	92	54	98	.35
Nitrous oxide	3	100	68	78	.60
Negative verbal reinforcement	0	NA	73	64	NA
<b>Advanced behavior guidance</b>					
Parental restraint	25	92	49	80	.20
Staff restraint	24	74	50	63	.60
Stabilization device	22	95	52	40	<.001
Hand-holding by a parent	15	93	57	91	1.0
Hand-holding by a staff member	6	100	66	79	.34
Oral sedation	3	100	64	84	1.0
General anesthesia	1	10	73	92	1.0

\* Chi-square test.

Table 5. PARENTAL OPINION ON BEHAVIOR GUIDANCE TECHNIQUE (BGT) EFFICACY FOR AUTISTIC CHILDREN

BGT	Technique used		Technique not used		P-value*
	No. of parents responding	% working well	No. of parents responding	% working well	
<b>Basic behavior guidance</b>					
Positive verbal reinforcement	78	92	5	80	.36
Tell-show-do	53	77	30	47	.01
Mouthprops	48	48	33	21	.02
Rewards	43	72	38	45	.01
Frequent breaks	24	67	52	37	.03
Distraction	16	63	62	47	.40
Nitrous oxide	4	75	74	15	.02
Negative verbal reinforcement	0	NA	79	35	NA
<b>Advanced behavior guidance</b>					
Parental restraint	32	66	47	34	.01
Staff restraint	26	35	51	24	.42
Stabilization device	25	96	52	17	<.001
Hand-holding by a parent	16	81	65	69	.38
Hand-holding by a staff member	7	86	72	29	.01
Oral sedation	2	50	77	29	1.0
General anesthesia	1	100	76	57	1.0

\* Chi-square test.

resulted in significantly more acceptance.<sup>32</sup> This study's parents did not differ significantly from other recent surveys that found the stabilization device, in general, to be the least acceptable BGT to parents. A 2002 survey described 42 parents who chose a stabilization device for their child and who declined GA or oral sedation. Ninety-two percent felt it was successful and only 5% were unhappy with their decision to use the stabilization device.<sup>31</sup> Our results mirror these findings: 95% of parents whose child had been treated in a stabilization device thought that it was acceptable, and 96% felt it was efficacious. These findings emphasize the importance of informed consent and its positive impact on parental acceptance.

Children with autism may be hyper- or hyposensitive to sensory stimuli, seeking out certain input while avoiding others. Sensory integration therapy for autism provides tactile, proprioceptive, and vestibular input to influence arousal and attention.<sup>19,33</sup> Anecdotal reports suggest that the stabilization device has a calming effect on an autistic child.<sup>34</sup> Dentists treating children with the stabilization device reported a calming effect in 20%. Without a control sample, it is unknown if the calming effect is greater than in other child populations.

Single-agent oral sedation was used for only 3 patients with 1 success. The sedation regimens suggested for autistic children include multiple oral and/or inhalation agents.<sup>35,36</sup> Due to contemporary monitoring and licensure standards, it is likely that oral sedation will become less available and not cost-effective for CSHCN.<sup>22</sup> Administering sedation to an uncooperative child could prove to be disastrous in the face of adverse sedation events.

Similar to other recent studies, this study's parents had a very positive attitude towards GA. Of the 85 children surveyed in our study, one underwent GA at the time of the survey and 14 were scheduled for future treatment under GA. Parental acceptance for GA has been linked to insurance.<sup>12</sup> GA's high cost can be prohibitive for uninsured or underinsured families. Among parents of autistic children, it is unknown if this applies as even with several attempts at in-office care, treatment may not be possible without GA.<sup>16</sup>

Aversive strategies, such as NVR, were not used by this study's dentists. Parents showed surprisingly high acceptance (>60%) of NVR, as described in the survey. NVR examples used in the survey included: "Sit still. If you don't sit still, you cannot go home." It is possible that, in responding to autistic children's challenging behaviors in other settings, parents use NVR.

A review of 8 philosophically differing education programs for autistic children found common elements that we suggest could be generalized to planning BGTs for these children in the dental office.<sup>37</sup> Some of these elements and the dental equivalents suggested by this study are:

1. Family involvement in treatment—Assess parental prediction of behavior, solicit parental input for BGTs, obtain informed consent, and have parents remain with their children during treatment and hold their hands.

2. A highly supportive and structured environment—Include the child's particular coping mechanism, have parents hold their children's hands, and use rewards.
3. Predictability and routine—Maintain continuity with the dentist, staff, operatory, and order of treatment procedures.
4. Functional approach to problem behaviors—Recognize that autistic patients are less likely to accept dental treatment than unaffected peers and are more likely to require advanced BGTs; also, obtain informed consent and reassess BGTs based on outcome.

A limitation of this study was that the presentation of a BGT likely varied among the 20 dentists participating in the study, which may have affected the parent's acceptance of a BGT. The surveys included photos and written explanations of the BGT. The verbal presentation may have altered parental attitudes, although other studies suggest that acceptance or rejection could result from additional information.<sup>6,7,10</sup>

The 2-hour calibration session included training to understand and execute the research instruments, but no formal reliability measures were computed. Further investigation is needed to warrant increased calibration measures.

## Conclusions

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

1. Parental accuracy in predicting cooperation of their autistic children for dental treatment varied both by initial vs returning patients and by procedure.
2. Parents of children with autism are likely to perceive the following approaches both as acceptable and working well: positive verbal reinforcement; tell-show-do; distraction; rewards; and hand-holding by a parent.
3. Parents of autistic children who received a behavior guidance technique reported it as highly acceptable, except for staff restraint.
4. Stabilization device acceptability was higher among parents of children treated using the technique compared to parents whose children were not treated using the stabilization device.

## Acknowledgements

The authors wish to thank the parents and children who participated in this study and their pediatric dentistry colleagues who assisted in the data collection.

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