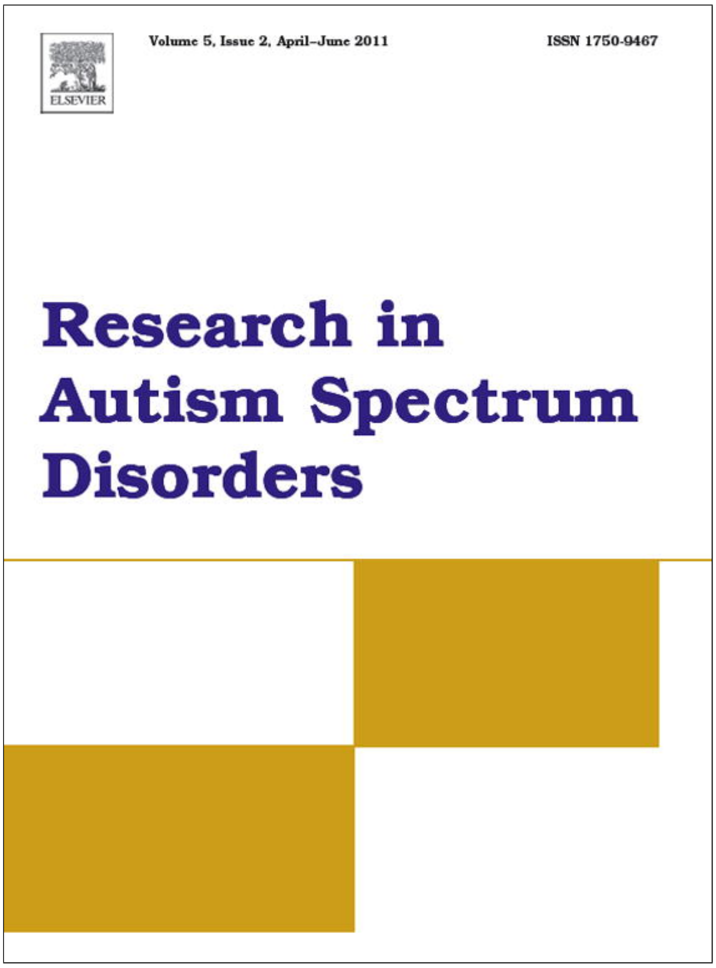
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Teaching children with autism spectrum disorders to cooperate with injections

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A B S T R A C T

When injections are necessary, young people with autism spectrum disorders (ASD) may exhibit responses that compromise their health care. Parents often report that their children with ASD struggle or attempt to flee when immunizations or other injections are attempted. This report describes our evaluation of procedures that enable children to cooperate with injections. A changing-criterion design with two replications in the United States and three replications in Turkey was used to assess the performance of five boys and one girl with ASD, ages 8–16. The teaching procedures, conducted in school settings, were relatively errorless. During generalization programming, the participants' skills transferred to different instructors who played the role of medical practitioner and to different school and community settings. Subsequently, in medical settings, they cooperated with doctors and nurses and successfully received important injections, such as long-overdue diphtheria, tetanus, and pertussis (DTaP) immunizations, tetanus boosters, and influenza and hepatitis B immunizations.

Parents recount many difficulties in attempting to help their children with ASD receive dental and pediatric services. Tantrums and attempts to escape sometimes lead to physical restraint, which may exacerbate youngsters' fearfulness and make it ever more difficult for them to receive treatment. Some physicians and dentists, after repeated experiences with youngsters who struggle and engage in aggressive and disruptive behavior, refuse to retain them as patients. Over time, it may become increasingly difficult for some parents to identify health care providers who are willing to assist. And it is not uncommon for youngsters with ASD to receive general anesthesia before they undergo relatively benign procedures, such as dental examination and treatment (Luscre & Center, 1996), or a few stitches needed to close small lacerations on knees or elbows. When we interviewed parents about their children's health care visits, some discussed the embarrassment of being asked to find a different pediatrician or dentist.

A review of the literature revealed many investigations of procedures to help typical children cooperate with dental care. For example, Allen and Stokes (1987) rewarded children ages 3–6 with escape, stickers, and praise and found that reinforcement for cooperative behavior during practice and during real dental appointments was effective in decreasing their disruptive behavior. A subsequent study (Stark et al., 1989) assessed the effectiveness of distraction; they showed four typical children a poster, told them a story, and delivered prizes if the youngsters correctly answered questions about the materials after each dental visit. Initially, anxiety and disruptive behavior decreased for all four children, but these results did not maintain for two of the children. In a 1992 investigation of dentist-implemented procedures (Allen, Loiben, Allen, &

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Stanley, 1992), the disruptive behavior of three children ages 3–7 decreased when brief escape from dental treatment was provided contingent upon cooperative behavior.

Recently, a few researchers have examined procedures that enable people with developmental disabilities to appropriately participate in dental care (Altabet, 2002; Conyers et al., 2004), and a small number of studies specifically target children with ASD. For example, Cuvo, Godard, Huckfeldt, and DeMattei (2010) used a package of training procedures to enable five children with ASD, ages 3–5, to comply with oral assessment; the target responses maintained and generalized across examiners and from analog to in vivo settings.

In contrast to studies of interventions to help children receive dental care, research on procedures to help young people receive injections and blood draws is virtually absent. In the single study identified, Shabani and Fisher (2006) reported using stimulus fading and differential reinforcement during outpatient clinic visits to help an 18-year-old with autism, mental retardation, and diabetes to cooperate with the use of a lancet on the tip of his index finger. Blood draws at a two-month follow-up were successful, and the youth's mother reported that she was able to use lancets to measure daily glucose levels. A review of the literature did not reveal any investigations relevant to helping young people with ASD receive injections.

Our research on teaching children with ASD to cooperate with injections began with three participants who attended the Princeton Child Development Institute's (PCDI's) school program and continued with three additional participants who attended the TOHUM School, a PCDI dissemination site in Istanbul.

1. Methods

1.1. Participants

Marc, Guy, and Bart attended PCDI's school program, and Osman, Yasemin, and Ziya were enrolled in TOHUM's school program. All participants attended school for 5.5 h per day, five days per week, and all had received independent diagnoses of autism. All 6 children had language delays and social interaction deficits but as a result of intervention, had acquired speech and developed basic reading and writing skills, ranging from kindergarten to third-grade level. Before the research began, parents were interviewed about their children's behavior when injections were given or attempted.

Marc, age 12, was enrolled in PCDI's preschool program at age 4; at the time of the study, he occasionally displayed stereotypic movements and non-contextual laughter. When interviewed about Marc's performance when receiving injections, his mother reported, "When the doctor came with the needle, Marc grabbed and twisted his hand. He did not follow directions to let go. He was restrained by me, a nurse, and the doctor so he could receive the shot."

Guy, a 13-year-old boy, entered PCDI at age 3 with minimal language and a history of tantrums. When the study began, tantrums were brief and low-rate. During an interview, his mother said that, on the last time she took him to get an injection, "he was very frightened and anxious…he struggled, screamed, cried, and tried to escape. It was awful."

Bart, age 16, began to attend PCDI's preschool at age 3. At the time of the investigation, he had an intervention program designed to decrease noncontextual laughter. When Bart's father was interviewed about his behavior when taken to the doctor's office to receive an injection, he said, "He cried and screamed and had a tantrum. At that point, he didn't receive an injection and we were told to find another doctor. We haven't taken him for a shot since he was three years old."

Osman was 8 years old. He began to attend TOHUM School when he was 5 years of age. His stereotypic responses included repetitive hand and arm movements, muscle tensing, and posturing. His mother reported, "He held his arm. I compelled him to have the injection and sit, (but) he didn't want to sit. He tried to escape, cried, and pushed me down. He needs measles, mumps, and scarlet fever immunizations."

Yasemin, the only girl in the study, was 8 years old. After an unsuccessful experience in an inclusion program in a public school, she was enrolled in TOHUM School at age 6. Her stereotypies included tensing and posturing. When interviewed, her mother said "She tried to escape…two persons had her sit down. She is overdue for diphtheria, whooping cough, tetanus and MMR."

Ziya, age 8, was enrolled in TOHUM School when he was 5 years old. At the time of the study, he sometimes exhibited crying and noncompliance. During the interview, his mother noted, "He said, 'No injection.' He cried a long time. His father restrained him in order for him to receive an injection."

In school, all 6 children routinely followed simple directions, such as "Come here," "Sit down," "Look at me," and "Put your hands down." All used token systems throughout their school days, and all received home programming services delivered by PCDI and TOHUM staff members.

All of the participants were overdue for important childhood immunizations. All parents gave informed consent for their children's participation in the study.

1.2. Settings

Teaching occurred in each child's usual classroom when other children were absent. A senior instructor initially played the role of medical practitioner and a second instructor (the student's home programmer) delivered tokens contingent upon correct responses. Participants did not sit at their usual places in the classroom; instead, they sat in a chair in a different area of the room. A tray containing medical supplies (for example, scissors, tape, alcohol pads, bandages, stethoscope, reflex hammer, ear scope, and later, a hypodermic needle) was placed on a table beside the chair.

During generalization programming and maintenance, sessions occurred in different school rooms that were unfamiliar to the participants. Such rooms included offices, conference rooms, and meeting rooms. Generalization sessions also took place in unfamiliar community settings such as office buildings and, when possible, in doctors' offices or clinics when medical personnel were absent. Real injections were given by medical personnel in settings selected by the participants' parents.

1.3. Dependent variables

The participant sat in a chair or on an examining table and remained seated until given permission to stand up. When instructed, learners put their hands on their knees or thighs, palms down, and kept them there until instructed to stand up. A participant consistently oriented toward the home programmer or parent who delivered tokens and did not look at the doctor or nurse, or the person playing that role. Throughout each session, the student wore a baseball cap that blocked his or her view of the medical practitioner's activities. The visor of the cap was pulled down and turned toward the side on which the medical practitioner (or the person playing that role) was standing, and the learner did not touch or remove the cap until given permission to do so. The participant spoke only to respond to questions or to make ‘‘polite'' responses such as ‘‘Hello,'' ‘‘Excuse me,'' or ‘‘Thank you''). If any of these responses was not displayed when required, was incorrectly performed, or was prompted, behavior on that task in the injection task analysis was scored incorrect.

In addition, correct responses on each task were scored only if they were completed without stereotypy or disruptive behavior. Stereotypy was defined for each participant, based on the definitions in his or her intervention programs. For example, Marc's performance of a task was scored incorrect if he engaged in behavior that was specified in his intervention program for noncontextual laughter. Similarly, Osman's response to a task was scored incorrect if he engaged in posturing that was defined in his intervention program.

Disruptive behavior referred to screaming, whining, or crying; grabbing or attempting to grab people or materials; destroying or attempting to destroy objects; attempting to flee; and engaging in or attempting to engage in aggressive responses (hitting, kicking, pinching, biting). If any of these responses was observed during a task, that task was scored incorrectly completed.

1.4. Experimental design

A changing criterion design with five replications was used to assess the effects of the intervention procedures. The rule for changing the criterion was: the participant must respond correctly on Task 1 on three consecutive occasions prior to the introduction of Task 2. A child must respond correctly on Tasks 1 and 2 on three consecutive occasions prior to the introduction of Task 3, and so on throughout the entire sequence of fifteen tasks. Thus, in each session, a participant had opportunities to practice all prior tasks, as well as the newest task.

1.5. Measurement procedures

Data sheets displayed 15 teaching tasks (see Table 1), 6 generalization steps (see Table 2), maintenance, and a final section used to score visits to medical settings for the purpose of receiving injections. Using a per-opportunity measure, a participant's performance during each task presentation was scored correct or incorrect. If a child made an error, was prompted, and then correctly performed a task, the task was scored incorrect. Agreements were scored only if both observers scored a child's performance as correct or incorrect when a given task was presented. Sessions were conducted once or twice per day.

During appointments with medical personnel, Tasks 1 through 15 were often not presented in the same sequence as they were during teaching; some tasks were not presented at all (e.g., some practitioners did not wear white coats, ice cubes and paper clips were not used, and hypodermic needles appeared at different times during the appointment); and some tasks were not relevant (e.g., the home programmer did not determine when a participant entered the doctor's office or clinic, or when the learner should stand up). Therefore, data on the dependent variable were collected only when a participant was receiving an injection, and were scored as (a) criterion performance––no error; (b) error was scored but participant received the injection without restraint; or (c) error was scored and the young person was restrained or did not receive the injection.

1.6. Experimental conditions

Baseline. Baseline data were not collected because it was likely that attempting injections without prior teaching would evoke errors that could delay or prevent acquisition of the target skills.

Teaching. Prior to each session, a participant who was wearing a long-sleeved shirt or blouse was asked to change into a short-sleeved shirt, and all participants were asked to wear baseball caps. If necessary, they were assisted in completing these tasks. After changing, a student was taken to a hallway or room near the teaching area, and was invited to sit down and wait in the ‘‘waiting room.''

During each teaching session, a familiar instructor (a senior staff member), played the role of medical practitioner. This person stood on the participant's left, conducted tasks, and asked questions and made statements similar to those the learner might encounter in a doctor's office, such as ‘‘How are you today?'' and ‘‘You will feel a little pinch.''

Table 1
Tasks presented to teach participants to cooperate with injections.

Task	Teaching
1	The home programmer (HP) approaches the participant and says, "The doctor will see you now," and "Please sit here." After 15 s of correct responding, HP gives permission to stand up and the session ends. The instrument tray is visible on the table, but the hypodermic needle is absent.
2	HP asks participant to put hands on knees, palms down and models the target response. After 15 s of correct responding, HP gives permission to stand up and the session ends.
3	HP asks the participant to look at her. A correct response requires that the learner turn toward HP and away from the staff member playing the role of doctor or nurse (N) for 15 s.
4	HP pulls baseball cap visor over the left side of the participant's face, blocking the view of N and the target arm (15 s).
5	N makes "instrument noises" by moving items on the instrument tray and tearing paper. Session ends after 15 s of correct responding on this task.
6	N wipes skin on participant's upper arm with alcohol pad (at least 5 s).
7	N pinches skin on participant's upper arm for 10 s.
8	Hypodermic needle in wrapper is partially visible on the instrument tray when the participant enters the room. It is half covered by other items on the tray.
9	The hypodermic needle in wrapper is completely visible on the instrument tray when the young person enters the room.
10	An ice cube, hidden from the participant's view, is touched to the skin that is pinched (3 s).
11a	An unwrapped hypodermic syringe is visible on the instrument tray when the participant enters the room; the cap is on the needle. An ice cube, hidden from the participant's view, is touched to the skin that is pinched (3 s).
11b	N firmly applies the end of a straightened paper clip (hidden from view) to the area that is pinched (10 s).
12	HP waits 15 s before giving the instruction to stand up.
13	N applies a bandage to the area of the simulated injection (10 s).
14	N places capped hypodermic needle on the instrument tray at the beginning of the session, as the participant enters the room.
15	N is wearing a white lab coat when the participant enters the room.

Another familiar instructor, the home programmer, stood on the child's right and delivered behavior-specific praise (e.g., "Good, you're looking at me!" and "Great, you're keeping your hands on your knees!"). The home programmer also contingently delivered tokens (coins), by placing them on Velcro™ dots attached to a clipboard that was continuously visible to the participant.

The token system was identical to the one used by participants throughout their school days. Token delivery was timed so that if participants correctly responded on all tasks presented during a session, they earned all of their tokens and immediately exchanged them for back-up rewards of their choice. Highly preferred rewards (longer-than-usual breaks, special snacks, and special activities) were reserved for correct responding during task presentation. If one or more errors occurred, students did not earn all of their tokens and did not exchange them at the end of sessions; instead, they were directed to return to their activity schedules.

When necessary, the home programmer used manual guidance to help participants keep their hands down. A participant was never permitted to stand up or leave sessions until all tasks were correctly completed; manual guidance was used to keep the student seated. When the learner was waiting quietly, the task was again presented, and the session ended when all tasks had been correctly completed.

Generalization programming. After a participant displayed correct, unprompted responses on three consecutive presentations of Tasks 1 through 15, generalization programming began. In Generalization Steps 1 through 5, different familiar instructors, and then unfamiliar instructors, played the role of nurse and tasks were presented in unfamiliar school settings, such as offices and meeting rooms (see Table 2). If a participant made any errors on these steps, he or she continued on that step until it was correctly completed on three consecutive assessments. After a youngster displayed three consecutive correct performances on each of these steps, Step 6 was introduced. In Step 6, a familiar instructor played the role of nurse in community settings, such as rooms in office buildings and rooms in local clinics or pediatricians' offices when medical personnel were not present.

Table 2
Programming generalization across persons and settings.

Step	Progression of generalization programming
1	A different but familiar instructor plays the role of N in the area of the classroom used during teaching.
2	An unfamiliar instructor plays the role of N in the area of the classroom used during teaching.
3	The instructor who originally played the role of N does so in an unfamiliar school setting (e.g., a meeting room, office, or conference room).
4	An unfamiliar instructor plays the role of N in a different, unfamiliar school setting.
5	Another unfamiliar instructor plays the role of N in another unfamiliar school setting.
6	A familiar instructor plays the role of N in community settings, such as office buildings and examination rooms at physicians' offices when cooperating medical professionals are absent.

Throughout generalization programming, participants' home programmers continued to be present and delivered tokens that were immediately exchanged after each session that was completed without error. On Step 6, when sessions occurred in community settings, the usual choices of back-up rewards were supplemented with opportunities to use tokens to purchase visits to fast-food restaurants or visits to markets to purchase snacks; these rewards, which postponed return to school, were routinely selected.

Maintenance. After a participant met criterion on all tasks presented during teaching as well as during generalization programming in school settings, maintenance was introduced, if necessary, until visits to generalization settings beyond the school could be scheduled. During this time, learners had at least two opportunities per week to practice all tasks in a variety of school settings and with a variety of instructors. If a participant made an error, teaching resumed and when the child once again displayed correct responses on Tasks 1 through 15 on three consecutive occasions, generalization programming was reinstated.

Similarly, after a youngster met criterion during generalization programming in community settings, maintenance sessions (Tasks 1 through 15 and Generalization Step 5) were conducted at least twice per week until the date of an appointment for an injection at a clinic or pediatrician's office.

Receiving injections. Appointments were made for participants to visit pediatricians' offices, clinics, or pharmacies selected by their parents. Children were accompanied by a familiar senior school staff member. Participants' parents were invited to attend appointments, and some did so. The staff member delivered tokens and praise, and prompted if necessary. If parents were in attendance, participants who received injections without error typically exchanged their tokens for a visit to a fast-food restaurant, followed by an early return home from school with the accompanying parent. If a parent did not attend, children exchanged their tokens for a visit to a fast-food restaurant and a return to school for a lengthy break to engage in activities of their choice, such as playing video games, using the computer, watching TV, or other preferred pursuits. If learners made any errors, they were returned to school and asked to resume their daily activities.

1.7. Interobserver agreement

Agreements were scored only if both observers' recordings were the same on each task. Percentage interobserver agreement was calculated by dividing number of agreements by total number of agreements and disagreements and multiplying the result by 100. At PCDI, interobserver agreement was obtained on 90% of sessions; at TOHUM School, interobserver agreement was obtained on 45% of sessions.

Mean interobserver agreement for PCDI participants was 99% for Marc (range = 90–100%); 100% for Guy; and 99% for Bart (range = 67–100%). At TOHUM School, mean interobserver agreement for Osman, Yasemin, and Ziya was 100%.

2. Results

After completing the program, all six participants received injections. Five children made no errors and Yasemin made one error (see Fig. 1). After receiving an influenza injection, she held her arm and cried.

The PCDI participants' errors during Teaching, Generalization Programming, and Maintenance Conditions were as follows: Marc made 7 errors in 85 sessions, Guy made 3 errors in 74 sessions, and Bart made 6 errors in 83 sessions. At TOHUM School, Osman made 19 errors in 106 sessions; Yasemin made 11 errors in 93 sessions; and Ziya made 2 errors in 78 sessions. If a learner made no errors, there would have been 360 opportunities to respond during Tasks 1 through 15, 270 opportunities to respond during Generalization Steps 1 through 6, and 99 opportunities to make a correct or incorrect response during maintenance (based on a mean of 6.6 maintenance sessions per participant). Thus, conservatively, the total number of opportunities for error was 729, but making errors resulted in more practice opportunities. Actual error rates varied from .02% for Ziya to 2% for Osman.

An error analysis showed that errors were scattered across tasks. Four participants made errors on Task 6; three made errors on Tasks 5 and 10; two made errors on Tasks 7, 11b, and 13; and Tasks 2, 3, 8, 11a, and 12 each generated one error. The remainder of tasks (Tasks 1, 4, 9, 14, and 15) were without error. There were 9 errors during generalization programming, and these were distributed across Steps 1, 3, 4, 5, and 6. Marc and Bart made no errors during generalization programming, Guy and Ziya each made one, Osman made 3, and Yasemin made 4. Only Bart made an error during Maintenance.

3. Discussion

The intervention procedures used in the study were differential reinforcement, verbal instructions and manual prompts, stimulus fading (fading in an aversive stimulus––the injection), and extinction of escape behavior. These procedures were relatively errorless, and errors resulted in more practice opportunities during which correct responding was rewarded.

The 15 tasks presented during the teaching condition were sequenced so that early tasks called for responses that had a long history of reinforcement, such as sitting down when asked to do so, putting hands in lap, and visually attending to an instructor. Tasks that were believed to be of greater difficulty (e.g., cooperating with pretend injections and making correct responses in the presence of a person wearing a white coat) were placed later in the task sequence. However, none of the participants made an error on Task 15, when the white coat appeared.

Both an ice cube and a straightened paper clip were used to simulate injections, because we were uncertain as to which of these simulations would best approximate a real injection. The ice cube generated five errors by Bart, Osman, and Ziya during Task 10 and four additional errors by Osman during Task 11a. When the straightened paper clip appeared in Task 11b, Marc and Bart each made one error.

The senior staff members who were present during the teaching condition were selected because they had lengthy histories with the participants and had acquired good instructional control. The error rate for TOHUM School participants (mean = 11 errors) was higher than for PCDI participants (mean = 6 errors). This may have been related to TOHUM School

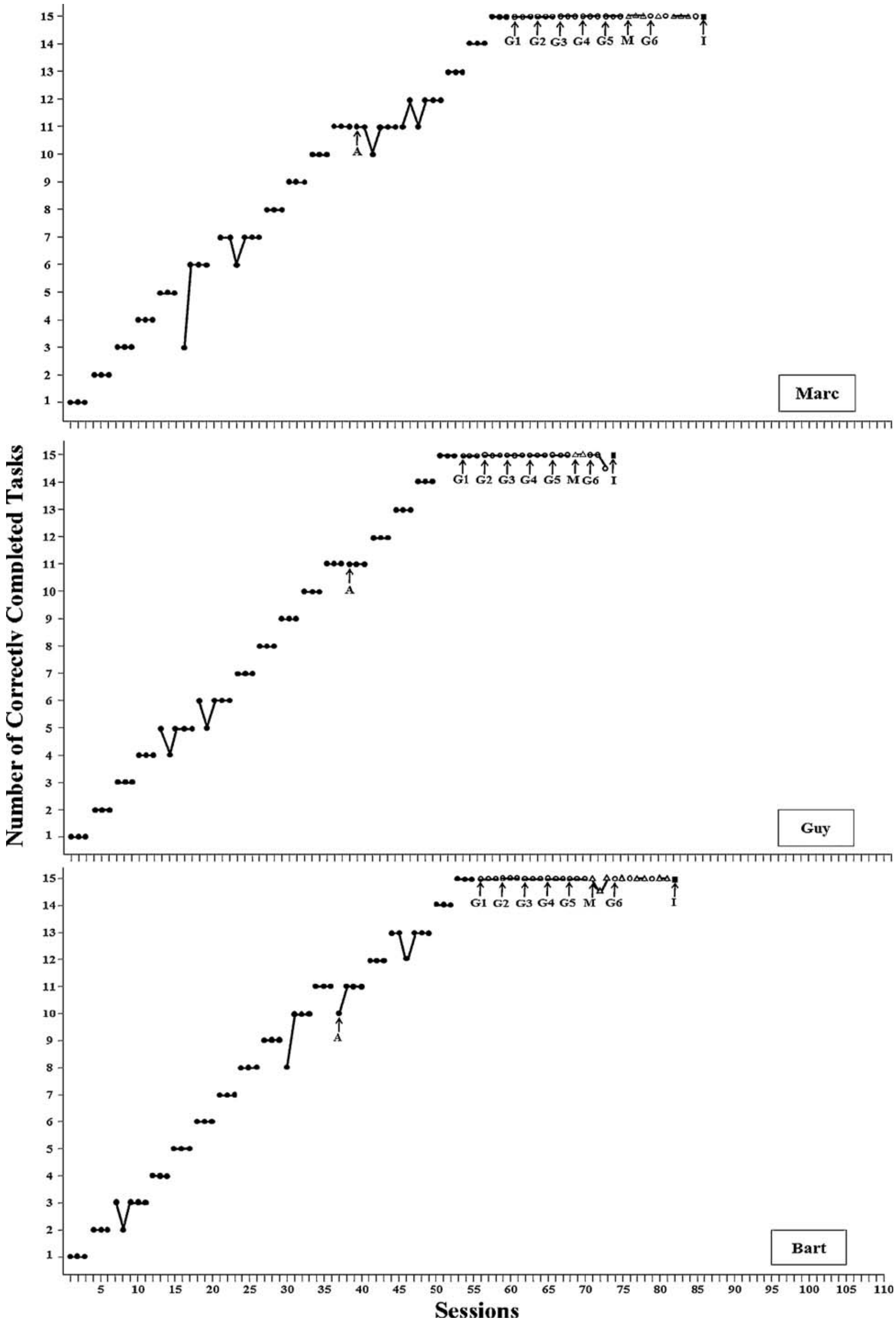

Fig. 1. Number of correctly completed tasks during Teaching, Generalization Programming (G1 through G6), and Maintenance Conditions (M). Arrow A identifies the session at which the paper clip replaced the ice cube. A medical appointment to receive a real injection is identified as I.

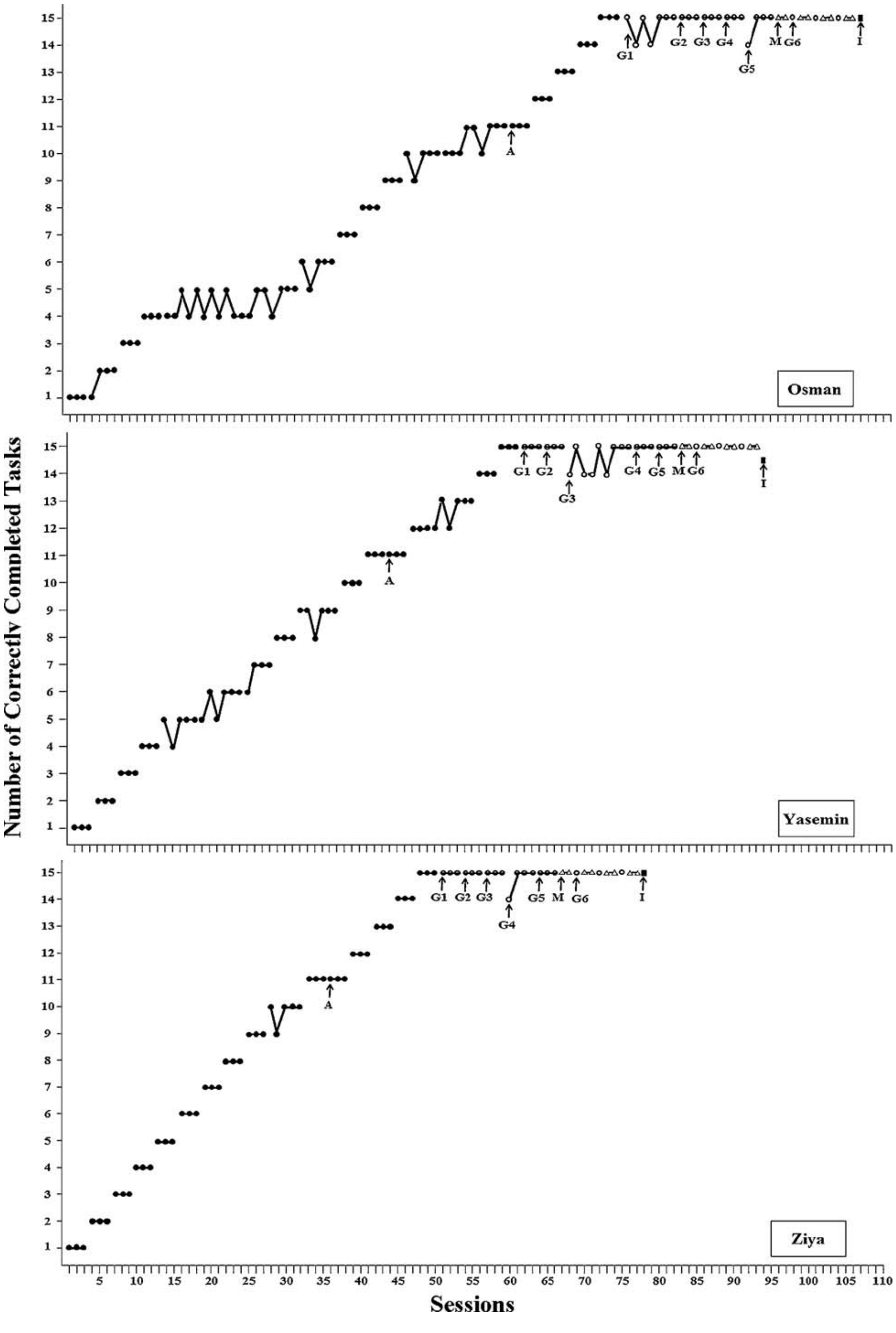

Fig. 1. (*Continued*).

students' shorter time in intervention. TOHUM Foundation's school program opened in 2006, and participants' mean number of years at TOHUM School was 3; students' mean number of years at PCDI was 10. Component analysis would be necessary in order to evaluate the importance of these variables.

Guy was the only student who made an error on a generalization session that immediately preceded his appointment to receive an injection. The error occurred in a pediatrician's office when medical personnel were absent––he turned his head to look at the target arm, rather than looking at the home programmer. Because the error did not involve disruptive behavior and was not incompatible with receiving an injection, and because the appointment had been made for some time, a staff member and his mother accompanied him to the doctor's office, where he succcessfully received a measles, mumps, rubella (MMR) immunization.

Although the research ended after participants received injections, sessions continued because most participants needed more than one injection. Partnering with parents was typically delayed until students completed Teaching and Generalization Conditions, because the young people who needed this program had lengthy histories of disruptive behavior in the presence of their parents who had accompanied them to doctor and dentist appointments.

During post-investigation sessions, parents were invited to be present at school when a senior staff member played the role of medical professional. When a student made no errors in the presence of a parent, the mother or father began to deliver tokens, praise, and back-up rewards. Subsequently, when parents and staff members took learners to medical appointments, parents gradually assumed responsibility for giving instructions and delivering rewards.

After young people completed the injection program, only minor revisions to the task sequence were necessary in order to prepare them for blood draws and Mantoux tests for tuberculosis. Soon after he completed the injection program, Marc began to have seizures, medication was prescribed, and regular blood draws were needed in order to assess levels of medication. Many of the tasks in the blood draw program were identical to the tasks in the injection program that he had mastered, and he completed the blood draw program in 65 sessions and with only one error, which occurred when his forearm (rather than his upper arm) was wiped with an alcohol pad.

Although the participants in this investigation displayed a range of academic, language, and social skills and diverse problem behavior, all were under good instructional control in their classrooms, all had learned to use token systems, and all had substantial experience with making choices of back-up rewards that were available when tokens were exchanged. Ongoing, intensive behavioral intervention provided an essential backdrop for this study.

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