

Teaching an Adolescent With Autism and Intellectual Disability to Tolerate Routine Medical Examination: Effects of a Behavioral Compliance Training Package

Rachel N. S. Cavalari
May Institute, Randolph, Massachusetts and
Binghamton University

Melanie DuBard, James K. Luiselli, and
Kirstin Birtwell
May Institute, Randolph, Massachusetts

The present study evaluated graduated exposure and positive reinforcement in a compliance training intervention package with an adolescent female who had autistic disorder, intellectual disability, and long-standing avoidance of routine medical examination. Intervention consisted of slowly introducing her to a 12-step examination hierarchy and reinforcing compliant responding within a changing criterion experimental design. Reinforcement for appropriate alternative behavior and modeling were also components of intervention. A behavioral clinician first implemented procedures that were subsequently generalized to nurses. The participant learned to comfortably tolerate a medical examination that she had resisted for nearly 2 years. We discuss clinical and research implications of the case.

Keywords: medical fears, shaping, systematic desensitization, differential reinforcement

Many children with intellectual and developmental disabilities (IDD) and autism spectrum disorder (ASD) have medical fears and phobias, which are typically demonstrated by intense emotional reactions and avoidance behavior in the presence of specific stimuli (Evans, Canavera, Kleinpeter, Maccubbin, & Taga, 2005; Gillis, Hammond-Natof, Lockshin, & Romanczyk, 2009; Luiselli, 2011; Matson & Love, 1990; Turner & Romanczyk, 2012). Fear of routine medical examinations, in particular, poses significant challenges to maintaining requisite health care, particularly for individuals with physical and psychiatric conditions. Most

research on treating medical fears among people who have IDD and ASD has evaluated graduated in vivo exposure paired with other behavioral techniques, such as stimulus shaping, positive reinforcement, and modeling (Conyers et al., 2004; Cuvo, Reagan, Ackerslund, Huckfeldt, & Kelly, 2010; Gillis et al., 2009; Luscre & Center, 1996; Shabani & Fisher, 2006). The basis of graduated in vivo exposure is to systematically present a feared stimulus to a person by either increasing salience of the stimulus or duration of stimulus presentation without provoking distress and avoidance. With repeated, successful exposure, the person is subsequently able to tolerate the previously feared stimulus. A key component in many of these interventions is incorporation of counterconditioning stimuli such as food, toys, and music that compete with anxiety. Most interventions also incorporate effective reinforcers to shape compliance with the required medical protocol (Grider, Luiselli, & Turcotte-Shamski, 2012; Luscre & Center, 1996; Slifer et al., 2011).

Focusing on medical concerns, researchers have evaluated graduated in vivo exposure treatment packages to reduce avoidance of dental procedures (Conyers et al., 2004; Luscre & Center, 1996), needle injections and routine

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Rachel N. S. Cavalari, May Institute, Randolph, Massachusetts, and Institute for Child Development, Department of Psychology, Binghamton University; Melanie DuBard, James K. Luiselli, and Kirstin Birtwell, May Institute, Randolph, Massachusetts.

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Correspondence concerning this article should be addressed to Rachel N. S. Cavalari, Department of Psychology, Binghamton University, P.O. Box 6000, Binghamton, NY 13902. E-mail: rstraub1@binghamton.edu

blood draws (Cromartie, Flood, & Luiselli, 2013; Grider et al., 2012; Shabani & Fisher, 2006; Slifer et al., 2011), and physical examinations (Cuvo et al., 2010; Gillis et al., 2009). In the present study, we implemented graduated in vivo exposure and positive reinforcement to promote compliance with routine medical examination in an adolescent female with autism who had a lengthy history of medical avoidance, which seriously compromised her health and access to preventive care. Notable features of the study were initiating treatment at her school, having natural care-providers apply procedures, and generalizing performance to nursing staff. The study also illustrates application of the changing criterion experimental design (Hartmann & Hall, 1976) to assess tolerance-building and compliance training treatment plans for medical avoidance problems among people who have ASD and IDD.

Method

Participant

Alice (a pseudonym) was a 16-year-old female diagnosed with autistic disorder and intellectual disability (full-scale IQ: 40). She communicated using one- to two-word phrases and occasionally with sentences for familiar requests. Alice's expressive, receptive, and pragmatic language skills were well below the expected level for her age. She also had limited self-care and adaptive living skills.

Alice's medical history revealed 20- to 30-pound fluctuations in weight over the course of a 2-year period, with most recent concerns surrounding significant weight loss and a body mass index in the underweight range (BMI = 17.5). She was also prescribed psychotropic medication to treat cyclical mood changes. Her parents voiced concerns about her health status, but Alice resisted medical treatment, even refusing to leave the family van when arriving at her primary care physician's office. She also engaged in challenging behavior when staff attempted to escort her to the nursing suite at her school or take her weight and height measurements in her classroom. With the exception of a passive physical examination that was conducted while she was sedated for dental procedures, Alice had not seen a physician in almost 2 years preceding the study.

Setting

The setting was a day and residential school for children and youth with IDD. Alice attended school each weekday from 9:00 a.m. to 3:00 p.m. in a classroom with five peers, a primary teacher, and three teacher assistants. The study was conducted in the nursing suite located within the school. The nursing suite had a reception area, central office, and several examination rooms similar to a conventional pediatric care setting.

Measurement

We constructed an examination hierarchy through consultation with nursing staff at the school and similar to the protocol by Cuvo et al. (2010). As shown in Table 1, the hierarchy had 12 steps that corresponded to the procedures, which comprised a medical examination. There were also 74 substeps that gradually presented Alice with increasing exposure to medical instruments and associated physical procedures. The primary dependent measure was the number of steps in the examination hierarchy that Alice completed compliantly.

Compliance was defined as Alice completing each step without (a) withdrawing any part of her body (e.g., pulling her hand away, leaning or stepping away) *any* distance from the presented instrument or procedure, (b) demonstrating problem behavior (aggression, throwing materials, stiffening body in response to physical prompts for more than 10 s), and (c) attempting to leave the examination room in the nursing suite. Verbal refusals were not included in the definition of compliance because Alice's observable avoidance behavior served as a clearer indication of her emotional state (Gillis et al., 2009; Grider et al., 2012; Jennett & Hagoian, 2008).

The intervention was conducted by a predoctoral intern in clinical psychology who had 5 years of experience working with individuals with ASD and IDD. The clinician had not worked with Alice prior to the intervention, aside from preintervention assessment described below. Two days per week at 9:00 a.m. and 2:00 p.m., the clinician entered the classroom and asked Alice to walk to the nursing suite. During sessions in the nursing suite, she recorded Alice's compliance with the examina-

Table 1
Desensitization Hierarchy for Medical Exam

| Targeted hierarchy | |
|---|---|
| Mastery component | Example verbal discriminative stimulus |
| Leave car/classroom | "It's time to go for a walk." |
| Enter building/hall and walk to medical suite/doctor's office | "Let's go inside/to the hall this way." |
| Stand in front of doorway to medical suite/doctor's office | "Stand/wait here, please." |
| Enter waiting room | "Let's go in this room. Go ahead." |
| 1. Sit in waiting room chair | "Sit over here" while pointing to chair. (Staff may sit with her) |
| 2. Comply with height measurements | "I'm going to see how tall you are. Stand here, please." |
| Tolerates standing in front of measuring tape 10 s | |
| Walk to exam room door upon staff request | "It's time to go to the next room. Walk this way, please." |
| Enter exam room | "Let's go inside. Go ahead." |
| 3. Comply with weight measurements | "I'm going to see how much you weigh. Stand here, please." |
| Stands on scale at least 5 s (max 10s) | |
| 4. Sit in chair in exam room 1 min | "Sit over here" while pointing to chair. (Staff may sit with her) |
| 5. Comply with blood pressure measurement | "I'm going to touch your arm to listen to your pulse." |
| Allow cuff to be placed around hand | |
| Allow cuff to be slid up to bicep while open | |
| Allow cuff to be tightened around arm with Velcro | Count as appropriate for seconds (5 s) or pumps (1–5+) |
| Tolerate stethoscope 5 s | |
| Tolerate 1 pump | |
| Tolerate 3 pumps | |
| Tolerate 5 or more pumps | |
| 6. Comply with lung exam | "I'm going to listen to your lungs/touch your back." |
| Tolerate stethoscope 3 s in 2 locations | |
| Tolerate stethoscope 5 s in 2 locations | |
| Takes one breath | |
| Takes 3 breaths | |
| Takes 4–6 breaths | |
| 7. Comply with heart exam | "I'm going to listen to your heart/chest." |
| Tolerate stethoscope 1 s | |
| Tolerate stethoscope 3 s | |
| Tolerate stethoscope 5 s | |
| Tolerate stethoscope 10s | |
| Tolerate stethoscope in 2 locations | |
| 8. Lay on exam table 30 s to 1 minute | "Lie down on the table." |
| 9. Comply with abdominal exam | "I'm going to listen to/touch your stomach." |
| Tolerates hand to abdomen contact in a single location 1 s | |
| Tolerates hand to abdomen contact in a single location 3 s | |
| Tolerates hand to abdomen contact in a single location 5 s | |
| Tolerates hand to abdomen contact in a single location 10 s | |
| Tolerates 1 palpation | |
| Tolerates 2 palpations | |
| Tolerates 3 palpations | |
| Tolerates 4 palpations | |
| 10. Comply with mouth/throat exam | "I'm going to look in your mouth." |
| Tolerates otoscope near open mouth 5 s | |
| 11. Comply with eye exam | "I'm going to look in your eyes." |
| Tolerates use of otoscope to view 1 eye for to 3 s | |
| 12. Comply with ear exam | "I'm going to look in your ears." |
| Tolerates otoscope near ear 1 to 3 s | |
| Tolerates otoscope touching ear for 1 to 3 s | |
| Tolerates use of otoscope to view ear for 1 s each | |
| Tolerates use of otoscope to view ear for 3 s each | |
| Tolerates use of otoscope to view ear for 5 s each | |

tion hierarchy relative to the conditions in effect during baseline and intervention phases (described below). The clinician was also responsible for assisting with the transfer of the protocol to nursing staff.

Preintervention Assessment

The clinician spoke to Alice's parents preceding the study to obtain a history and identify her stimulus and activity preferences. Similar information was obtained from the primary classroom teacher through a teacher stimulus preference survey. Results of this indirect assessment suggested that Alice enjoyed many foods, music, puzzles, and blocks. Her preferences were then confirmed in a paired-stimulus preference assessment (Fisher et al., 1992). Separate assessments were conducted for edible and tangible items, as recommended by DeLeon, Iwata, and Roscoe (1997). Results identified three types of candy, music, videos, blocks, and puzzles; however, candy and other edible items were significantly more preferred compared with toys and activities when assessed across the school day. Thus, edibles were more likely to serve as a powerful reinforcer for compliant behavior in the present intervention compared with available alternatives. Upon consultation with Alice's parents relative to her preferences and low weight, it was determined that edible items would be used for reinforcement during the intervention.

Design and Procedures

We evaluated the effects of a graduated exposure and positive reinforcement treatment package, including modeling and reinforcement for appropriate alternative behavior, in a changing criterion design. The criteria represented gradually increasing steps in the examination hierarchy that received positive reinforcement when Alice complied with them.

Prerequisite skill training. Because it was unclear whether Alice was familiar with body part labels and verbal instructions including various body parts that would be used during intervention, we taught her word-object associations involved in medical examination performance requests. Errorless learning and prompt fading instructional procedures were implemented by using full physical prompts to assist Alice with correctly pointing to body

parts upon request during initial trials. Over time, prompts were faded to gesture and model prompts, as needed. Using these procedures, Alice learned to point to her head, ear, nose, mouth, chest, back, stomach, arm, hand, legs, and feet. The baseline phase started when she achieved an average of least 70% correct responses, either independently or following a model, to provide evidence of familiarity with terms.

Baseline. After walking to and entering the nursing suite with Alice, the clinician presented her with the first step in the examination hierarchy (sit in the waiting room chair). If Alice complied, she was presented the next step in sequence. When Alice did not comply with a step, the clinician terminated the session and returned her to the classroom. During baseline sessions the clinician simply presented the examination hierarchy steps without accompanying reinforcement.

Graduated exposure and positive reinforcement. A social story detailing each step of a medical examination was presented to Alice on a daily basis upon initiation of treatment (i.e., simultaneous with nursing suite visits). The classroom teacher read the social story to Alice each day during a morning period. Alice was required to be oriented to the book when the social story was being read. Additionally, the social story was available to Alice by placing it on her desk for easy access in between scheduled activities.

Prior to leaving the classroom, Alice was asked to choose one of her three preferred edibles for the upcoming session in the nursing suite. If she refused these options, she was permitted to select an edible of her choice from her lunch bag or from the classroom supply closet. As in the baseline phase, the clinician presented Alice with steps in the examination hierarchy. She was required to complete each new step compliantly during three consecutive sessions before advancing to the next step. In addition, the clinician or a staff person modeled the behavior that was expected at each step while in the nursing suite with Alice. The staff person who attended nursing suite visits with Alice differed at each session. Alice received praise and a small piece of candy when she complied with the current step and all of the previously mastered steps in the examination hierarchy. The clinician and the staff person also encour-

aged Alice throughout the session with nonspecific praise and approval (e.g., “That’s it, you’re doing fine.”) and verbal reminders. Starting at step 9 of the examination hierarchy, a supervising nurse conducted all of the remaining sessions with Alice. The clinician remained in the sessions to record data but did not actively intervene with Alice. A staff person also stood in the doorway or just outside the examination room in the hallway to provide behavior management support consistent with Alice’s school-based behavior intervention plan, as needed.

For those examination hierarchy steps that featured medical instruments, the clinician counted the designated seconds aloud with Alice while holding up fingers for each number specified in the hierarchy substep. This procedure was implemented to gradually shape increased compliance with more difficult steps. Contingent on noncompliance at any step, the clinician and staff person withdrew their attention and ceased interacting with Alice. She was required to remain in the nursing suite until quiet and when challenging behaviors had ceased for 10 s. When Alice responded accordingly, the clinician returned her to the classroom with a reminder that she should “try harder” at the next visit to the nursing suite. If Alice asked to leave the nursing suite at any time without engaging in challenging behavior (i.e., “I want to go now” or “Back to classroom”), she was immediately returned to her classroom to reinforce her appropriate requesting behavior.

Step-Forward Probe Sessions

Probe sessions were conducted during the study to assess compliance with examination hierarchy steps that Alice had not yet encountered. During probe sessions the clinician presented steps to Alice similar to baseline conditions. That is, she presented the steps without positive reinforcement for compliance and terminated the session when Alice requested or contingent on challenging behavior. After each probe session conducted up through step 6, Alice was returned to the last examination hierarchy step with which she had previously complied. From steps 7 onward, probes guided more rapid progression through the final hierarchy steps.

Results

Figure 1 shows the number of steps in the examination hierarchy Alice completed compliantly during baseline and treatment phases. In baseline, she did not comply with the first step of the examination hierarchy during three consecutive sessions. With treatment, Alice gradually complied with hierarchy steps each time they were advanced. She had one occasion in which she did not earn reinforcement due to avoidance behavior displayed in the later stages of intervention.

In addition, Figure 1 reveals that although step-forward probes were included early on, it was determined that rapid movement through initial steps with lower demand characteristics might not allow Alice sufficient time to acclimate to the treatment setting prior to the introduction of medical instruments (i.e., stimuli previously identified as likely to occasion avoidance behavior). Steps involving blood pressure measurements and the lung, heart/chest, and ear examinations required numerous substeps of increasing proximity and increasing duration of tolerance for the instruments. Of note, nursing staff were brought in to conduct the medical examination when the target step involved the abdominal area, at which time Alice’s compliance with examination requests immediately generalized to them. Furthermore, a series of step-forward probes in the final four steps of the intervention indicated rapid compliance with all but the last step of the examination hierarchy when the nurse implemented intervention. Compliance with the final step involving the ear exam was particularly difficult for Alice, taking almost as long to master as the initial exposure to the blood pressure cuff and stethoscope (16 and 14 sessions, respectively). Overall, Alice was able to tolerate the full medical examination over the course of 57 sessions in a span of less than 4 months.

Discussion

Consistent with previous research on medical avoidance (Conyers et al., 2004; Cuvo et al., 2010; Gillis et al., 2009; Grider et al., 2012; Luscre & Center, 1996; Shabani & Fisher, 2006; Slifer et al., 2011), the present study successfully increased compliance with medical examination procedures using graduated expo-

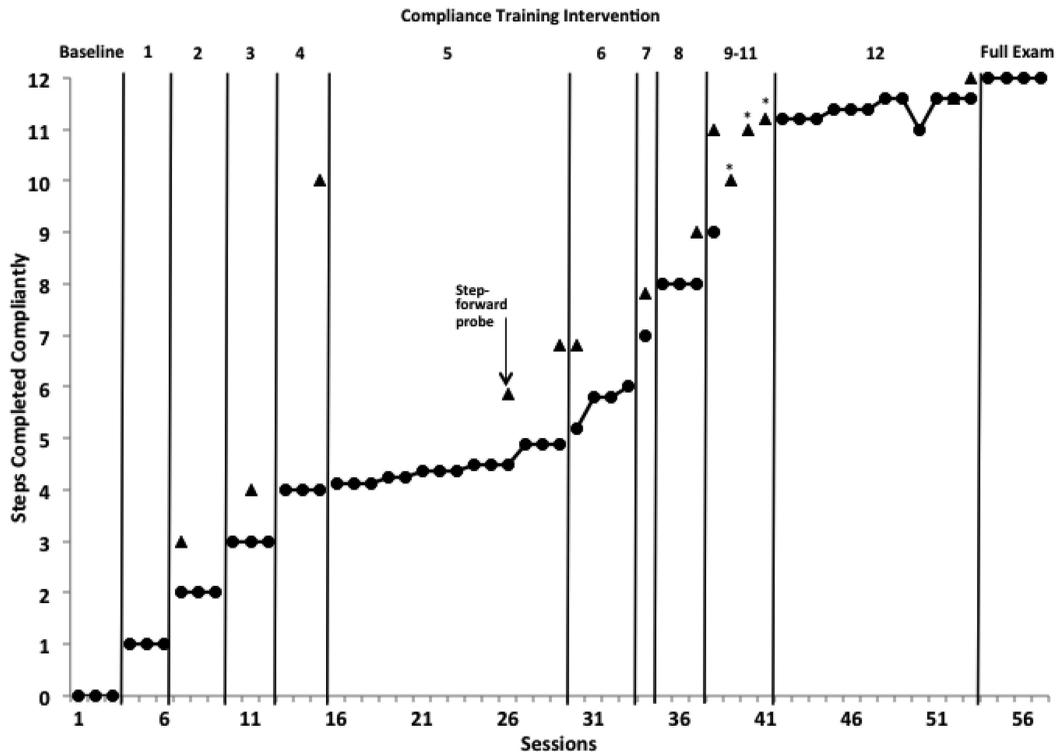


Figure 1. Number of steps in the hierarchy that Alice completed compliantly. Phase labels indicate targeted criterion step. Steps 5 and onward have sub-steps for gradual increase in mastery to complete the full step (ascending line to reach criterion step requirements). Asterisks indicate the transition to nursing staff during generalization programming.

sure and positive reinforcement. Notably, there was steady acquisition of skills and generalization across interventionists. However, Alice required many sessions to achieve full compliance. There was one extended acquisition phase when she was initially exposed to medical instruments, as might be expected from her protracted history of avoidance behavior. A second extended acquisition phase was encountered when she reached the final hierarchy step that entailed examining her ears with an otoscope. One explanation for this outcome is that Alice was able to see the medical instruments during earlier steps whereas with the ear examination, the otoscope was out of her visual field. With further exposure, she was able to master this final step and eventually tolerate a complete examination successfully.

In addition to graduated exposure and positive reinforcement, the compliance training intervention with Alice had other procedures. As

described, the clinician and staff person delivered nonspecific praise and encouragement, and modeled hierarchy steps. Also, we included a form of functional communication training (FCT) by allowing Alice to terminate sessions on verbal request. Similarly, most medical compliance research with people who have IDD and ASD has combined several intervention procedures, but certainly future studies might profit by evaluating the contribution of individual components.

Our study purposefully moved at a slow pace to accommodate Alice's learning history and to prevent avoidance behavior that would have delayed progress. Indeed, probe sessions revealed that she required the full compliance training intervention before successfully tolerating all of the steps in the examination hierarchy, although latter steps other than the ear exam showed rapid acquisition and generalization to nursing staff. Therefore, another goal for

future research with individuals who have long-standing medical avoidance would be evaluating strategies to hasten progress earlier in intervention.

Intervention with Alice began with the clinician, familiar to her only from preference assessment sessions, implementing all procedures. Our purpose was to first establish early compliance with the examination hierarchy before introducing unfamiliar nursing staff, whose uniforms might cue avoidance behavior. As revealed in the baseline phase, the mere presence of the clinician was insufficient in promoting compliance. That is, Alice did not progress through the examination hierarchy until the clinician introduced graduated exposure combined with modeling and positive reinforcement. Once Alice had achieved the majority of steps in the examination hierarchy she was able to respond positively to nursing staff.

The changing criterion design confirmed the effects of the behavioral compliance training package in teaching Alice to comply with a medical examination, but we did not include criterion reversals as an experimental manipulation. Given Alice's history of noncompliance and overdue need for medical evaluation we decided that extending treatment was clinically contraindicated. Another aspect of the study is that we did not formally assess inter-observer agreement or treatment integrity. One additional shortcoming is the absence of follow-up data and evaluation of examination compliance with different people and in novel settings such as a physician's office. It would be beneficial for clinicians to continue evaluating maintenance and generalization of mastered skills in naturalistic settings, including primary care settings and specialty clinics. Clearly, under the conditions that constituted the study, Alice was able to participate compliantly with a medical examination by nursing professionals who could comment and advise about her health care.

In summary, the results of this case study suggest that behavioral compliance training, consisting of graduated exposure, modeling, and positive reinforcement, represents a promising approach to teaching youth with ASD and IDD to tolerate necessary medical examinations. Our findings suggest further that intervention can be successful without

resorting to "forced compliance" procedures or similar methods that could compromise outcome, such as sedation and passive examination. Finding nonaversive methods to establish compliance with medical procedures is certainly a clinical and research priority for people who have learning challenges and repeated negative experiences in health care settings.

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