

Chapter 2

Compliance with Medical Routines

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Compliance with medical routines is an important part of basic health care for everyone, but especially individuals with intellectual and developmental disabilities (IDD). Compliance with medical routines may be especially important for individuals with IDD because, as a group, individuals with IDD have poorer health than those in the general population; a problem that tends to be more pronounced in individuals with severe disabilities (Janicki et al. 1999). While poorer health results from a complex combination of variables, including genetics, income, and isolation, the lack of compliance with medical routines is a significant factor (Krahn et al. 2006). So, while many diseases and illnesses are preventable or treatable, the benefits only accrue if patients cooperate with the procedures involved in the delivery of medical care.

Perhaps the factor most responsible for noncompliance is the fear generated by common medical procedures. Routine health care can require patients to tolerate a wide variety of medical procedures of varying degrees of invasiveness. For example, routine health care procedures can range from the relatively mild intrusions of blood pressure cuffs, pill swallowing, temperature taking, and throat swabs to more invasive procedures such as blood draws, immunization injections, tooth extractions, and biopsies. Many of these routine medical procedures can be distressing and can generate considerable fear and anxiety in anyone, even when the procedures themselves are not a threat in any biological sense (O'Hare et al. 1989). Compounding this problem is the fact that individuals with IDD have been found to endorse a greater number and intensity of fears than normative samples

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(Knapp et al. 1992). For example, individuals with Autism Spectrum Disorders exhibit higher rates of medical fears than typically developing individuals, with almost a third of individuals with IDD showing marked avoidance and total non-compliance with even the most basic medical exams (Gillis et al. 2009). In addition, the more intense and unfamiliar the sensory experiences associated with those medical procedures, the more intense are the avoidance and noncompliance exhibited by those with IDD. Indeed, the literature is replete with evidence of compliance problems during relatively common medical procedures such as physical examinations (Gillis et al. 2009), blood draws (Grider et al. 2012), immunizations (Wolff and Symons 2012), and nebulizer treatments (Reimers et al. 1988). However, the list also includes compliance problems with less common but critical health care routines such as cleaning of central lines (McComas et al. 1998), blood tests (Slifer et al. 2011), EEG evaluations (DeMore et al. 2009), blood transfusions (Gorski and Westbrook 2002), and catheterization (Gorski et al. 2004).

The fact that routine medical procedures might generate fear and anxiety should not be surprising. Many fears of medical procedures are developmentally appropriate. For example, typical young children exhibit fears of unusual or unfamiliar stimuli or loud or sudden noises. They also exhibit predictable fears associated with strangers, separation, loss of support, masks and dark (e.g., Silverman 2011). By school age, typical children show developmentally appropriate fears of bodily injury, blood and injections (Gullone 2005). Now consider that many medical and dental procedures have precisely these features. Dentists wear masks and use equipment that makes loud and sudden noises. Nurses are often strangers who draw blood. Imaging technicians typically ask that patients enter dark rooms, then lay back and wait alone for periods of time. Most, if not all of these procedures also include sensory experiences that are unusual, unfamiliar, and often uncomfortable. That anyone might wish to escape or avoid these situations is both logical and predictable.

Conceptually, we understand that many fear behaviors are respondent events; unconditioned responses elicited by unconditioned stimuli in the environment. Unconditioned stimuli may include the prick of a needle during an immunization injection, loud noises or vibrations from dental instruments, or placement in an isolated, confined space like an MRI scanner. The unconditioned responses can include mild, nonintrusive sweating, heart palpitations, rigidity, shallow breathing, and nausea or more disruptive behaviors such as flinching, fainting and vomiting. The disruptions are compounded when many of the previously nonthreatening sights and sounds of the health care environment (e.g., the sight of a nurse, the clothes he wears, the room where services are provided, etc.), through repeated pairing with unpleasant events, gradually become conditioned stimuli that elicit similar fear responses. Higher order conditioning can eventually result in more and more previously neutral stimuli that can elicit fears that are also referred to as conditioned emotional responses.

Conditioned emotional responses can also be strengthened and maintained by their consequences because these emotional responses often allow the individual to escape or avoid contact with threatening or feared events. That is, the escape or

avoidance of contact with feared medical routines reinforces noncompliance, even though at times, the escape and avoidance are temporary at best. These behaviors can include a range of verbal and physical protests. The intensity of these protests can range from mild delay tactics to severe aggression. Verbal protests often include crying, moaning, complaining and requests for termination. Physical protests can involve physically blocking or pushing away health care providers and their equipment and may involve running away. More severe protests can include biting, hitting, and kicking. Unfortunately, here again because of repeated pairings with unpleasant events, previously neutral stimuli can acquire the ability to evoke noncompliant behaviors that, in the past, have produced escape or avoidance.

It is these escape and avoidance behaviors in particular that are at the heart of most noncompliance and have the potential to severely impact health outcomes. First, these disruptive avoidance behaviors can create risks of injury to everyone involved, leading health care providers to rely on restrictive means of gaining compliance (e.g., sedation or restraint). Many of these passive restraint procedures can themselves increase risks for serious and dangerous health complications (e.g., over sedation). Second the challenges associated with trying to manage disruptive behaviors can deter health providers from a willingness to provide services in the first place, reducing access to care (Lennox and Kerr 1997). Third, caregivers may elect to avoid some preventive or elective health care procedures because of the physical risks and emotional embarrassment experienced when dealing with noncompliance. Finally, noncompliance can interfere with the full completion of procedures and disrupt a provider's concentration, thereby diminish the quality of care being delivered. As a result of these complications associated with noncompliance with medical routines, even a minor illness could create functional impairments and subsequent declines in health, resulting in increased dependency on others for care (Rimmer 1999).

Ultimately, the noncompliance with basic health care can have profound effects on very specific aspects of long term health and well-being. For example, individuals with IDD have been found to have significantly more unmet dental oral health needs such as fewer restored or repaired teeth and more missing or decayed teeth than in normative samples (Cumella et al. 2000; McKinney et al. 2014). Unmet oral health needs have also been strongly linked to respiratory disease (Azarpazhooh and Leake 2006) as well as to systemic conditions such as coronary heart disease and stroke (Seymour et al. 2007). These poorer health outcomes are attributable in large part to both inadequate hygiene and preventive care, inadequacies that are generally rooted in the avoidance of and noncompliance with the sensory and procedural demands of simple tasks like taking x-rays and cleaning teeth as well as more invasive ones like drilling and filling (Lewis et al. 2002).

Long term health risks from noncompliance are also found in the complications that follow failed MRIs. Recent studies of aging diseases have found that over a third of the individuals with IDD would not cooperate enough to generate quality imaging, even with sedation (Prasher et al. 2003). Common problems included refusal to go into the scanner and refusal to stay in the scanner for fear of being left alone in confined spaces. Perhaps more important, of those individuals

who required sedation to complete the imagining studies, one in five experienced serious and dangerous complications from sedation that required emergency intervention. Thus, poor compliance has been a major factor limiting the use of MRIs with IDD and ultimately limiting what is known about aging diseases in this population.

Conceptual Considerations

Treatment of medical noncompliance should be developed with consideration that the noncompliance has both respondent and operant components. Interestingly, although consequences are typically considered to be the “mainsprings of behavior control” (Brady 1978, p. v), the conceptual analysis would suggest that the focus of treatment for medical noncompliance should center on its central respondent conditioning characteristics. Treatment begins by arranging for respondent extinction of the fear responses. To do so, stimuli that have been conditioned in the past to elicit fear responses and escape behavior are now repeatedly presented to the individual (in vivo exposure) in a hierarchy from least feared to most feared. The hierarchy is arranged so that less salient stimuli are presented first so that the initial exposures do not elicit fear or evoke avoidance behavior. The salience of a stimulus can be varied for example, by size of the stimulus, distance from the stimulus, and/or duration of exposure. Then the salience of the stimulus exposures can be increased slowly so as not to elicit fear and avoidance responding.

This *graduated exposure* can be enhanced or strengthened to the extent that the feared stimuli are gradually presented while the individual is relaxed. This requires either teaching a relaxation response (e.g., progressive muscle relaxation) or eliciting one by presenting stimuli that previously have been associated with being relaxed, such as watching movies, holding a favorite blanket, or listening to music. This process of pairing relaxation with graduated exposure can result in counter-conditioning, in which previously feared stimuli eventually come to elicit less intense fear responses and instead may even elicit pleasant responses.

Graduated exposure can also be enhanced or strengthened by considering the operant characteristics of the disruptive noncompliance behaviors. That is, many disruptive noncompliant behaviors are maintained by escape and avoidance of the planned medical routines behaviors, even if only temporary. As a result, one might consider strategies that prevent escape or avoidance (i.e., escape extinction). However, escape extinction procedures themselves can be predicted to evoke “bursts” of escape behavior, escalating in intensity, that further increase risks of harm to individuals with IDD and their caregivers or medical providers.

As an alternative to escape extinction, practitioners have typically developed approaches that emphasize reinforcement of cooperative behaviors (i.e., sitting or lying still and quiet), that are incompatible with noncompliance with medical routines (i.e., DRI procedures). These behaviors are initially reinforced in the presence of the least threatening or least feared stimuli associated with the medical

routine to minimize the likelihood that escape behaviors are evoked and maximize the likelihood of success in exhibiting the desired behaviors. Gradually then, the more threatening, fearful, or uncomfortable aspects of a medical routine are “faded in”, but only after the individual has experienced success (i.e., accessed reinforcement) for tolerating less threatening, less aversive conditions.

Note that the core feature of these enhanced approaches always involves the individual experiencing graduated, *in vivo* exposure to feared stimuli resulting, hypothetically, in respondent extinction. The addition of a relaxation response focuses additionally on counterconditioning. Here, the point of emphasis is on the individual being relaxed *before* the gradual presentation of the feared stimuli and then maintaining relaxation during the presentations. This particular form of graduated exposure is commonly called systematic desensitization (King et al. 2005). In contrast, the addition of a positive consequence focuses additionally on operant reinforcement of incompatible behaviors. Here, the point of emphasis is on delivering reinforcement *after* the presentation of the fear stimuli contingent on the individual exhibiting cooperative behaviors.

Research Findings

An evidence-based practice always begins with a review of the empirical research findings on the best available treatments. Doing so promotes effective practice, improves patient outcomes, and enhances public health (APA 2006). In order to evaluate the research findings on interventions to address noncompliance with medical routines in the IDD population, we looked at two relatively recent reviews of the literature regarding treatment of fears and/or phobias. Both were designed to critically evaluate the literature and determine which treatments, if any, met criteria for classification as “well-established” or “probably efficacious” treatments (Chambless and Ollendick 2001).

In their review of the literature on treatment of phobic responses in typically developing children (e.g., fear of dogs, flying, dark, snakes, tests, etc.), Davis and Ollendick (2005) identified two well-established treatments. The first treatment, what they called “reinforced practice”, is an operant procedure involving repeated, controlled, graduated exposures after which the phobic individual receives reinforcement for not engaging in avoidance behavior. The second well-established treatment, called “participant modeling,” involves having an individual watch a model interact with feared stimuli with no aversive outcome, purportedly resulting in vicarious extinction of the phobic responses in the observer who then must approach and interact with the phobic stimuli themselves. Davis and Ollendick (2005) also found systematic desensitization to be probably efficacious for treatment of behavioral avoidance and subjective fear. Finally, they found cognitive behavior therapy, which focuses on changing cognitions, to also be probably efficacious in typically developing children.

In contrast to the review by Davis and Olendick, which focused on the treatment of phobic responses in typically developing children, Jennett and Hagopian (2008) focused their review more specifically on the empirical evidence for treatment of phobic responses in individuals with IDD. They found 12 well-controlled single case experimental studies demonstrating treatment efficacy with phobic avoidance responses to stimuli as wide ranging as stairs, dogs, swimming pools, animatronic objects, needles and dental exams. The treatments that were found efficacious were comprised of seven main components, including graduated exposure, contingent reinforcement, prompting, modeling, escape extinction, and use of distracting/relaxing stimuli. Graduated exposure was the only component used in all treatment packages. The authors concluded that behavioral treatment that focuses on learning principles and provides direct and graduated exposure is well established for treating phobic responses in individuals with IDD.

Because these reviews did not look specifically at phobic avoidance responses to medical procedures by individuals with IDD, we did an additional search of the literature. We were interested in any additional studies not covered in previous reviews that (1) targeted individuals with IDD who were resistant, avoidant, or noncompliant with (2) preventive, diagnostic, or treatment-related medical and/or dental procedures. As a result, we searched databases PubMed, Medline, and Psych Info using key words and combinations of key words that included terms such as medical or dental noncompliance, resistance, phobia, or avoidance as well as intellectual and/or developmental disability. Our goal was not to conduct a critical review of the studies, but to evaluate the extent to which studies targeting medical noncompliance in individuals with IDD were found to include the empirically supported approaches identified previously by critical reviews.

Our search identified 27 studies with participants with IDD (see Table 2.1), predominantly children, ranging in age from 22 months to 41 years old. Diagnoses included those with autism, mild to severe intellectual disabilities, and developmental delay. The routines that were addressed included dental exams and cleaning, pill swallowing, physical exams, nebulizer treatment, needle sticks, central line care, and wearing of positive airway pressure masks. The most common routines targeted for intervention involved dental exams and needle sticks.

Assessment components. Given that many individuals with IDD often have limited ability to report on private experiences such as fear or anxiety, all of the studies employed direct observations of behavior as the primary measure of treatment outcome. Typical “fear” behaviors that were measured included aggression, protests, refusals, screams, and turning away or running. The most common dependent variable was the percentage of steps completed within the medical/dental routine. In baseline, the researchers typically exposed participants to the medical/dental procedure that was targeted and then documented the frequency and/or intensity of avoidance behaviors as well as the number/percentage of steps completed in the routine. These initial observations were also critical in conducting a task analysis so that the therapists could understand what tasks were involved in completing each step of the routine in sequence and also for understanding which stimuli elicited the most intense avoidance and escape behaviors.

Table 2.1 Summary of studies identified

Author(s)	Medical/dental routine	Population	Study design	Treatment components	Treatment outcomes
Altabet (2002)	Dental exam and clean	63 adults	Control group design	Dist + GE + IM	Tx group completed more steps of routine. No differences in sedation or restraint
Beck et al. (2005)	Pill swallowing	8 children, 4–9 yrs	AB design with replication across participants	GE + Rfimt	7 of 8 participants were able to swallow target pill at end of treatment, 6 of 8 maintained success at home
Boj and Davila (1989)	Dental exam	28, 3–4 yrs	Matched control group design	VM	Tx group had higher heart rates and no differences in behavior or anxiety ratings
Cavalari et al. (2013)	Physical examination	16 year-old	Changing criterion	GE + Rfimt + IM	Participant was able to complete full exam by end of treatment
Conyers et al. (2004)	Dental exam	6 adult ages 33–54	Multiple baseline	GE + Rfimt + VM	VM was effective for 1 participant. All participants completed all 18 steps when desensitization package was implemented
Cuvo et al. (2010a)	Dental exam	5 children, 3–5 yrs	Multiple probe across participants	Dist + GE + Rfimt + VM + EE	Participants demonstrated compliance with the exams and showed maintenance of responding
Cuvo et al. (2010b)	Physical examination	6 children, 3–6 yrs	Multiple probe across participants	Dist + GE + Rfimt + VM + EE	Participants demonstrated compliance with the exams and showed maintenance of responding
Davit et al. (2011)	Venipuncture compliance	58 children, 0–21 yrs	Quasi-randomized trial	GE	All increased compliance with steps toward blood draw
DeMore et al. (2009)	Overnight EEG evaluation	17 children, 4–17 yrs	Case study	GE + Rfimt + IM + EE	9 tolerated all training steps and 15 (88 %) tolerated all 21 electrode placements for 9 h actual EEG

(continued)

Table 2.1 (continued)

Author(s)	Medical/dental routine	Population	Study design	Treatment components	Treatment outcomes
Ghuman et al. (2004)	Pill swallowing	4 children, 5–6 yrs	Case study	GE + Rfnt	Two learned to swallow targeted pills in 3 sessions; 1 in 5 sessions; 1 withdrew
Gillis et al. (2009)	Physical examination	18 children 2–13 yrs	Pre- post- design	GE + Rfnt + IM	15 of 18 participants met physical exam criterion after 25 sessions. Three took 38, 42, and 62 sessions to meet criterion
Gorski et al. (2004)	Dialysis, catheterization, medication refusal	3 boys, 10–14 yrs	Changing criterion	Dist + GE + BM + Rfnt	Increased compliance with specified tasks to 90–100 % completion
Grider et al. (2012)	Blood draw	21 year-old	ABCD—case study design	Dist + GE + Rfnt	Participant reached 100 % compliance after 27 exposure trials
Hagopian et al. (2001)	Blood-injury-injection	19 year-old male	Changing criterion	Dist + GE + Rfnt	The participant was able to sit unrestrained for blood draw procedure at the end of treatment
Isong et al. (2014)	Dental exam and cleaning	80, 7–17 yrs	Randomized controlled trial	VM versus Dist versus VM + Dist	No significant differences between groups, although Dist and Dist + video Modeling did show significant improvements within group
Luscre and Center (1996)	Dental exam	3 children, 6–9 yrs	Multiple baseline across participants	Dist + GE + IM + Rfnt	The participants showed and increased to 85–100 % steps completed in an analog and in vivo settings
Lunskey et al. (2003)	Breast, pelvic exams	22 women	Pre- post- assessments	Dist + GE	Participants showed improved knowledge, beliefs about coping
Maguire et al. (1996)	Dental procedures	4 adults	Multiple baseline across participants	GE + Rfnt	All participants showed an improvement in cooperation and decrease in resistance. Results maintained
McComas et al. (1998)	Central- venous line care	Infant, 22 mo	Multiple schedule design	BM + Rfnt + EE	The child was more compliant with the low-probability requests following high-probability requests

(continued)

Table 2.1 (continued)

Author(s)	Medical/dental routine	Population	Study design	Treatment components	Treatment outcomes
Orellana et al. (2014)	Dental exam	38 children and 34 adults	Pre post assessment	GE + VM	There were significantly more components completed post treatment
Reimers et al. (1988)	Nebulizer treatment	Child, 2 yrs	Case study: ABC design	GE + Rfimt + EE	The participant consistently wore mask for 20 min treatment and maintained for 3 months
Riviere et al. (2011)	Medical examination	2 children, 6–8 yrs	ABABCB	BM + Rfimt	Participants increased compliance with low-probability requests
Shabani and Fisher (2006)	Blood draw (needle phobia)	18 year-old	Variation of an ABAB reversal design	GE + Rfimt	The participant was able to complete blood sample procedures and the behavior generalized to other settings
Slifer et al. (2007)	Positive airway (PAP) mask	4 children, 3–5 yrs	Multiple baseline	Dist + GE + Rfimt + EE	All participants tolerated wearing the PAP during sleep
Slifer et al. (2008)	Electroencephalogram	7 children, 2–10 yrs	AB replicated across subjects	Dist + GE + Rfimt + EE	All participants showed 100 % compliance with EEG without restraint, anesthesia, or sedation
Slifer et al. (2011)	Needle sticks	8 children, 4–16 yrs	ABAB	Dist + GE + Rfimt + EE	Participants cooperated with real needlestick after 4–15 sessions
Wolff and Symons (2012)	Needle-to-skin contact	Adult male	Changing criterion	GE + Rfimt + EE	The participant was compliant with needle-to-skin contact

Note GE Graduated exposure, Rfimt Reinforcement, Dist Distraction/Relaxation, BM Behavioral momentum, EE Escape extinction, VM Video modeling, IM In vivo modeling

To assist in behavior measurement, some studies used the Brief Behavioral Distress Scale (Tucker et al. 2001), a tool that has demonstrated good reliability and validity. Observers record the essential steps of the medical/dental procedure and then record the occurrence and nonoccurrence of the clearly defined target behaviors (i.e., noninterfering distress behaviors, potentially interfering distress behaviors, interfering distress behaviors, and active coping response without verbal delay) for each step. A *Total Distress Score* and *Active Coping Response Score* are calculated, which allows for comparison across procedures that have varying numbers of steps.

Several studies also included structured rating scales during the behavioral assessment. For example, the Behavioral Observation Assessment (BOA; Gillis and Romanczyk, n.d.) is used to rate participant behaviors on a 7-point Likert scale, from negative/avoidant to positive/approach. The instrument also prompts observers to include information about the current treatment step and behaviors specific to each step. The tool is used for progress monitoring and treatment modifications. Some studies targeting dental exams or dental cleaning included the Frankl scale (Frankl et al. 1962), a 4 point Likert scale that is widely used throughout clinical dentistry to provide subjectively ratings of cooperation and compliance during treatment. Ratings from the Frankl Scale have been found to be highly correlated with independent, direct observations of escape and avoidance behaviors in children (Allen et al. 2003).

Treatment components. Across the 27 studies that were reviewed, the most common components used in treatment of fear avoidance and noncompliance with medical/dental routines in individuals with IDD were graduated exposure and contingent reinforcement.

Graduated exposure. All of the treatment interventions included some aspect of in vivo exposure to the feared/avoided stimuli and 23 of the 27 included some effort to conduct these exposures gradually. Note that the investigators used a wide array of labels for interventions that included core features of graduated exposure. Sometimes these labels were used interchangeably with the term graduated exposure (e.g., systematic desensitization, in vivo desensitization, contact desensitization, in vivo graduated exposure, fading, etc.) and sometimes these labels draw attention to the fact that the graduate exposure was preceded by efforts to elicit relaxation (e.g., counterconditioning) or was part of a treatment package (e.g., behavioral compliance training, reinforced practice, differential reinforcement, etc.).

A review of their procedures indicates that the gradual presentation of feared stimuli can be accomplished in a number of ways. The first is to simply present the stimuli in the order in which they will be encountered in the actual procedure or routine, but to conduct a thorough task analysis so that the steps can be broken down into substeps if necessary to promote success during exposures. The second approach is to reorder the stimuli into a fear hierarchy in which the steps that evoke the least avoidance responses are presented first, even if they are presented out of sequence, and the steps that evoke the most avoidance responding are saved for later. Regardless of which approach is used, steps in an exposure protocol can

be sequenced based on dimensions such as duration of exposure to the stimulus, size of the stimulus, or distance from a stimulus (Jennett and Hagopian 2008). Over two thirds of the studies included actual exposure hierarchies to guide the steps and dimensions to be presented during the exposure.

Exposures sequenced according to task analysis. Cavalari et al. (2013) developed an exposure protocol that was sequenced according to the 12-steps of a typical routine medical examination for a 16 year-old female with autism. Compliance with the steps was evaluated during baseline by presenting each step in sequence until noncompliance was demonstrated. Exposures then followed the typical sequence but were “graduated” by requiring the patient to demonstrate repeated compliance with each step prior to advancing to the next step. In addition, sub-steps were created to increase compliance with what were observed in baseline to be more difficult steps (e.g., gradually increasing the time in contact with certain medical instruments).

Once graduated exposure begins, it may be necessary to revise the sequence of steps to promote compliance. For example, Grider et al. (2012) originally developed a 12-step exposure sequence of a blood draw routine, but the adult male with autism was unable to progress past the seventh step (i.e., exposure to syringe with needle). Therefore, a step in which the syringe was displayed without the needle attached was added to the exposure sequence. The addition of the step helped the participant to progress to the next planned step.

Time exposed to the stimulus. Reimers et al. (1988) implemented a hierarchy based on an increasing number of minutes of wearing a mask during nebulizer treatment. The child was required to meet the specified time criteria to gain access to a preferred edible. The first criterion was 3 s of mask wearing and the terminal criterion was 20 min, the amount of time needed to complete the nebulizer treatment. In the early steps of the hierarchy, small increases in the amount of time were required (e.g., 30 s to 1 min). As treatment progressed, larger increases in criteria were required (e.g., 5 min 30 s to 10 min 30 s).

Size of the stimulus. Beck et al. (2005) treated noncompliance with pill swallowing by gradually exposing children to pills of increasing size, beginning with a very tiny pill about the size of a cupcake sprinkle. They then used a hierarchy of nine mock pills of increasing size. The children started with the smallest size pill and progressed to the next pill size contingent on success with pill swallowing on two to three trials until they had reached the terminal pill size.

Distance from the stimulus. Shabani and Fisher (2006) gradually decreased the distance from a participant’s index finger to a lancet device used to draw blood samples. Through an initial assessment, it was determined to start at a distance of 61 cm from the finger because the participant did not show signs of distress at this distance. After two to three successful trials (i.e., arm kept in designated location for blood draw), the experimenters moved to the next closer step and continued with closer and closer exposures at distances of 46, 31, 8, 5, 1 cm and finally an actual blood draw.

In one study treating needle phobia using a similar “fading in” graduated approach, Wolff and Symons (2012) found that a male with autism and IDD would

not tolerate the needle moving closer than about 12 feet. At that point they introduced a “warning stimulus” to show the individual how long the exposure would last. In this case, the warning stimulus may actually have enhanced the salience of duration, making the exposure less aversive.

One challenge for any therapist implementing a treatment program involving graduated exposure with individuals with IDD is deciding when to progress to the next step in the hierarchy. Criteria established for moving to the next step varied in the studies reviewed. The majority of protocols required two to three trials of compliance/no disruptive behavior (e.g., Beck et al. 2005; Cuvo et al. 2010a, b; Wolff and Symons 2012) before moving to the next step. Others required that the participant appear relaxed or calm or comfortable with a step before progressing (e.g., Conyers et al. 2004; Slifer et al. 2011) and recommended moving back to a previous step to help a child feel comfortable if necessary (e.g., Davit et al. 2011). Some protocols required that the participant receive a neutral or positive rating on an assessment measure (Gillis et al. 2009) before progressing. Still others increased the demands on a scheduled basis, independent of how the participant performed or appeared (e.g., Gorski et al. 2004; McComas et al. 1998). For the remainder of the studies, the progression to the next step was unclear from the description of some of the treatments or more subjective. For example, Slifer et al. (2008), noted that the “pace was one that challenged and taught the child, but did not overly distress the child” and Slifer et al. (2007) reported only that the participants progressed gradually through the steps.

Contingent reinforcement. Eighty percent of studies included reinforcement contingent on desired behavior and usually in combination with graduated exposure. Only in two studies involving efforts to increase compliance with behavioral momentum was reinforcement used without graduated exposure. Reinforcement was delivered contingent upon appropriate approach behaviors, successful completion of a step, or compliance with substeps in the medical/dental routine. Caregiver interviews and preference assessments were often used to identify probable reinforcers (e.g., Cuvo et al. 2010b; Gillis et al. 2009). For example, Cuvo et al. (2010a, b) asked parents and the child’s clinician to complete a questionnaire of the child’s preferred items. The items were then presented in a brief paired stimulus preference assessment (Fisher et al. 1992) every 2 weeks to determine which items to use contingent on completion of steps.

Other researchers have used conditioned reinforcers, such as tokens or money to reinforce compliance. For example, Maguire et al. (1996), provided adult males with mild to severe intellectual disabilities specific praise and access to monetary compensation for demonstrating cooperative behavior during each 30 s segment of the dental treatment procedure. Hagopian et al. (2001) provided tokens contingent on compliance every 10 s (faded to 20 s) that could be exchanged following the session for preferred items.

Other treatment components. While 74 % of the studies used combinations of graduated exposure and contingent reinforcement, about 40 % of the studies included either in vivo or video modeling, distraction/relaxation procedures, or prompting procedures.

Modeling. When modeling was included in a treatment, whether in vivo modeling or video modeling, it was typically used as a supplement to graduated exposure and reinforcement. In most cases, it was a medical provider or a therapist who actually was performing as a model, in some cases modeling appropriate behavior while undergoing the entire routine and in other cases modeling acceptance of specific steps within a routine. For example, dentists often use a procedure call Tell-Show-Do (Orellana et al. 2014), in which they provide sensory and procedural information, show the instruments they will be using, and then model for their patients the acceptance of being touched by instruments like tooth explorers, mirrors, or drills. However, they do not typically model acceptance of every step in an exam, such as getting in the chair or accepting the light being turned on. In addition, this approach would also typically be combined with components like graduated exposures and contingent reinforcement (e.g., Maguire et al. 1996).

Several studies used a typically developing child as a model and video recorded the model successfully completing a medical/dental exam (Cuvo et al. 2010a, b). Parents were then given the video recording on a DVD and asked to have their child watch the video daily at home in preparation for exposure and reinforcement sessions in clinic.

Two studies have attempted to examine the efficacy of modeling alone to address medical/dental noncompliance. Conyers et al. (2004) found that watching a video of a well-known staff person undergoing each of the procedures in a dental exam did eliminate resistance in one adult with IDD, but two others showed no change in avoidance behavior until in vivo graduated exposure was introduced. Isong et al. (2014) also found that a group exposed to video modeling experienced no reductions in distress or noncompliance compared to a control group when undergoing preventive dental exams. This suggests that for some individuals, the vicarious exposure encountered with video modeling may not be enough. Luscre and Center (1996) also noted problems with ensuring that participants actually attended to a modeling video depicting a typical peer undergoing dental treatment.

Distraction/Relaxation. A number of investigators acknowledge the value of trying to elicit positive responses that can counter the fear responses that may be elicited during in vivo exposure (e.g., Luscre and Center 1996). For example, Slifer et al. (2007) included access to preferred activities during exposure trials of positive airway pressure mask wearing in order to produce an “emotional state that is incompatible with the anxiety (i.e., pleasure and relaxation)”. This was hypothesized to inhibit the anxiety response typically elicited by the procedure. This type of counterconditioning can be achieved by providing the individual with noncontingent access to pleasurable stimuli that include things like movies, TV, toys, or music (e.g., Hagopian et al. 2001), but can also be achieved by teaching specific relaxation responses like progressive muscle relaxation or diaphragmatic breathing (Lunsky et al. 2003; Gorski et al. 2004). These efforts at distracting or relaxing are typically initiated before exposure trials begin and then continue during the exposure trials. Whether access to these pleasurable activities actually elicit relaxation or functioning as distractors (or both) is unknown. Grider et al. (2012) suggested that access to a preferred video during difficult steps in an exposure

protocol involving blood draws helped to distract the participant from the blood draw procedure, making it easier to complete. However, it is equally possible that the preferred video also elicited a calm, relaxed response that also made the exposures easier to complete.

Prompts. Some protocols have included prompts to help evoke the desired calm and cooperative behaviors needed to complete the mental-dental routine. Cavalari et al. (2013) developed a social story to prompt desired behavior during a routine physical examination. The story was read to an adolescent with autism and IDD prior to each graduated exposure session to prompt compliance and was available throughout the day during breaks. Other investigators have included photographs depicting the steps in the procedure to prompt appropriate behavior (e.g., Orellana et al. 2014). Cuvo et al. (2010b), had a physician assistant show children with autism a picture of another child successfully tolerating each step in a physical exam as a visual prompt for appropriate behavior. If the child did not comply, the child was again prompted by presentation of the picture paired with a verbal direction.

Behavioral momentum. Two studies were found to forego the traditional exposure-based approaches to medical/dental noncompliance described previously and instead evaluated increasing compliance using behavioral momentum. In this approach, the probability of complying with demands associated with a medical routine (i.e., low probability requests) is increased by preceding those demands with a string of demands for compliance with very easy tasks (i.e., high probability requests). In both studies, the presentation of high probability requests just prior to the presentation of low probability requests resulted in increases in compliance in the medical routine for a toddler needing central venous line care (McComas et al. 1998), and for children with autism undergoing a physical exam (Riviere et al. 2011).

Managing noncompliance. Each of the components describe above are designed to reduce the probability of problem behaviors occurring from the outset and/or to reinforce more appropriate responding. Nevertheless, it is important to consider how one will respond to noncompliance when it does occur. Responses to noncompliance varied across the studies, but typically involved either (1) physically blocking escape attempts and physically guiding compliance (escape prevented), (2) taking brief breaks from trials, ignoring the problem behavior, and then continuing exposure trials (escape permitted for brief periods) or (3) ending exposure trials when problems occurred (escape permitted that day). The first approach, escape extinction, aims to further weaken undesirable behaviors by eliminating one of the primary consequences thought to be responsible for maintaining noncompliance. While the latter two approaches offer only temporary escape (because exposure trials ultimately begin again), even temporary escape or avoidance can help maintain fear and noncompliance (Allen and Wallace 2013). Regardless of the approach taken to address noncompliance, these procedures were never used in isolation, but were used in combination with efforts to reduce the probability of noncompliance while reinforcing incompatible alternatives.

Escape extinction. Escape extinction was used by about a third of the investigators as a component of their intervention package. For example, Reimers et al. (1988) added escape extinction after they found that their graduated exposure and contingent reinforcement decreased avoidance behaviors when a nebulizer mask was first presented to a toddler with a developmental delay, but did not increase the amount of time the child left a mask on for nebulizer treatment. When they added escape extinction (i.e., the child was no longer allowed to remove the mask), there was a gradual increase in mask wearing and he was eventually able to wear the mask for the duration of the treatment. The appropriate mask wearing maintained following treatment with caregivers only periodically providing praise for mask wearing. In another study evaluating procedures for teaching children with IDD to tolerate needle sticks necessary for immunizations and/or blood draws, the children were not permitted to escape or avoid any of the procedures via redirecting, blocking and physically guiding the children to stay in the situation and complete each exposure (Slifer et al. 2011).

Practice Recommendations

Recommendation 1: The results of a conceptual analysis of medical/dental non-compliance suggested that conditioning is responsible for previously neutral stimuli acquiring the ability to both elicit emotional responses and evoke avoidance behaviors. Thus, one could take a preventive approach to dealing with noncompliance by taking early steps prior to the emergence of problem behaviors to increase the probability that neutral stimuli in medical and dental settings are conditioned to elicit relaxed behavior and evoke approach responses (Table 2.2). So, for example, rather than waiting until children are sick or have a cavity to visit the pediatrician or dentist, respectively, one could recommend to parents and caregivers that they make planned “field trips” to those settings when children are well with the intention of making the trip highly reinforcing in the presence of stimuli that are likely neutral or of low stimulus salience. These trips could be and probably should be short; no more than 15 min. A trip to the dentist might include playing with preferred toys in the exam room, interacting with staff and professionals who do NOT have masks and gloves on, riding the chair up and down, exploring nooks and crannies with the dental mirror, shining the dental light at objects in the room and choosing from different color toothbrushes before going home. A trip to the pediatrician might involve playing with preferred toys in the exam room, interacting with a staff person or medical professional who has no equipment, masks or gloves on, reading a short book, playing with a toy stethoscope and eventually trying it out on a parent, receiving a preferred trinket or edible and going home. Subsequent trips might include gradual exposure to slightly more salient stimuli, but because these are conducted by parents and caregivers and not trained clinicians, it is best to place the emphasis on exposure to stimuli not likely to already

Table 2.2 Summary of recommendations

<i>Preventing the need for treatment</i>
1. Parents/caregivers gets permission to plan multiple 10 min “field trips” to medical/dental clinic
2. Providers are asked to approve visit with only relaxing and reinforcing activities
3. Parents request no exposure to masks, gowns, gloves, or typical medical/dental instruments
4. Parents bring preferred toys, activities, edibles with them
5. Emphasis on ending visit while individual is relaxed and enjoying themselves
<i>Preparation for treatment of medical/dental noncompliance</i>
1. Conduct a task analysis
2. Develop a fear hierarchy
3. Conduct no-treatment exposures; observe the intensity of behavior, features of most salient stimuli, and how far the client is able to progress
4. Revise the task analysis to include any necessary substeps
5. Conduct a preference assessment
<i>Treatment of medical/dental noncompliance</i>
1. Provide noncontingent access to some preferred items to distract/relax the individual
2. Use in vivo modeling of appropriate behavior
3. Begin graduated exposure and provide reinforcement for compliance
4. Progress to the next step when the individual has been compliant with the current step and appears relaxed
5. Back up to easier steps if necessary to establish success

be conditioned as aversive. Planning multiple trips with relaxed and reinforcing experiences will be important for increasing the probability that neutral or low salience stimuli acquire conditioned calming or reinforcing properties. Of course, medical/dental staff will not have much time to invest in these activities and it is important to know that medical and dental professionals are not typically paid for their time; they are paid for procedures that are performed. So, it may be necessary to be highly flexible about when these type of activities are planned; often at the end of the day or during periods of low clinical activity. However, it may be more important to find a medical or dental professional who is experienced or comfortable with individuals with disabilities and understands that these early investments of time on positive conditioning and reap benefits in terms of patient loyalty and in terms of the ability to provide quality care with minimal risk.

Recommendation 2: The result of the research review appear clear: those who are interested in an evidence-based approach to addressing noncompliance with medical or dental procedures will start with in vivo graduated exposure as the core component in their treatment protocol (Table 2.2). Of course, an evidence-based practice always takes into consideration the unique needs of the individual client as well as the expertise of the practitioner when developing a treatment protocol and, perhaps as a result, there are certainly examples (albeit few) within the literature where in vivo graduated exposure was not used. Determining how best to

approach the exposures will likely first require conducting an initial task analysis to determine all of the steps that would typically be included in the medical or dental routine involved.

Once all of the steps have been identified, the client will likely need to undergo one or more no-treatment (baseline) exposures to each step in the routine to allow observations about the intensity of avoidance behavior associated with each stimulus and each step and to see which steps and stimuli the client can tolerate and which must be terminated because of noncompliance. Thus, even if an individual cannot tolerate, for example, the blood pressure cuff at the beginning of a physical exam, or cannot tolerate the x-ray at the beginning of a dental exam, the initial assessment would continue on with other planned steps to allow an assessment of behavior at each step in the routine. This will help determine where to begin with treatment as it may not be necessary to conduct exposure training with every step in a medical or dental routine if only certain steps are disrupted or terminated.

This initial observation should also help evaluate whether to create “substeps” for some routines (i.e., breaking some steps into smaller steps), and which features of relevant stimuli (e.g., distance, size, duration, or intensity of exposure) are most salient and most amenable to gradual presentation. Some studies include sample hierarchies for graduated exposure that are generic enough to be useful in many typical situations where noncompliance might appear in individuals with IDD, including dental exams (i.e., Altabet 2002; Cuvo et al. 2010a), physical exams (e.g., Cavalari et al. 2013), blood draw routines (e.g., Slifer et al. 2011; Grider et al. 2012) and pill swallowing (e.g., Beck et al. 2005).

Recommendation 3: Include a preference assessment during treatment development to identify tangible items and passive activities that can be used as reinforcers delivered contingent upon desired calm, “coping” behaviors after each exposure (Table 2.2). These may include edibles, music, videogames, TV, toys, and/or tokens/money that can be exchanged later. Consider making noncontingent access to some of these preferred items available just before each session of graduate exposures to distract/relax the individual before the exposures begin.

Recommendation 4: Consider including in vivo modeling by a parent or caregiver of appropriate behavior prior to or during graduated exposures. This approach is low cost and could be easily incorporated with minimal disruption to the routine. Note that modeling has been found ineffective as a lone intervention for dental routines.

Recommendation 5: Give careful consideration to how disruptive behavior will be addressed. Most researchers have demonstrated good success without including escape extinction, but doing so may require a more gradual approach to exposures that lengthens the course of treatment. Rejecting escape extinction may also reduce some risks of injury to the individual and the providers who might be asked to use physical guidance or blocking. However, it is important to assess the medical necessity of treatment to determine whether allowing escape from treatment presents its own risks.

Research Recommendations

Although the research literature shows considerable agreement about the key components of an effective intervention to address medical/dental noncompliance, there are important questions that remain unanswered about these components. The vast majority of the studies on medical/dental noncompliance have implemented treatment packages that include a variety of components, so the independent effects of the individual components or the summative effects of multiple components are not well known. These issues are important for the advancement of both science and practice. For example, evaluating the power of respondent extinction and counterconditioning alone are important for a science like applied behavior analysis that tends to emphasize the operant aspects of behavior change. But component analyses are also important for practitioners who may not have the time or resources to implement complex intervention packages; an approach that researchers sometimes rely on to maximize treatment outcomes.

Practitioners would also benefit from research that attempts to clarify the best criteria for deciding when to advance exposures. Most procedures required mastery (i.e., compliance) with the current step on two or three sessions before moving on to the next step, but focusing on compliance alone during exposures may lead to practitioners progressing when fear responses have not yet been extinguished. Yet it is unknown whether asking practitioners to continue with exposures until calm behavior is observed adds anything valuable to a protocol. Furthermore, it is not clear how best to operationalize “calm” or whether adding more objective measures of fear responses (e.g., heart rate) might be useful alternatives.

Perhaps not surprisingly, the majority of interventions targeting medical/dental noncompliance in individuals with IDD have been developed within the field of applied behavior analysis. As a result, the most well supported interventions have numerous features characteristic of applied behavior analysis; they tend to be explicitly behavioral, individualized, function-driven treatments evaluated within small *n* research studies that emphasize demonstrations of functional relations and internal validity. While this approach is highly valued within a natural science of behavior, interventions that are highly individualized do not lend themselves to wide dissemination or adoption, even within applied behavior analysis and certainly not within medical/dental clinics where these problems are typically first encountered. However, there are enough common elements to treating medical noncompliance that they could be standardized to create a manualized protocol. Randomized controlled trials could then provide additional demonstrations of generality of the intervention, something thought to be important to the dissemination of an intervention (Barlow et al. 2009).

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