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REVIEW

A Scoping Review of the Healthcare and Hygiene Literature for Individuals with Intellectual and Developmental Disabilities

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Abstract

Objectives Previous reviews highlight the similarities in teaching healthcare and hygiene routines to individuals with and without intellectual and developmental disabilities. Additionally, similar interventions are used when interfering behaviors occur. Although these routines are topographically distinct, there are enough similarities to suggest effective procedures for one routine may be used to inform another. This scooping review aims to identify effective teaching and intervention procedures for healthcare and hygiene routines specifically for individuals with intellectual and developmental disabilities. We also evaluated the extent to which functional analyses were conducted; a dimension not included in previous reviews.

Methods Eligible articles targeted compliance or tolerance within the context of a defined healthcare or hygiene routine as a dependent variable and used an experimental design with a demonstration of experimental control. Articles were identified through PsycINFO, PubMed, and Academic Search Premier databases. Additionally, a hand search of five related journals was conducted. Data were collected on dependent variables, functional analyses, baseline contingencies, teaching procedures, and additional experimental components.

Results A total of 52 articles met inclusion criteria. Most experiments produced positive outcomes. The findings show all experiments involved a treatment package with multiple components. The most common teaching procedures were graduated exposure and DRA. A lack of functional analyses and social validity was noted.

Conclusions Component analyses are needed to identify the most effective and efficient procedures. Pyramidal training to teach medical professionals how to provide preventative pyramidal training should be explored.

Keywords Healthcare · Hygiene · Developmental disability · Intellectual disability · Autism spectrum disorder

Maintaining good health promotes greater well-being and quality of life (Centers for Disease Control & Prevention, 2018). However, research indicates there is a large health disparity between individuals with intellectual and developmental disabilities (IDD) and the neurotypical population (Drum et al., 2009). For example, people with IDD have higher rates of epilepsy, diabetes, obesity, and high blood pressure (Drum et al., 2009; Havercamp & Scott, 2015), and these chronic health concerns can raise additional health complications and amass extensive medical costs (Ervin & Merrick, 2014). Unfortunately, there are several social, economic, and environmental barriers that result in individuals with IDD often receiving poorer quality healthcare compared to their neurotypical peers; these include difficulties accessing proper healthcare, delays in diagnosis, and medical professionals' lack of knowledge in behavior management techniques (Hernandez & Ikkanda, 2011; Hosking et al., 2016). As a result, more than one-third of deaths among adults with IDD result from amenable conditions, compared to less than one-quarter of deaths among neurotypical adults (Hosking et al., 2016).

Further, individuals with IDD often experience difficulties identifying and describing symptoms of illness, and may exhibit challenging behaviors during healthcare procedures, which compounds systematic barriers to proper healthcare (Collado et al., 2008). Exhibiting challenging behaviors during invasive medical procedures may lead to chemical or

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physical restraints and sedation to complete even routine medical examinations (Hernandez & Ikkanda, 2011; Kupzyk & Allen, 2019). Additionally, challenging behaviors exhibited by people with IDD may lead to incomplete participation in healthcare routines, resulting in inconclusive medical results or future avoidance of necessary procedures. Failure to tolerate or participate in healthcare procedures, such as routine hygiene tasks, increases the risk of injury and infection for both individuals with IDD and those closest to them (Jess & Dozier, 2020). For example, the Coronavirus Disease of 2019 (COVID-19) pandemic recently highlighted the importance of performing daily personal hygiene tasks, such as handwashing, to prevent the spread of the disease. Failure to complete such routines may result in an individual with IDD acquiring infections and transmitting the infection to family members as well. In the case of COVID-19, the severity of health complications can range from mild symptoms to severe respiratory illnesses requiring acute medical attention (Centers for Disease Control & Prevention, 2021).

Moreover, challenging behaviors exhibited by individuals with IDD during medical and hygiene procedures makes it more difficult for medical professionals to deliver treatment effectively; at times, even securing services from medical professionals can be delayed when individuals do not participate in these procedures (Hernandez & Ikkanda, 2011; Kupzyk & Allen, 2019). Within the field of dentistry, Hernandez and Ikkanda (2011) reported a lack of evidenced-based behavior management techniques used to address challenging behaviors exhibited by individuals with IDD. As such, these and other medical professionals may not be prepared to provide treatment to individuals who exhibit challenging behaviors. Hernandez and Ikkanda recommended the use of behavior-analytic procedures to effectively manage these behaviors during routine examinations and treatment.

One underlying reason for lack of cooperation during healthcare and hygiene routines can be attributed to fear (Fallea et al., 2016; Gillis et al., 2009; Kupzyk & Allen, 2019). As there are several stimuli present and sensations that occur in medical environments that elicit unconditioned responses, these fears can have both respondent and operant components (Silverman, 2011). For example, during an eye exam, a puff of air in the eye serves as an unconditioned stimulus and elicits an unconditioned response (i.e., an eye blink). Other unconditioned stimuli involved in healthcare and hygiene routines include bright lights, loud noises, and needle pricks. Unconditioned responses, such as moving away, occur to avoid or escape the startle or pain. As unconditioned responses are reinforced by resulting in termination of the sensation or procedure altogether, an operant function of escape develops for the response. For example, a child continuously pulling her hand away as her mother attempts to cut her nails may result in escape. Previously neutral stimuli, such as the nail clippers or her mother's toiletry bag, may begin to elicit the same avoidance behaviors, now as conditioned responses. This combination of respondent and operant components involved in fear within the context of healthcare and hygiene routines demonstrates why treatment packages are often necessary (Kupzyk & Allen, 2019).

Thus, it is not surprising that researchers and clinicians have been evaluating strategies to increase cooperation during healthcare and hygiene routines. As identified in a review of the literature by Jennett and Hagopian (2008), treatment to reduce phobic avoidance involves multiple components, including in-vivo exposure, a hierarchy of steps for desensitization, contingent reinforcement, prompting, modeling, extinction, and the use of distracting stimuli. In the recent literature, treatment packages for phobic avoidance of healthcare and hygiene routines often entails graduated exposure and reinforcement. For example, Carter et al. (2019) created a task analysis for gradual exposure to dental routines. Reinforcement was delivered for participant cooperation during each step, and subsequently faded once mastery was achieved. Following treatment, both participants cooperated with the dental routine in a simulated dental office, and one of the participants tolerated a dental cleaning in an actual dentist office.

Recently, Halbur et al. (2021) taught children with autism spectrum disorder (ASD) to tolerate face masks or face shields. Experimenters replicated previously evaluated treatment packages (Cox et al., 2017; Sivaraman et al., 2020) consisting of graduated exposure, prompts, and differential reinforcement during in-person and telehealth sessions. Additionally, experimenters included an escape-extinction component for challenging behaviors. Following the intervention, participants tolerated face coverings for at least 5 min during work or another activity. Other experiments have demonstrated the efficacy of graduated exposure and reinforcement without escape extinction to increase tolerance with routines such as haircuts (e.g., Buckley et al., 2020) and nail clipping (e.g., Dowdy et al., 2018).

Some of the literature has also evaluated additional strategies or treatment components when intervening on phobic responses to healthcare and hygiene routines. For example, Kupzyk et al. (2021) incorporated coping skill instruction into a treatment package to promote cooperation with eye exams with one neurotypical participant. Behavior change was measured using the Subjective Units of Distress Scale (SUDS), the percentage of exam steps completed, distress behavior, and coping behaviors. Kupzyk et al. suggested education may produce some benefits, but in-vivo practice may have a greater impact on behavior change.

There are several related literature reviews related to healthcare and hygiene routines. Neely et al. (2016) reviewed generalization and maintenance of functional living skills with individuals with ASD. Training in the natural setting or to a preset criterion produced the greatest maintenance,

however, few studies were reviewed given limited inclusion of generalization and maintenance data. Wertalik and Kubina (2017) evaluated studies that sought to improve personal care skills with individuals with ASD. The outcomes found more than half of the participants could not complete the skill independently following the intervention. Kupzyk and Allen (2019) reviewed studies aimed at increasing compliance with medical and dental routines with individuals with IDD. At the conclusion of the review, Kupzyk and Allen provided recommendations for prevention, preparation, and treatment of noncompliance during medical and dental procedures. Most recently, Jess and Doizer (2020) conducted a review of studies to increase handwashing in children. The authors suggested a combination of antecedent and consequence strategies to be most effective. Across previous reviews, researchers noted the need for component analyses to determine the effects of the individual components that comprise treatment packages. This would inform which components are necessary and potentially identify components that are not. By reducing the number of components, treatment packages could be easier to implement.

Aside from different populations and routines, the previous reviews highlight the similarities in teaching healthcare and hygiene routines. Similar parameters were included in previous reviews, such as the format of training (e.g., in vivo, video model) and procedural components (e.g., chaining, stimulus fading). Additionally, similar interventions are used when interfering behaviors occur during healthcare and hygiene routines. For example, graduated exposure and reinforcement can be used to teach compliance during dental exams, haircuts, or to increase tolerance for wearing face masks. Although these routines are topographically distinct, there are enough similarities to suggest effective procedures for one routine may be used to inform another which warrants a scoping review. A scoping review could be used to identify the evidence across similar procedures and identify key factors (Munn et al., 2018). Additionally, reviewing articles involving either healthcare or hygiene routines provides a larger number of studies to discuss.

Therefore, the purpose of the current review was to evaluate the literature aimed at increasing compliance during both healthcare and hygiene routines with individuals with IDD. The current review is similar to Kupzyk and Allen (2019), given the same population and similar routines. However, Kupzyk and Allen specifically identified articles aimed at reducing non-compliance during medical and dental procedures. Additionally, Kupzyk and Allen discussed treatment for fear and avoidance responses, highlighting graduated exposure as a consistent, evidence-based treatment component. In the current review, a history of non-compliance or avoidance behaviors was not required. This is important because not all individuals with IDD engage in non-compliance or avoidance during healthcare and hygiene routines. One aim of the current review was to evaluate procedures used to teach skills related to these routines, whether compliance was a concern or not. Additionally, we evaluated the extent to which functional analyses were conducted, a dimension not included in previous reviews.

Method

Search Procedures and Inclusionary Criteria

The search procedures followed the guidelines outlined by Tricco et al. (2018) for conducting a scoping review (see Online Supplemental Materials). We conducted a search in September 2021 through the PsycINFO, PubMed, and Academic Search Premier databases to identify relevant articles. We used the following Boolean string: AB("compliance" AND "autis* OR intellectual disabilit*" AND "healthcare OR hygiene OR dental OR medical OR self care" NOT "sleep" NOT "toileting"). Search results were restricted to empirical articles published in English-language, peer-reviewed journals. Next, we conducted a hand search of all volumes and advance-online publications for the following journals: *Journal of Applied Behavior Analysis* (JABA), *Behavioral Interventions* (BIN), *Behavior Analysis in Practice* (BAP), *Behavior Analysis: Research and Practice* (BARP), and *Advances in Neurodevelopmental Disorders.* We conducted a hand search of these journals because we reasoned these were the outlets that would contain studies meeting our inclusionary criteria.

Additionally, we used the reference lists of retained articles to conduct a backward search identifying articles that were not found during the database and journal hand searches. We then conducted a forward search of the articles retained via Google Scholar® using the "Cited by" feature. The full text of all retained records were reviewed for inclusion of individual participant data; any records lacking these data were excluded.

We examined keywords in the titles and abstracts of the articles yielded by the database and hand searches to determine the potential relevance for this review and applied the inclusionary criteria to those articles. For inclusion in this review, articles had to (a) be published in a peer-reviewed journal in English; (b) report individual participant data, including baseline data or some similar condition; (c) target compliance or tolerance within the context of a defined healthcare or hygiene routine as a dependent variable; and (d) use an experimental design with a demonstration of experimental control. Criteria for experimental control in single-case designs were that the design provided at least three demonstrations of experimental effect at three different points in time, the design controlled for common threats to internal validity (i.e., technological definitions of

the dependent and independent variables), the intervention resulted in a pattern of responding most likely produced by manipulations to the independent variable, the design controlled for common threats to internal validity, and multiple measures of the dependent variable were provided (Horner et al., 2005). Studies pertaining to sleep and toilet training were excluded as other reviews have specifically targeted those expansive literatures (e.g., Johnson et al., 2021; Kroeger & Sorensen-Burnworth, 2009; Luiselli, 2016; Mannion & Leader, 2014).

We identified 86 articles through the database search and after duplicates were removed, 71 articles were identified. We found 22 articles through the journal hand searches. Forward and backward searches yielded an additional 61 articles, for a total of 154 articles. After the inclusion and exclusion criteria were applied, a total of 52 articles (containing 54 experiments) were included in the review. It should be noted Experiment 3 of Cox et al. (2017) served as an extension of Experiment 2 assessing generalization and was not counted as an additional experiment.

An independent rater examined each article obtained through the search process to determine whether it met the inclusion or exclusion criteria. An agreement was defined as both raters indicating an article either met inclusion criteria or exclusion criteria. A disagreement was defined as one rater indicating an article met inclusion or exclusion criteria and the other rater indicating the opposite. In the event of a disagreement, both raters met to discuss the article until agreement was achieved. Interrater agreement was calculated by dividing the number of agreements by the number of agreements plus disagreements and multiplying by 100. Each rater reviewed all articles identified in the electronic search, hand search, and forward and backward searches. Interrater agreement was 100%.

Coding Criteria

Retained articles were coded along the following dimensions: participant and setting characteristics; dependent variables; inclusion of a functional assessment; specific baseline contingencies; data collection procedures used; experimental design; teaching procedures used; outcomes; generalization and maintenance measures; and social validity measures. If a single article contained multiple experiments, each experiment was coded separately.

Participant and Setting Characteristics

Participant characteristic data were collected, including age, sex (i.e., male or female), gender (i.e., trans- or cisgender man or woman, nonbinary), clinical diagnosis, and the setting in which the target behaviors were taught. Participant age was categorized according to groups used by the Centers for Disease Control and Prevention, National Center for Injury Prevention and Control (2016). Specifically, ages were coded as toddlers (1–4), early adolescents (5–9), late adolescents (10–14), teenagers (15–19), or adults (20 and older). The groups included ages through the end of the last year. For example, a four-and-a-half-year-old would be coded as a toddler and a 9-and-a-half-year-old would be coded as an early adolescent. Participant diagnoses were coded according to the *Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition* (American Psychiatric Association, 2013) as ASD, attention-deficit/hyperactivity disorder (ADHD), intellectual disability, Down Syndrome, learning disability, or a combination. The training setting was coded as natural, clinical, or both. A natural setting was defined as a setting where the target behavior should occur, such as a home or hospital. A clinical setting was defined as an analogue setting, such as a simulated dentist or doctor's office.

Dependent Variables

Data were collected on dependent variables in each experiment by coding the type of healthcare or hygiene routine taught and whether the participant was required to engage in passive compliance, active compliance, or both. *Healthcare* routines were defined as routines completed to prevent, diagnose, or treat a healthcare condition. *Hygiene* routines were defined as routines performed to prevent disease or sickness and maintain health and cleanliness. Routines were coded along the following subcategories: handwashing, physical examination, dental procedures, wearing masks, wearing medical devices, toothbrushing, showering, feminine hygiene, nail cutting, venipuncture, MRI test, pill swallowing, hair care (e.g., haircuts, hair brushing), bathroom hygiene (e.g., wiping after bowel movements), and skin care (e.g., applying lotion). *Passive compliance* indicated participants were taught to tolerate an unpleasant event or refrain from exhibiting behaviors that interfered with completing the hygiene or medical routine (e.g., blood draw, wearing a medical device). *Active compliance* indicated participants were taught to perform a specific response (e.g., shaving, handwashing).

Functional Assessment

We collected data on reports of functional assessment data prior to the onset of intervention procedures using a binary measure (*Yes* or *No*), and coded for both direct assessments and indirect assessments. We coded *direct assessment* if the study reported employing a functional analysis procedure to identify the function of dependent variables, regardless of the inclusion of those data in the final report. *Indirect assessments* were defined as a description that contained

the antecedent, behavior, and consequence (e.g., caregiver interview, Functional Assessment Screening Tool [FAST]) to identify the potential function. We also coded the behavioral function identified by these assessments per participant. These included automatic reinforcement, negative reinforcement (escape/avoidance), social positive reinforcement (attention), positive reinforcement (access to tangibles), and multiply-controlled. For multiply-controlled results, we further specified the relevant functions maintaining the interfering behavior.

Baseline Contingencies

Data were collected on the contingencies implemented during the baseline phase by coding the consequences following compliance and/or non-compliance during the completion of target steps (if applicable). Consequences for compliance were coded as reinforcement, next step presented, brief escape, or not specified. Consequences for non-compliance were coded as termination, brief escape, or escape extinction. When multiple consequences were available across response classes (e.g., the procedure was terminated following challenging behavior, and praise was delivered for each step completed correctly), we coded both contingencies. For example, this could look like *termination or praise*. Not specified was coded when insufficient detail was provided to determine consequences. No baseline was coded for articles that did not include a baseline phase.

Experimental Design

Studies were coded on the experimental design used to evaluate the effects of the treatment package. We coded all included experiments as either *group design* or *single-subject design*. Single-subject designs were further coded as the specific type of experimental design, including multiple baseline, nonconcurrent multiple baseline, multiple probe, changing criterion, reversal, and alternating treatments design. Group designs were also further coded as the specific type of experimental design, including matched between-group, randomized control trial, and AB. Group designs were further coded by the specific type of group design, such as between-subject or within-subject designs. This information was considered important to determine whether this research was conducted using a variety of experimental designs.

Teaching Procedures

Data were collected on the format of teaching, whether it was in vivo, video model, or both. Data were also collected on the teaching procedures used and coded as graduated exposure, shaping, chaining procedure, differential reinforcement of alternative behavior (DRA), differential reinforcement of other behavior (DRO), non-contingent reinforcement (NCR), reinforcement fading, escape extinction, without escape extinction, or other. In vivo *model* was defined as training that involved the instructor modeling the healthcare or hygiene routine with the participant(s) present. *Video model* was defined as training presented in a video demonstrating the healthcare or hygiene routine. *Graduated exposure* was defined as a systematic plan to slowly reinforce completion or tolerate steps of the routine or increase compliance with a routine for longer durations. When specified in the original report, we coded whether the graduated exposure procedure was sequential (i.e., progressed sequentially through the steps of the routine) or targeted (i.e., only addressed the necessary steps of the routine). Stimulus fading (where the antecedent stimulus changes gradually and the topography of the response stays the same) and contact desensitization (gradual exposure to aversive stimuli plus reinforcement) procedures were also coded as subcategories of the graduated exposure category. *Shaping* was defined as the training of responses successively closer and closer to the terminal goal. *Chaining procedure* was defined as training the steps of the routine using total task, forward, or backward chaining procedures. We also coded whether probes of the terminal goal ever occurred during teaching using a binary measure (*Yes* or *No*). Terminal goal probes were further coded to specify when during teaching they occurred.

Target Behavior

Data were collected on the target behavior as stated by the experimenter, whether it was a skill deficit, interfering behavior, or not reported. A skill deficit was defined as a skill the participant could not complete independently. Interfering behavior was defined as any response that prevented completion of the routine. Not reported was coded when insufficient information was provided.

Outcomes

Participant performance data were coded. Outcomes were categorized as *positive* (i.e., all participants achieved reported mastery criterion), *mixed* (i.e., a subset of participants achieved the mastery criterion), or *negative* (i.e., no participants achieved the mastery criterion). Our categorization was based on the mastery criterion specified by each experiment. When a mastery criterion was not specified, we reported outcomes based on the results specified by the authors.

Generalization and Maintenance

Data were collected on whether generalization was assessed for the healthcare or hygiene routine selected within each experiment using a binary measure (*Yes* or *No*). If generalization was assessed, the results of generalization were coded for each article. Generalization results were coded as *positive* (i.e., all participants achieved generalization), *mixed* (i.e., some, but not all, participants achieved mastery), or *negative* (i.e., no participants achieved mastery). Assessment of generalization was further coded by the type of generalization assessed (i.e., setting, people, and/or stimuli).

Additionally, data were collected on the inclusion of maintenance assessment and data reporting using a binary measure (*Yes* or *No*). If maintenance was assessed, the length of the maintenance follow-up period (e.g., 1 to 2 weeks, 1 month, or more than 1 month following the termination of the training phase) and the results were coded. The maintenance results were coded as *positive* (i.e., all participants continued at mastery criterion or above), *negative* (i.e., all participants failed to score at mastery criterion), or *mixed* (i.e., some but not all participants continued at mastery criterion or above).

Social Validity

We collected data on social validity using a binary measure (*Yes* or *No*). If social validity was included, we coded the type assessed and specified whether each social validity measure assessed the experiment's goals, procedures, or outcomes. Additionally, we collected data on the respondents of each social validity measure; respondents were coded as the *consumer*, the *provider*, a *consumer's caregiver*, or some combination of these groups. Social validity results were coded as positive, mixed, or negative. *Positive* social validity results were defined as all respondents reporting satisfaction with the goals, procedures, or outcomes. *Mixed* social validity results were defined as only some of the respondents reporting satisfaction with the goals, procedures, or outcomes. *Negative* social validity results were defined as none of the respondents reporting satisfaction with the goals, procedures, or outcomes.

Interobserver Agreement

An independent rater randomly selected and coded 31% of the articles that met the inclusionary criteria. For training, the independent rater was provided with written descriptions of each parameter. Then the author and rater practiced coding two articles together. Next the rater practiced coding three articles independently. Item-by-item agreement was used to assess each parameter coded. An agreement was defined as both the author and rater coding the same response. A disagreement was defined as the author and rater marking different responses. Interobserver agreement was calculated by dividing the number of agreements by the number of agreements plus disagreements and multiplying by 100. Interobserver agreement across parameters was 100%.

Results

Participant and Setting Characteristics

Participants included more males (70.6%) than females (29.4%). None of the experiments reviewed reported gender. The most commonly reported diagnoses were ASD (53.5%) and intellectual disability (52.9%), followed by ADHD (4.3%) and Down Syndrome (2.7%). Several experiments (12.8%) reported a combination, including diagnoses such as Fetal Alcohol Syndrome, Oppositional Defiant Disorder, and Marfan Syndrome. Ages were reported for most participants (89.8%); otherwise, age ranges were provided. Participants were primarily early adolescents (30.9%). The remaining participants were adults (22.6%), late adolescents (18.5%), teenagers (14.9%), and toddlers (13.1%). Table 1 shows more experiments were conducted in a clinical setting (61.1%), than the natural setting (27.8%). Six experiments (11.1%) used both clinical and natural settings.

Dependent Variables

A summary of the type of routine, compliance, and target behavior is provided in Table 1. There were slightly more healthcare routines targeted (59.3%) than hygiene routines (44.4%). One experiment (Riviere et al., 2011) targeted both healthcare and hygiene routines. Compliance was more often passive (57.4%) rather than active (37.0%). Three experiments (5.6%) included both passive and active compliance (Carter et al., 2019; Maguire et al., 1996; Snell et al., 1989). The most common types of routines were wearing medical devices (16.7%) and toothbrushing (14.8%). An equal number of experiments evaluated hair care (13.0%) and dental procedures (13.0%). Similarly, an equal number of experiments evaluated feminine hygiene (11.1%) and venipuncture (11.1%). Physical exams (7.4%) and wearing masks (7.4%) were the next most common, followed by handwashing (5.6%), MRI (5.6%), and nail cutting (3.6%). The remaining routines were evaluated in one experiment each: showering (1.9%), pill swallowing (1.9%), bathroom hygiene (1.9%), and skin care (1.9%). These percentages total to more than 100% as some experiments targeted multiple routines.

Table 1 Setting, type of routine, compliance, and target behavior

Citation	Setting	Type of Routine	Compliance	Routine	Target Behavior
Birkan et al. (2011)	Clinical	Healthcare	Passive	Venipuncture	Interfering
Bishop et al. (2013)	Natural	Hygiene	Active	Toothbrushing	Interfering
Bouter and Smeets (1979)	Clinical	Hygiene	Active	Toothbrushing	Skill deficit
Buckley et al. (2020)	Clinical	Hygiene	Passive	Hair care	Interfering
Carter et al. (2019)	Clinical	Healthcare	Both	Dental exam	Interfering
Cavalari et al. (2013)	Clinical	Healthcare	Passive	Physical exam	Interfering
Conyers et al. (2004)	Clinical	Healthcare	Passive	Dental exam	Interfering
Cook et al. (2015)	Clinical	Healthcare	Passive	Wearing medical devices	Interfering
Cox et al. (2017) EXP 1	Clinical	Healthcare	Passive	MRI	Interfering
Cox et al. (2017) EXP 2 & 3	Both	Healthcare	Passive	MRI	Interfering
Cromartie et al. (2014)	Clinical	Healthcare	Passive	Venipuncture	Interfering
Cuvo et al. (2010a)	Both	Healthcare	Passive	Dental exam	Interfering
Cuvo et al. (2010b)	Natural	Healthcare	Passive	Physical exam	Interfering
DeLeon et al. (2008)	Clinical	Healthcare	Passive	Wearing medical devices	Interfering
Deochand et al. (2019)	Natural	Hygiene	Active	Handwashing	Skill deficit
Dowdy et al. (2018)	Clinical	Hygiene	Passive	Nail cutting	Interfering
Dufour and Lanovaz (2020)	Natural	Healthcare	Passive	Wearing medical devices	Interfering
Ellis et al. (2006)	Natural	Healthcare	Both	Skin care	Interfering
Epps et al. (1990)	Natural	Hygiene	Active	Feminine hygiene	Skill deficit
Ersoy et al. (2009)	Natural	Hygiene	Active	Feminine hygiene	Skill deficit
Fowler et al. (1978)	Natural	Hygiene	Active	Toothbrushing, Hair care	Interfering
Frank-Crawford et al. (2021)	Clinical	Hygiene	Active	Wearing masks	Interfering
Gajic et al. (2021)	Clinical	Hygiene	Passive	Hair care	Interfering
Halbur et al. (2021)	Clinical	Hygiene	Passive	Wearing masks	Skill deficit
Horner and Keilitz (1975)	Clinical	Hygiene	Active	Toothbrushing	Skill deficit
Kissel et al. (1983)	Clinical	Hygiene	Active	Handwashing, Toothbrushing, Hair care	Skill deficit
Klett and Turan (2012)	Natural	Hygiene	Active	Feminine hygiene	Skill deficit
Lillie et al. (2021)	Clinical	Hygiene	Passive	Wearing masks	Skill deficit
Luscre and Center (1996)	Clinical	Healthcare	Passive	Dental exam	Interfering
Maguire et al. (1996)	Natural	Healthcare	Passive	Dental exam	Interfering
Matson et al. (1990)	Both	Hygiene	Active	Toothbrushing, Hair care	Skill deficit
McComas et al. (1998)	Clinical	Healthcare	Passive	Wearing medical devices	Interfering
McConnell et al. (2020)	Clinical	Healthcare	Passive	Dental exam	Interfering
Meindl et al. (2019)	Both	Healthcare	Passive	Venipuncture	Interfering
Nipe et al. (2018)	Clinical	Healthcare	Passive	Wearing medical devices	Interfering
Piazza et al. (1997)	Clinical	Hygiene	Active	Toothbrushing, Showering, Hair care, Bathroom hygiene	Interfering
Richling et al. (2011)	Natural	Healthcare	Passive	Wearing medical devices	Interfering
Richman et al. (1986)	Natural	Hygiene	Active	Feminine hygiene	Skill deficit
Richman et al. (1984)	Clinical	Hygiene	Active	Feminine hygiene	Skill deficit
Riviere et al. (2011)	Both	Both	Passive	Physical exam, Nail cutting	Interfering
Schiff et al. (2011)	Clinical	Healthcare	Passive	Pill swallowing	Interfering
Schumacher and Rapp (2011)	Clinical	Hygiene	Passive	Hair care	Interfering
Shabani and Fisher (2006)	Clinical	Healthcare	Passive	Venipuncture	Interfering
Sivaraman et al. (2021)	Both	Hygiene	Active	Wearing masks	Interfering
Slifer et al. (2002)	Clinical	Healthcare	Passive	*f*MRI	Interfering
Snell et al. (1989)	Clinical	Hygiene	Both	Toothbrushing	Interfering
Stuesser and Roscoe (2020)	Clinical	Healthcare	Passive	Physical exam, Venipuncture	Interfering
Szalwinski et al. (2019)	Clinical	Healthcare	Passive	Dental exam	Interfering
Tarnowski and Drabman (1987)	Natural	Healthcare	Active	Wearing medical devices	Skill deficit

Table 1 (continued)

Citation	Setting	Type of Routine	Compliance	Routine	Target Behavior
Tucker and Berry (1980) EXP 1	Clinical	Healthcare	Active	Wearing medical devices	Skill deficit
Tucker and Berry (1980) EXP 2	Clinical	Healthcare	Active	Wearing medical devices	Skill deficit
Veazey et al. (2016)	Natural	Hygiene	Active	Feminine hygiene	Skill deficit
Walmsley et al. (2013)	Natural	Hygiene	Active	Handwashing	Skill deficit
Wolff & Symons (2012)	Clinical	Healthcare	Passive	Venipuncture	Interfering

Functional Assessment

The vast majority of experiments did not report functional assessment data (88.9%). Of the six experiments that did include a functional assessment, most experiments reported direct measures (83%; McConnell et al., 2020; Nipe et al., 2018; Piazza et al., 1997; Stuesser & Roscoe, 2020; Szalwinski et al., 2019). One experiment reported both direct and indirect measures (17%; Cuvo et al. 2010a, b). All functional assessments indicated behaviors were maintained by negative reinforcement (escape).

Baseline Contingencies

More than half of experiments (61.8%) reported contingencies during baseline. When compliance occurred during baseline, the most common procedure was to proceed to the next step in the routine (74.2%). Some experiments positively (16.1%) or negatively (3.2%) reinforced compliance. Two experiments (6.5%) presented both reinforcement and proceeded to the next step when compliance occurred. Baseline contingencies for non-compliance were reported for almost three-quarters of experiments (74.0%). Non-compliance most often resulted in termination (57.5%), whereas fewer experiments provided brief escape (22.5%) or escape extinction (20.0%). The remaining experiments (22.2%) either did not specify baseline contingencies or did not report baseline procedures.

Experimental Procedures

The most common experimental design used was a multiple baseline design (38.9%). The next most common design was changing criterion design (20.4%). Nonconcurrent multiple baseline design (13.0%) and reversal designs (13.0%) were equally employed. One experiment (McComas et al., 1998) used an alternating treatments design. Lillie et al. (2021) used both a nonconcurrent multiple baseline design and changing criterion design. In the experiment by Halbur et al. (2021), procedures for five dyads were implemented using a multiple probe design, and procedures for the remaining dyad were implemented using a nonconcurrent multiple baseline design. In Experiment 2 of Tucker and Berry (1980), experimenters used a multiple baseline and multiple probe design. No experiments that used group designs met inclusion criteria.

Teaching Procedures

A summary of training format, teaching procedures, and outcomes is provided in Table 2. Most experiments employed in-vivo training (88.9%). Five experiments (9.3%) provided both in-vivo training and video modeling, whereas one experiment (1.9%) used video modeling only. Graduated exposure was the most common teaching procedure (50.0%). Sequential graduated exposure procedures were used most often (40.7%), followed by stimulus fading (37.0%). The remaining experiments that used graduated exposure either involved targeted graduated exposure (14.8%) or contact desensitization (7.4%). The next most common teaching procedure included was DRA (42.6%). More experiments did not include escape extinction (31.5%), than those that did (25.9%). Chaining was used in almost one-third of experiments (29.6%), either using the total task method (81.3%) or forward chaining (18.8%). Reinforcement fading (22.2%) was slightly more common than DRO (14.8%) procedures. NCR procedures were used only in six experiments (11.1%). Shaping was used in the fewest number of experiments (3.7%). Almost a third of experiments (31.5%) included additional procedures coded as other, with components such as social stories, response blocking, and picture prompts (a full list of other components is available from the last author).

Almost one third of experiments (29.6%) included probes of the terminal goal. Most commonly these probes were following a predetermined mastery criterion (50.0%); otherwise, probes of the terminal goal were ongoing (37.5%), or when probes occurred was not specified (12.5%).

Table 2 Procedures used for each type of routine and outcomes

Routine	Outcomes		
	Mixed	Negative	Positive
Bathroom hygiene			
DRA, SR + fading, EE, NCR			1
Dental exam			
DRA, EE, NCR, GE, Other	1		
DRA, SR + fading, GE	1		1
DRA, w/o EE, GE			1
EE, GE			1
w/o EE, GE	1	1	
Feminine hygiene			
Chaining	2		2
DRA, Chaining, Other	1		
Other	1		
*f*MRI			
DRA, Other			1
Hair care			
Chaining	2		
Chaining, Other			1
DRA, SR + fading, EE, NCR			1
DRA, w/o EE, GE			2
GE			1
Handwashing			
Chaining	1		
Chaining, Other	1		
DRA, Other	1		
MRI			
DRA, EE, GE			1
SR + fading, DRO	1		
Nail cutting			
DRA, SR + fading, EE, Other			1
DRA, w/o EE			1
Physical exam			
DRA, SR + fading, EE, Other			1
DRA, w/o EE, GE			1
DRO, EE, GE, Shaping			1
w/o EE, GE, Other			1
Pill swallowing			
w/o EE, GE			1
Showering			
DRA, SR + fading, EE, NCR			1
Skin care			
DRA, GE, Other			1
Toothbrushing			
Chaining	3		1
Chaining, Other			1
DRA, SR + fading, EE, NCR			1
DRA, w/o EE, GE			1
SR + fading, Chaining	1		
Venipuncture			
DRA, EE, GE, Other			2
DRA, w/o EE, GE			1
DRO, w/o EE			1
DRO, w/o EE, GE			1
EE, GE			1
Wearing masks			
DRA, EE, GE	1		
DRA, SR + fading, DRO, EE, w/o EE, NCR, Other	1		
DRA, w/o EE, GE, Shaping, Other			1
SR + fading, DRO, w/o EE			1
Wearing medical devices			
Chaining	1		2
DRA, EE, Other			1
DRA, SR + fading, EE, NCR, Other			1
NCR, Other			1
SR + fading, DRO, EE			1
SR + fading, DRO, w/o EE			1
SR + fading, w/o EE, NCR			1

Note. The numbers refer to the numbers of experiments falling into each outcome category. *DRA* differential reinforcement of alternative behavior; *DRO* differential reinforcement of other behavior; *SR + fading* reinforcement fading, *NCR* Non-contingent reinforcement; *EE* escape extinction; *GE* graduated exposure

Target Behavior

Over two thirds of experiments (68.5%) targeted interfering behavior. The remaining experiments (31.5%) were conducted to address a skill deficit.

Outcomes

Most experiments found positive outcomes (66.7%). Almost one third of experiments found mixed outcomes (31.5%). One experiment (McConnell et al., 2020) found negative outcomes.

Generalization and Maintenance

Generalization was assessed in more than half of the experiments (55.6%); however, generalization data were only included for a portion of these experiments (86.7%). Most generalization outcomes were positive (73.1%), with the remaining coded as mixed (26.9%). The type

of generalization assessed was most commonly setting (73.1%) and people (57.7%). Additionally, generalization was assessed across stimuli (34.6%) and behaviors (11.5%). These percentages total to more than 100% as some experiments assessed multiple types of generalization.

Maintenance was assessed in almost half of the experiments (53.7%), however, like generalization only a portion of these experiments included maintenance data (93.1%). Maintenance data were collected more than a month after the experiment (63%), within 1–2 weeks (48.1%), or after one month (33.3%). These percentages total to more than 100% as some experiments collected maintenance data multiple times. Like generalization outcomes, most maintenance outcomes were positive (77.8%), with a few mixed outcomes (22.2%). We also calculated maintenance outcomes by setting to assess whether setting had an effect. Out of the articles that assessed maintenance and reported outcomes, almost two thirds were conducted in a clinical setting (63%), nearly a quarter in a natural setting (22.2%), with the remaining conducted in both settings (14.8%). Maintenance outcomes for studies in a clinical setting were mostly positive (82.4%), with a few mixed (17.6%). Maintenance outcomes for studies in a natural setting were also mostly positive (83.3%), with one mixed outcome (16.7%). Maintenance outcomes for studies in both settings were equally positive (50%) and mixed (50%).

Social Validity

Few experiments (13.0%) collected social validity data—all included an evaluation of the social validity of outcomes. A subset of these experiments assessed the social validity of procedures (85.7%) and experimental goals (28.6%). The respondents included the consumer's caregiver (71.4%), the provider (14.3%), or a combination of caregivers and providers (14.3%). Most social validity outcomes were positive (85.7%), with one mixed outcome (Snell et al., 1989).

Discussion

The purpose of this review was to summarize the research on compliance with healthcare and hygiene routines for individuals with IDD, identify gaps in the literature, and provide recommendations for future research. The experiments in the current review represent a wide variety of healthcare and hygiene routines, as demonstrated by the dependent variables results. The most common teaching procedures were graduated exposure and DRA. Interfering behavior was targeted more than skill deficits. Outcomes were more likely to be positive, with approximately half of the experiments including measures of generalization and maintenance. In the following discussion, first we discuss similarities and differences between the current and previous literature reviews related to healthcare and hygiene. Second, we discuss the current findings related to the recommendations by Kupzyk and Allen (2019). Next, we highlight interesting findings, followed by limitations and suggestions for future researchers. We conclude with implications.

Similar to Jennett and Hagopian (2008), reinforcement was a consistent component across experiments. In the current review, this most often treatment involved DRA procedures. Another commonality to previous reviews (e.g., Jennett & Hagopian, 2008; Kupzyk & Allen, 2019), all experiments used multiple procedures. Given all experiments used a package of procedures, the effects of each procedure in isolation are unclear, and component analyses might be useful avenues to explore for future researchers.

Ward-Horner and Sturmey (2010) described two methods for conducting component analysis, dropout and add-in. The dropout method involves introducing an entire treatment package from the beginning and observing the effects as components are systematically removed. The add-in method involves evaluating individual components, or combinations of components, and observing the effects as components are systematically added and the entire treatment package is presented. Ward-Horner and Sturmey suggested the dropout method should be used when clinical intervention is the priority, whereas the add-in method should be used when the efficacy of a treatment package has been demonstrated and the necessity of each component needs to be determined. The latter method would be appropriate for teaching compliance with healthcare and hygiene routines. In the current review, some of the common packages included: graduated exposure, DRA, and escape extinction; graduated exposure, DRA, without escape extinction; or graduated exposure, DRA, and reinforcement fading. Any of these combinations would be helpful to evaluate. The experiments teaching compliance with dental exams demonstrate a variety of effective components. For example, Carter et al. (2019) found positive outcomes with the following procedures: DRA, reinforcement fading, and graduated exposure. However, positive outcomes were found by Maguire et al. (1996) with DRA, graduated exposure, and without escape extinction. And Szalwinski et al. (2019) found positive outcomes with escape extinction and graduated exposure. An add-in analysis could be used to determine the effects of DRA and graduated exposure, with additional components added as necessary.

There were also a few differences in our findings compared to previous reviews. For example, Neely et al. (2016) found training functional living skills in the natural setting produced the greatest maintenance. In the current review, the maintenance outcomes of experiments that were conducted in clinical settings versus natural settings were seemingly comparable. It is unclear why setting may have not had as

great of an effect in the current review. Additional procedural details that may have had an impact on this difference, such as the specific skills targeted, were not reported by Neely et al. Another difference that was noted was the use of video models. In the current review, only one experiment used video modeling. Whereas, in the review by Wertalik and Kubina (2017), nine of 13 experiments used video models. One reason for this difference may be attributable to the aims of the research. The current review included studies aimed at reducing noncompliance and challenging behaviors. Video modeling is not a common strategy to reduce challenging behaviors. However, "participant modeling" is a well-established treatment for phobic responses in neurotypical children (Davis & Ollendick, 2005). Research is needed to determine if viewing in vivo models engaging in the healthcare or hygiene routine would be effective for individuals with IDD.

To address non-compliance with medical or dental routines, Kupzyk and Allen (2019) listed recommendations for prevention, preparation, and treatment. Prevention recommendations involve identifying professionals who would allow brief preliminary visits, or "field trips", to expose the client to the environment with preferred stimuli available (e.g., toys, edibles), in the absence of demands and potentially aversive stimuli (e.g., gowns, medical instruments). In the ideal scenario, this recommendation would be implemented. However, the extent to which professionals are willing to allow field trips is unclear. The articles included in the current review were more likely to use a simulated environment, such as an office that was converted to resemble an examination room with medical utensils and staff, when possible. Future research should compare the efficacy of simulated environments to interventions that had preliminary visits, to determine under what circumstances, if any, simulations are sufficient. The preparation and treatment recommendations were more often included in articles in the current review. For example, almost a third of experiments created a task analysis of the routine and one half included graduated exposure (noted by Kupzyk and Allen as a "core component"). Additionally, more than half of experiments included reinforcement, both for compliance and non-contingently.

Now we turn to interesting findings we would like to highlight. This review measured the prevalence of functional behavior assessment conducted prior to implementation of treatment. This type of assessment may inform researchers and clinicians about the relevant antecedents and consequences that influence challenging behavior during healthcare and hygiene routines. A functional behavior assessment may include direct (i.e., functional analysis) and indirect assessment (i.e., FAST, antecedent-behavior-consequence description), and in particular, the consequences indicated should match the functions addressed in the baseline contingencies. Function-based treatments have been found to be more effective than interventions that are not based on function (e.g., Ingram et al., 2005; Newcomer & Lewis, 2004). In a paper describing treatments for escape-maintained problem-behavior the authors noted, "Identifying the function of problem behavior is a necessary precondition before selecting each of these interventions" (p. 26; Geiger et al., 2010). Yet only six experiments reported the use of a functional analysis; more frequently, the experiments reported noncompliance behaviors with a hypothesized function based on parent and teacher anecdotes without verification of the controlling consequence(s).

Only two articles provided rationale for why functional analyses were not conducted. One reason reported by Ellis et al. (2006) pertained to ethical concerns for repeatedly presenting feared stimuli. Lillie et al. (2021) reported a functional analysis was not conducted because it was unlikely participants had a history of reinforcement for the novel target behavior (i.e., wearing a face mask). General barriers to conducting functional behavior assessments have been identified, including time, resources, and expertise (Hanley, 2011; Oliver et al., 2015). It should be noted there are adaptations to functional analyses to address these barriers, such as brief (Kahng & Iwata, 1999) and trial-based functional analyses (Bloom et al., 2011). Regardless, a behavior analyst treating non-compliance during healthcare and hygiene routines has to consider the cost/benefit of conducting a functional analysis. The severity of the behavior and/or necessity of the medical procedure may warrant immediate intervention. Future researchers should consider arranging procedures in a manner that would allow for the predictive validity to be assessed. This would involve a comparison of interventions, one indicated by the results of a functional analysis and the other not (Tiger & Effertz, 2021). Considering only a small handful of articles included a functional analysis, yet most reported positive outcomes, it is possible a functional behavior assessment is not necessary to identify effective interventions for non-compliance during healthcare and hygiene routines.

We also found most experiments did not measure social validity. Despite ongoing calls to increase the inclusion of social validity (e.g., Kennedy, 1992; Snodgrass et al., 2018), this review found a lack of social validity assessment for the interventions in this research. Only seven articles used social validity measures. Inclusion of social validity measures such as the Treatment Acceptability Rating Form (TARF; Reimers & Wacker, 1988) and Treatment Acceptability Rating Form-Revised (TARF-R; Reimers et al., 1992), when completed by a caregiver or medical professional may provide useful information to researchers and clinicians about the feasibility of treatment procedures and outcomes. Assent is another participant measure that was not found in any study that may further illuminate on the social validity of

treatment procedures and outcomes, particularly in situations when participants indicated noncompliance to engage in research. Future research should evaluate the participants' quality of life, particularly when noncompliance is a barrier in the implementation of the healthcare and hygiene routines.

Related to terminology, consideration should be taken for the keywords and language used in this type of research. This terminology may be subject to shifts in perception about applied behavior analytic service delivery. In particular, the term "compliance" was used as a primary search keyword due to the prevalence of this term in the research literature when addressing individual engagement with tasks that were associated with avoidance or challenging behaviors. However, it is worth noting that in recent years, this term may be less widely used due to recent concerns and criticisms about the field of applied behavior analysis in promoting overall compliance in children with ASD (e.g., Sandoval-Norton & Shkedy, 2019). More recent publications may steer away from using this term, and future reviews of the literature should consider additional terms as keywords (e.g., "engagement").

A few limitations with the research as it currently stands may be discussed further. While all articles in this review reported participant sex, we did not find any articles that reported gender. Participant gender information may be gathered in research to identify individuals who do not identify with the sex assigned at birth. Furthermore, the gender diversity of autistic and intellectually disabled populations may be further understood with reporting gender, particularly when including non-binary terms (Jones et al., 2020). An additional limitation of this review is the lack of distinction between therapist-implemented, caregiver-implemented, in person, and telehealth teaching procedures. More attention to the delivery of treatment may further expand social validity of interventions and increase generalization of performance outcomes. Another limitation is the exclusion of "gray literature" Tincani and Travers (2019). Future researchers should include such literature to better inform recommendations for future researchers and clinical practice.

Overall, the research on compliance with healthcare procedures and hygiene skills may still be developed to address the needs of individuals with IDD. Additionally, other related skills may be evaluated and taught as coping strategies (i.e., deep breaths, squeezing a stress ball, closing eyes, counting) when teaching the participants to engage in passive compliance. It would be helpful if future research in this area also included measures of phobic responses, through heart rate or a tool such as SUDS (Kupzyk et al., 2021). These could provide additional data to guide treatment. Additional research on preventative training may be beneficial, particularly by beginning desensitization and tolerance training in advance of problem behavior observed in natural settings. The recommendations provided by Kupzyk and Allen (2019) outline prevention steps, as well as treatment steps, that should be considered. Furthermore, pyramidal training or train-the-trainer approach should be explored to teach medical professionals how to provide preventative training should be explored (Ahlers-Schmidt et al., 2017; Mery et al., 2022). For example, a pyramidal training arrangement could involve a skilled professional teaching a small group of medical personnel compliance procedures. Following training, the medical personnel train other staff or caregivers how to implement the procedures. This training approach has shown to be an effective and efficient teaching strategy and enhance maintenance of trainer and trainee performance Demchak et al. (1992).

As for the implications of the findings across routines, there are similarities indicating useful findings may inform related routines. For example, procedures for health exams should consider starting by evaluating the treatment package of DRA, graduated guidance, without escape extinction. This combination of procedures was effective for both dental (Carter et al., 2019) and physical exams (Stuesser & Roscoe, 2020). This same treatment package was also effective for two experiments that targeted haircuts (Buckley et al., 2020; Schumacher & Rapp, 2011), which may be useful for nail cutting as well. For researchers teaching participants to tolerate wearing face masks, the literature related to tolerance of medical devices may be useful. Halbur et al. (2021) found mixed outcomes when teaching participants to wear face masks when using DRA, graduated exposure, and escape extinction. In contrast, Lillie et al. (2021) found positive outcomes when teaching participants to wear face masks using DRO, stimulus fading, without escape extinction. These were the same procedures Dufour and Lanovaz (2020) used to effectively teach participants to tolerate wearing medical devices.

The current findings have a few clinical implications for behavior analysts to consider. We do not have data to determine the extent to which preliminary healthcare visits are arranged for individuals with IDD. However, incorporating prevention measures could reduce the need for treatment of non-compliance during healthcare routines. This will require collaboration with dentists, physicians, and other medical professionals. Similarly for hygiene routines, it would be beneficial to collaborate with barbers and hairdressers. Additional implications supported by the current results support the efficacy of interventions that do not include escape extinction. We encourage researchers to follow our recommendations for component analyses to identify the most parsimonious procedures.

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Declarations

Ethics Approval This article does not contain any studies with human participants or animals performed by any of the authors.

Conflict of Interest The authors declare no competing interests.

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*Denotes studies included in the current review.

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