

In Review

Treatments for the Challenging Behaviours of Adults With Intellectual Disabilities

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Objective: To provide an overview and critical assessment of common problems and best evidence practice in treatments for the challenging behaviours (CBs) of adults with intellectual disabilities (IDs).

Method: Commonly observed problems that present obstacles to successful treatment plans are discussed, followed by an analysis of available research on the efficacy of behavioural and pharmacological therapies.

Results: Behavioural and pharmacological interventions are most commonly used when addressing CBs in people with IDs. However, within each of these techniques, there are methods that have support in the literature for efficacy and those that do not. As clinicians, it is important to follow research so that we are engaging in best practices when developing treatment plans for CBs.

Conclusions: One of the most consuming issues for psychiatrists and other mental health professionals who work with people who evince developmental disabilities, such as IDs, are CBs. These problems are very dangerous and are a major impediment to independent, less restrictive living. However, there is a major gap between what researchers show is effective and much of what occurs in real-world settings.



Objectif : Offrir un aperçu et une évaluation critique des problèmes communs et des pratiques exemplaires fondées sur des données probantes dans les traitements de comportements difficiles (CD) d'adultes souffrant de déficiences intellectuelles (DI).

Méthode : Les problèmes communément observés qui présentent des obstacles à la réussite des plans de traitement sont présentés, suivis d'une analyse des études disponibles sur l'efficacité des thérapies comportementales et pharmacologiques.

Résultats : Les interventions comportementales et pharmacologiques sont les plus souvent utilisées pour traiter les CD chez les personnes souffrant de DI. Cependant, dans chacune de ces techniques, il y a des méthodes soutenues dans la littérature pour leur efficacité et d'autres qui ne le sont pas. En tant que cliniciens, il importe de suivre la recherche afin de faire en sorte d'appliquer les pratiques exemplaires dans l'élaboration des plans de traitement pour les CD.

Conclusions : L'une des questions les plus prenantes pour les psychiatres et autres professionnels de la santé mentale qui travaillent avec des personnes manifestant des déficiences développementales, comme les DI, consiste dans les CD. Ces problèmes sont très dangereux et sont un empêchement majeur à une vie indépendante, moins restrictive. Toutefois, il y a un écart important entre ce que les chercheurs démontrent comme étant efficace et ce qui se passe vraiment en grande partie dans des contextes réels.

Intellectual disabilities occur in about 3% of the North American population, with most in the mild-to-moderate range of functioning. A host of problems occur at high rates for people with IDs, including epilepsy, major social and communication deficits, comorbid psychopathology, and CBs.¹⁻⁸ Some of the most serious and frequently studied CBs include aggression, pica (eating inedible objects), SIB, property destruction, and rumination.⁹⁻¹¹ Psychiatrists and other mental health professionals are expected to be knowledgeable about these problems, and how to effectively treat them. These behaviours are a major impediment to independent living, dangerous, and consume a disproportionately high amount of mental health resources. Our review provides an overview of interventions commonly used to treat these problems, an analysis of what works and what does not work, and what is inconclusive, given current data.

Commonly Observed Problems

The first author of this review, Dr Matson, has consulted with community agencies and developmental centres in more than 35 states and numerous countries. Based on these consultations during 3 decades, common patterns and errors in treating CBs have been noted. Our review will start with these commonly observed problems, and will be followed by an analysis of available research on the efficacy of behavioural and pharmacological therapies.

Diagnoses Given After the Drug Trial Starts

Diagnoses should drive treatment. Diagnoses can be thought of as a shorthand that is linked to specific evidence-based interventions. Following this formula is important to ensure best clinical practice. In reality, however, pharmacotherapy is often prescribed because of the sedating effects to the patient, staff expectations about potential effects, or because professional staff have, in their opinion, run out of viable treatment options. A frequently observed phenomenon to justify this practice for CBs is to add an Axis I diagnosis based on the Diagnostic and Statistical Manual of Mental

Clinical Implications

- We review common mistakes in treatment and how to avoid and correct them in clinical practice.
- We provide research to support claims of efficacious and ineffective treatment techniques—important knowledge for clinicians and the general public.

Limitations

- While our review is representative of current research, it is not an exhaustive literature search.
- The scope of our review is limited in that extensive instructions for carrying out treatments are not provided.

Disorders¹² after the fact. Frequently, these diagnoses are not supported by the use of mental health tests designed specifically for this population, such as the Diagnostic Assessment for the Severely Handicapped—II,^{13,14} the Assessment for the Dually Diagnosed,¹⁵ and the Psychiatric Assessment Schedule for Adults with Developmental Disabilities.^{16,17} Often times these diagnoses are also generic and have not been systematically studied in the empirical literature on IDs (for example, impulse control disorder). These practices are a red flag and should be avoided. Multidisciplinary diagnoses involve interviewing the patient and patient observation, interview of staff using standardized measures, such as those noted above, and patient history, and efforts to systematically pinpoint causes of the behaviours within the context of a multidisciplinary team, where possible, is optimal (see functional assessment section). Treatment should follow from this data, and regular follow-up of treatment effectiveness should be employed.

Equating CB With Psychopathology Symptoms

A common but poor practice is to provide a diagnosis of a particular mental health disorder, but then to track CB to determine drug effectiveness. This approach is problematic in 2 ways. First, core symptoms of depression are a more direct and better measure of treatment effectiveness for depression. Second, CBs have not been established as equivalents of specific symptoms of a mental health disorder.¹⁸⁻²² In fact, the opposite has been found; CBs are almost exclusively independent regarding cause and when they co-occur.

Lack of Functional Assessment

There is broad consensus that CBs are largely due to environmental factors. For example, in an analysis of 173 papers using functional assessment, researchers identified an environmental cause for 97% of the people.²³ We are aware that there is a positive bias to published research. As a result, these data are likely inflated. Nonetheless, the rates are very high. Also, while biological models and operant and (or) ABA models have been proposed, most studies have tested the ABA model. Commonly identified causes of CB include gaining attention, escape from demands or undesired tasks, self-stimulation, and seeking tangible items (for example,

Abbreviations

ABA	applied behaviour analysis
ABC	antecedent-behaviour-consequence
CB	challenging behaviour
DR	differential reinforcement
DRA	DR of alternate behaviour
DRI	DR of incompatible behaviour
DRL	DR of low rates
DRO	DR of other behaviour
EFA	experimental functional analysis
ID	intellectual disability
PBS	positive behavioural support
QABF	Questions About Behaviour Function
SIB	self-injurious behaviour

food or toys). Poor coping and social skills are also common contributors.

Functional assessment is the methodology used to establish environmental causes. Four specific methods are used within the functional assessment paradigm. Scatterplots involve graphing the time of day that a CB occurs across days or weeks. This method is used to establish patterns when the behaviours are most likely to occur.²⁴ For example, if CB occurs only during vocational training, additional analysis of that setting would be conducted to address the possibility that problem behaviours occur due to agitation produced by excessive noise or movement by others, the client's perception of the workshop tasks as highly onerous, and so on.

A second method involves ABC charts. Data are collected by staff or family members in real time. The assumption is that what occurs just before or just after the CB constitutes the cause of the problem behaviour. When a consistent pattern of antecedents and (or) consequences is noted, the cause of the CB can be identified.

A third method of functional assessment is EFA. This method has the most available research, and has been very important for establishing the environmental conditions that can cause and (or) maintain CBs. This method is time intensive, taking many hours of introducing contrived situations to mimic real-life events that produce CBs. Different conditions are paired with each CB to determine which condition is most likely to elicit the CB. Conditions typically include attention, escape, tangible, and alone. For example, if CB was maintained by self-stimulation, the alone condition would result in the highest rates of CB. However, owing to the time-intensive nature of EFA, it is rarely used outside of university laboratories or inpatient university hospital settings (see Iwata et al²⁵ for a more detailed description of EFA).

The most viable, quick, and widely used method of functional assessment in a clinical setting is one of the specific rating scales. The measure with the best psychometrics is the QABF.^{10,26-31} The QABF has well-established reliability and validity and can be completed and scored in 15 to 20 minutes. The test has 5 factors, which have been developed based on the EFA: attention, escape, physical (that is, the person is acting out owing to pain), tangible (that is, seeking food or other items), and nonsocial (that is, often self-stimulation).³²

For the clinician, the best approach to functional assessment of most patients will likely be a combination of 2 or 3 methods (for example, a rating scale in addition to a scatterplot and [or] ABC chart). For most patients, this method will result in the identification of maintaining variables. When environmental causes are identified, psychologically based interventions that directly address the cause should be put in place. For example, an escape function owing to loud noise may mean attempting to alter the environment by offering activities in less congested areas. If an escape function is due to activities that are onerous, changing the activity or providing a denser reinforcement schedule may be in order. This technology

is essential and should be considered before prescribing a pharmacotherapy treatment approach.

Inadequate Monitoring of the Therapeutic Window

An endemic problem in pharmacotherapy research and practice is the failure to assess for cost (for example, side effects) and benefits (for example, deceleration of frequency and intensity of CB). Typically, psychotropics are deemed effective if the CB decreases in frequency and (or) intensity. Sedation may have an effect on memory and learning, as well as frequency and (or) intensity of CB. However, sedation and long-term neurological effects, such as tardive dyskinesia, are rarely assessed systematically.^{33,34} We argue that such an evaluation should be mandatory as a means of taking a more holistic, balanced approach to treatment effectiveness.

Modification of Treatment Plan Based on Anecdotal Information, Compared With Objective Data

In many cases, the clinician will spend time conducting a functional assessment and developing and implementing a treatment plan, but will fail to include a formal data collection system. Although staff and individual reports may be useful for delineating changes that have improved quality of life, objective data are crucial for guiding treatment. Staff or parent reports may also be flawed in different ways. In the case of high-frequency, severe CB, staff may be unable to detect small decreases in frequency without objective frequency tracking. Conversely, by merely investing time and effort into a treatment plan, staff may detect a placebo effect and report improvements in behaviour despite no objective evidence of decreases in frequency or severity. Therefore, data collection is important for the clinician and for demonstrating change (or lack thereof) to the caregiver. Through direct observation and use of time sampling, or other ways to count frequency data, the clinician can assess the effectiveness of the intervention and make decisions regarding modifications to, and termination of, the treatment plan.

What Works and What Does Not

Numerous treatments have been proposed to address CBs in people with IDs. However, in addition to techniques with empirical support, there are also techniques that have gained popularity despite little evidence for their effectiveness. Below, common treatment techniques and research regarding efficacy are reviewed.

Behavioural Treatments

PBS was developed in the late 1980s in response to arguments against aversive techniques.³⁵ The emphasis of PBS is to incorporate nonaversive behavioural interventions with increasing respect, improving interpersonal relationships, and building personal competency. Tenets of ABA are often the behavioural components included in PBS. The least restrictive behavioural intervention that is effective should be used. Research has supported the efficacy of many nonaversive behavioural interventions for various CBs.³⁶⁻³⁸

However, ABA researchers acknowledge that there may be cases where more restrictive, and sometimes aversive, behavioural interventions are needed (as discussed later).

DR is a commonly used nonaversive behavioural technique used to decrease CB. There are 4 types of DR: DRI, DRA, DRO, and DRL. DRI involves reinforcing behaviour that cannot be emitted simultaneously with the target behaviour (for example, reinforcing appropriate vocalizations while extinguishing inappropriate vocalizations). DRA is similar to DRI in that an appropriate behaviour is reinforced; however, the appropriate behaviour does not have to be incompatible with the target behaviour (for example, rewarding staying on-task while extinguishing inappropriate vocalizations). DRO reinforces specific time intervals during which the target behaviour does not occur, regardless of other behaviours. DRL is used with behaviours that occur at high rates and when the goal is to reduce, not eliminate, the occurrence of the target behaviour. DRO and DRA, respectively, are the most commonly used techniques in eliminating CBs.³⁹

The effectiveness of DR techniques has been demonstrated across numerous studies. Chowdhury and Benson³⁹ conducted a review of case studies employing DR as both solo and combined treatment interventions for adults with ID. Overall, they found that DR, both alone and as part of a treatment package, was effective in reducing or eliminating CBs in most people. The target behaviours included SIB, rumination, inappropriate vocalizations, aggression, pica, disruptive behaviours, hand mouthing, stripping, trichotillomania, and property destruction. All of the participants had varying levels of IDs and the target behaviours varied in frequency and severity. While limitations exist with these data, as with any group of studies, the results of the review provide strong evidence that DR is an effective behavioural intervention for people with IDs.

Despite the support for the efficacy of behavioural principles about reinforcement and extinction for decreasing CBs, there are some instances where these techniques appear ineffective. Neidert et al⁴⁰ note several factors that may contribute to problems with using reinforcement. One common problem is the use of inappropriate stimuli. Items considered reinforcing to typically developing people may not be reinforcing for people with IDs. For example, while praise and social touch (for example, a pat on the back or a hug) may be pleasant for one person, a person with a tactile aversion may find it unpleasant. Without a preference assessment, it may be difficult to identify adequately potent reinforcers. Even once an appropriate reinforcer is found, problems with satiation may occur.⁴¹ For example, if a person has just eaten lunch, an edible reinforcer may be less potent than when the person is hungry. The same factors apply for nonedible reinforcers. Therefore, it is important to have multiple reinforcers that can be alternated and to closely monitor the effectiveness of the reinforcer during treatment. An additional issue with reinforcement concerns whether the CB is the result of a skill, compared with a motivational deficit.⁴⁰ That is, an individual may exhibit aggression to escape work tasks because they

do not possess the skill to appropriately communicate or because it is a more effective technique (that is, easier, faster, and provides immediate results). In the situation of a skill deficit, successful treatment must include teaching an appropriate replacement behaviour so that reinforcement can be delivered appropriately.

In addition to ABA principles of reinforcement and extinction, a multitude of other behavioural treatment techniques have been employed in an attempt to address CBs in people with IDs. Anger management training has been used in many cases where aggression is a target behaviour for people with mild and moderate IDs. Rose et al⁴² conducted an anger management group for people with IDs and their caregivers. Through an intake assessment, personal journal writing, and staff interview, clinicians were able to gather information regarding the nature of the CBs and antecedents. Self-reports of emotion were also given by the participants to connect occurrences of CBs to emotional states. Role-playing with caregivers was conducted for the participants to observe, and then the therapists would troubleshoot real scenarios that had occurred in the participants' lives during the week. Following the group training, measures of anger and depression indicated improvements for participants, compared with a wait-listed control group. However, there were several limitations to their study.⁴² The authors did not keep data on the frequency of CB to determine if a reduction in anger resulted in a decrease in aggression. Staff report did indicate anecdotal evidence of fewer incidents of aggression. In addition, many behaviour interventions were put in place during the group training to target the behavioural triggers identified. Nonetheless, their study demonstrates that people with mild and moderate levels of ID are capable of insight into their emotions and the connection to their target behaviours.

Relaxation training is another technique sometimes used to address CBs. The Snoezelen room is a specific sensory environment often used with people with severe and profound levels of ID as a form of relaxation and sensory integration. It is generally a dark room with multiple forms of sensory stimulation (for example, music, light-up objects, vibrating objects, and spinning lights). While studies of the Snoezelen room have produced lower rates of CBs while in the room, the rates of CBs typically return to baseline once the person is back in their typical environment.⁴³ While the Snoezelen room may be a useful component of a person's daily schedule for relaxation and sensory enjoyment, it should not be considered an effective intervention for CBs. In fact, use of a Snoezelen room in response to an individual engaging in CB may serve to reinforce the CB. Thus caution should be exercised when recommending the use of such a room, and therapists should be clear about the primary goal of such an intervention.

While the least restrictive model is considered best practice for managing CBs in people with IDs, there are severe instances where more aversive techniques must be employed for the safety of the individual and others. Methods, such as response-cost and overcorrection, have been added to

PBS techniques that were not successful alone for reducing CBs. The use of more restrictive interventions is acceptable when clinically warranted. The technique most often debated is the use of restraint.⁴⁴ Used inappropriately, restraint can result in many negative effects, including both physical and emotional trauma. As a result of the risks associated with restraints, many developmental centres have eliminated their use. However, eliminating restraint without an appropriate alternative also involves risk of injury from severe CBs. Williams⁴⁴ outlines several techniques that have been used to successfully reduce and eliminate restraint, including gradual fading of the restraint, staff and (or) caregiver education, prevention strategies aimed at triggers, using time, compared with response, contingent release from restraint procedures, and successful behavioural treatments. That said, caution should be exercised when incorporating no-restraint policies into treatment. For example, support staff may fear that even appropriate use of restraint during crisis situations may be punished and therefore delay or avoid its use during dangerous episodes of CB. It is the policy of many professional groups that the rare use of restraint of patients with severe CBs where behavioural and (or) pharmacological interventions do not adequately reduce the severity of a behaviour that places the individual and others in imminent danger is acceptable. Professional clinical judgment should be exercised in these patients with severe CB.

Pharmacotherapy

Prescription of psychotropics to manage CBs has become a common practice for people with IDs. This is concerning for several reasons. People with IDs may react differently to psychotropics, compared with people with typical development.⁴⁵ To begin, people with IDs already exhibit impairments in memory, learning, and motor skills that may be further exacerbated by medications, with side effects also affecting these skills. There is also significant comorbidity with medical issues in people with IDs, further complicating side effects and potential interactions with psychotropics and other medications that are prescribed for these medical conditions.

Research has been mixed, at best, regarding the efficacy of medication use for CBs in people with IDs. Numerous reviews of psychotropics have been conducted and, overall, the results have suggested a need for more rigorously controlled studies, use of placebo control groups, and long-term follow-up to assess the benefits and side effects of this group of interventions.^{45–50} Why, then, do psychotropics continue to be prescribed for this population? First, Turk et al.⁵¹ note that there is often pressure on psychiatrists from caregivers and other professionals to address behavioural issues using medication. As Matson and Wilkins⁵² point out, many support staff have limited training in alternative methods, making carrying out behavioural intervention in developmental centres and community homes difficult. As a result, many staff will often turn to psychiatry to prescribe medication as an easy fix.

Note that not all use of psychotropics in people with IDs is inappropriate. There is high comorbidity with psychiatric disorders and IDs, which may require the use of psychotropics to manage psychiatric symptoms.^{48,52,53} In addition, in people with severe CBs, where behavioural interventions have been minimally effective, psychotropics may be warranted, even if the effects are primarily sedative in nature. That said, in patients where an environmental factor underlies the CBs, behavioural interventions should be the first line of treatment. However, in some instances, pharmacotherapy may be a helpful additional therapy. Coordination across disciplines is very important in these instances.

Conclusions

CBs are a common and troubling issue when working with people with IDs. CBs further exacerbate impairments in social relationships and can harm a person's chance of living successfully in the community. Fortunately, there is a wealth of research focused on finding effective treatments to improve the quality of life for these people and their caregivers. Behavioural interventions are regarded as the first line of treatment for most CBs and have been found to be highly effective across various behaviours and settings. In cases where psychiatric comorbidity and (or) severe CBs complicate behavioural treatment, psychopharmacology may be a useful addition to the treatment program. Only through clinical investigation, functional assessment, data-driven decision making, and professional collaboration can a truly effective treatment plan be developed and successfully implemented.

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