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COMMENTARY

Pediatric Pain and Neurodevelopmental Disorders: Implications for Research and Practice in Behavior Analysis

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Abstract

Individuals diagnosed with a neurodevelopmental disorder also are commonly diagnosed with a medical comorbidity. Because of this, it is estimated that this population experiences nearly twice the incidence of pain or discomfort as their neurotypical peers. Although behavior analysts consider the effect of biological variables on a client's behavior, considerations of pain appear to be underdiscussed and understudied. The purpose of this article is to discuss how pain may interact with the efficacy of behavior analytic assessments and treatments, provide potential solutions to the barriers associated with pain states, and describe avenues to promote clinical research to improve our behavior analysis of pediatric pain while developing treatments for behavior problems such as aggression.

Keywords autism spectrum disorder · comorbidities · health · neurodevelopmental disorders · pediatric pain · private events

Consideration of biological variables is essential for effective behavior analytic assessment and treatment. One understudied biological variable may be the role of pediatric pain in individuals with neurodevelopmental disorders (NDs), such as autism spectrum disorder (ASD).[1] Physicians believe that individuals with NDs are

[1] Given the relevance of ASD to most behavior analytic scientist-practitioners (Behavior Analyst Certification Board [BACB], n.d.), many of the examples within this commentary will highlight the impact of pain on behavior analytic services with individuals with ASD; however, we posit that our behavior analysis of pain is relevant to most individuals with neurodevelopmental disorders.

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predisposed to more severe and a higher incidence of pain compared to their neurotypical peers (Walsh et al., 2013). In fact, individuals with a ND are 12% more likely to injure themselves (or experience acute pain; Jain et al., 2014) and 40% more likely to experience chronic pain (Petersen et al., 2006). Consideration of pain is important as the occurrence of pain disrupts an individual's quality of life by negatively affecting sleep quality and participation in school, social, and physical activities (Palermo, 2000). On a familial level, recurrent pain states can exacerbate a caregiver's already heightened predisposition to stress (Walsh et al., 2013) and other psychological issues, such as depression (Schreibman, 2000).

Despite the establishment of an ethical guideline to consider biological variables in assessment and treatment (cf. *Ethics Code for Behavior Analysts*; BACB, 2022), behavior analysts likely have received little guidance on how to effectively consider, manage, and treat their client's pain states. To our knowledge, there are few educational resources for behavior analysts on how to effectively manage pain states within a multidisciplinary team (but see, for example, Newhouse-Oisten et al., 2017, for a discussion on interdisciplinary collaboration for medication). Furthermore, there seems to be a paucity of research related to the assessment and treatment of behavior problems in NDs with consideration of pain. In behavior analysis, pain has been evaluated more often in the basic (e.g., Azrin et al., 1963, 1964; Manning & Vierck et al., 1973) than applied literature (see Carr & Owen-DeSchyver, 2007, as a notable exception). Although there is ample research on pain management for adults with NDs (Gatzounis et al., 2012) and developing evidence of the role of pain in the occurrence of problem behavior (e.g., May & Kennedy, 2010), behavior analysts have not fully explored or developed comprehensive bio-behavioral assessments and treatments, as called for by Cataldo and Harris (1982) four decades ago. The lag in its development may be due to the difficulty associated with assessing and then intervening on private-events, like pain-related responses.

We pose that there are at least five pain-related barriers when considering pain as behavior analysts. First, deficits in social communication skills commonly observed in individuals with a ND (Moore, 2015) likely mean the child does not have the skills to tell someone they are in pain, which, in turn, affects their ability to request help to attenuate the pain state. Deficits in social communication also may pose a challenge in successfully teaching these skills. Second, ASD diagnostic criteria related to hyper- or hyporeactivity to sensory experiences may reduce attentiveness on the part of medical professionals. Third, research suggests that pain states may manifest as increases in problem behavior, like crying, aggression, self-injury, or stereotypic behavior (May & Kennedy, 2010); such behavior may further impede an individual's health and quality of life. Fourth, an increased probability of problem behavior due to the incidence of pain may impede accurate behavior analytic assessment of environmental variables that contribute to maintenance of the behavior. Finally, pain also likely has an interaction effect with behavioral treatment, which may limit the efficacy of our interventions. In sum, pain can impede the accuracy and success of behavior analytic assessment and treatment.

Given the high likelihood that individuals with NDs experience acute and chronic pain states and the likelihood that they are unable to tact pain states, it is important that behavior analysts understand their professional role in incorporating pain variables into the behavior analysis of their client's pain. This means clinicians and researchers need to begin, or advance, their exploration on the assessment and treatment of pain in individuals with NDs. The purpose of this article is to, first, describe the impediments to incorporating variables related to pediatric pain into our assessment and treatment and, second, to propose potential solutions to those impediments as behavior analysts are well poised to improve our understanding of the effects of pediatric pain on accurate assessment and treatment of problem and prosocial replacement behaviors.

Overview of Pediatric Pain in Neurodevelopmental Disorders

The more affected an individual is by a disability, the less likely health problems will be diagnosed and treated (Symons et al., 2009). This is problematic because undiagnosed and untreated health problems may reduce an individual's life expectancy and increase the probability of health complications (Cooper et al., 2004). Common health comorbidities experienced by individuals with NDs include, among others: gastrointestinal problems (e.g., constipation, diarrhea, reflux, vomiting, and abdominal discomfort; Horvath & Perman, 2002), allergies (e.g., respiratory, food, and skin; Gurney et al., 2006), seizure disorders, hormonal imbalances, and recurrent infections (Bauman, 2006). In a recent review by Al-Beltagi (2021), comorbidity prevalence data show that individuals with NDs, when compared to neurotypical children, "are 1.6 times more likely to have eczema or skin allergies, 1.8 times more likely to have asthma and food allergies, 2.1 times more likely to have frequent ear infections, 2.2 times more likely to have severe headaches, 3.5 times more likely to have diarrhea or colitis, and 7 times more likely to report gastrointestinal problems" (p. 16). Moreover, co-occurring medical conditions have been positively correlated with the age of a child, their diagnostic rating of level of severity of ASD, and the use of pharmacological agents (Brondino et al., 2019). Some research suggests that the prevalence of chronic pain in children with NDs is as high as 73% compared to approximately 33% of neurotypical individuals (Petersen et al., 2006). For children with NDs these co-occurring medical conditions frequently go undetected; that is, they present with occult, or hidden, medical conditions. Occult medical conditions are prevalent among children who are nonverbal or possess limited language skills (Copeland & Buch, 2020). Untreated medical comorbidities can negatively affect a child's developmental progress and severely compromise their learning (Copeland & Buch, 2020).

Depending on the underlying cause of pain, children may experience different types of pain sensations. Understanding the different pain states is essential for clients to effectively communicate their symptoms to medical professionals and may also benefit how we teach them to tact and alleviate pain. First, pain is typically categorized into two types: acute or chronic pain. Acute pain is short-term pain that occurs suddenly and has a specific cause, like tissue damage (Cheng, 2018). Acute pain tends to be described as "sharp" or "intense" and gradually goes away across time. However, it is common for acute pain to reoccur, wherein it is commonly described as recurrent pain (Allen & Mathews, 1998). Acute and recurrent pain states typically have an identifiable etiology that can be addressed medically or through environmental modifications. In contrast, chronic pain is categorized as pain that lasts for longer than 6 months, even after the original injury has healed (Cheng, 2018). The proximal cause of chronic pain may not be as easily identifiable as acute or recurrent pain thereby reducing the probability of preventing the onset of pain and potentially making it less responsive to common medical treatments. Chronic pain is more likely to affect an individual's quality of life, as described above. Physicians further delineate pain types by describing four different sensations of pain. First, nociceptive pain is typically described similar to acute pain in that it is commonly the result of tissue damage, like falling or postsurgical pain (Cheng, 2018). Second, neuropathic pain is caused by nerve irritation and is often described as "burning," "tingling," "stabbing," or "pins and needles" (Cheng, 2018). Third, idiopathic pain is pain that persists after trauma or arises without any apparent cause (Cheng, 2018). That is, physicians are unable to detect the source of the individual's pain. Fourth, psychogenic pain is pain caused or exacerbated by mental, emotional, or behavioral factors. Common examples of psychogenic pain include headaches, muscle pain, back pain, and stomachaches, which are diminished or eliminated when the psychological factors are resolved. It should also be noted that sometimes individuals also experience mixed pain or multiple forms of the aforementioned pain states (Cheng, 2018). One example of this is individuals diagnosed with fibromyalgia who typically describe their pain as neuropathic; however, the specific source of the pain is difficult to locate (idiopathic), and their pain can be exacerbated by mental and emotional factors (psychogenic). Each of these subcategories of pain are likely experienced by an individual with NDs and understanding its origin may help our understanding of how to teach our clients how to prepare and cope with its occurrence.

Barriers to Assessment and Treatment

Deficits in Social Communication

Given the private—or covert—nature of pain, the importance of communication skills is apparent. In addition to the ability to discriminate the occurrence of pain, communication skills are essential to describing the type, severity, and location of pain; requesting assistance with pain management; and then communicating the efficacy of the pain management interventions used. As such, communication is critical for pain assessment and management (Henry & Matthias, 2018), and verbal self-report of pain is still commonly relied upon by practitioners (Failla et al., 2020). This complicates pain management for individuals with ASD in particular, because deficits in social communication is one of the diagnostic criteria (Moore, 2015). In particular, individuals with ASD demonstrate difficulties in expressive (mands, tacts, intraverbals) and receptive (listener) language (Sundberg, 2008). These deficits typically produce barriers for children with ASD by affecting their ability to engage in social interactions and communicate their wants and needs. As such, the complexity of communicating pain states affects and sometimes completely removes the opportunity for individuals with deficits in social communication skills to receive effective pain management.

In addition to deficits in social communication, individuals with NDs typically demonstrate disordered patterns of nonverbal communication. This may be problematic as children with NDs may not show typical nonverbal cues of pain and discomfort, like facial expressions (Liu et al., 2020). For example, researchers have found that the severity of the ND can negatively affect the accuracy of a caregiver's ranking of their child's pain when using common pain assessment scales (e.g., The Non-Communicating Children's Pain Checklist [NCCPC-R]; McGrath et al., 1998). Furthermore, caregivers of children with NDs are commonly concerned that they cannot tell when their child is in pain or not feeling well (Courtemanche & Black, 2016). These deficits may reduce the accuracy of a caregiver's pain assessment and then reduce the immediacy of pain management strategies (Prkachin & Craig, 1995). Thus, deficits in pain communication and expression can negatively affect the immediacy and quality of care for children with NDs.

Effect of Diagnosis on Medical Treatment

Pain is one of the most common reasons for an individual to seek assistance from a health-care professional (Prkachin & Craig, 1995). As such, the individual or their caregiver's ability to effectively describe the pain state experienced or express the severity of pain is of the utmost importance for efficient and accurate pain management. However, as previously discussed, it is likely that social communication deficits displayed by individuals with NDs greatly affects the accuracy of pain assessment and immediacy and efficacy of pain management. A second core diagnostic characteristic of ASD is restricted and repetitive behaviors. One area of restricted, repetitive behavior criteria highlighted by the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (*DSM-5*; American Psychiatric Association, 2013) is sensory sensitivity. In particular, the *DSM-5* suggests common among individuals with ASD is hyper- or hypoactivity to sensory input or unusual interest in sensory aspects of the environment. Clinicians frequently cite reduced sensitivity or indifference to pain as a characteristic meeting the sensory sensitivity criteria (Failla et al., 2020). Because individuals with ASD may not express their physical discomfort in the same way as their neurotypical peers (e.g., crying, moaning, seeking comfort), caregivers and medical professionals are likely to interpret this as pain insensitivity, or they otherwise assume that the child is not in pain (Allely, 2013). Such misinterpretations and assumptions are potentially problematic because there is little evidence to suggest that the absence of overt responsiveness to pain is indicative of an increased pain threshold or the absence of pain experiences (Failla et al., 2020). This stereotyped belief likely reduces the accuracy of medical professionals' assessment of pain states in individuals with NDs (Barney et al., 2020).

Pain Manifesting through Problem Behavior

Albeit limited, some research suggests that increases in problematic behavior likely serve as an indicator of pain and discomfort (May & Kennedy, 2010). For example, using functional analysis methodology, Kennedy and Meyer (1996) demonstrated increases in arm and hand biting on days when one participant (Rudolfo) expressed allergy symptoms (swollen, reddened, and irritated eyes) compared to days when the symptoms were not present. On a larger scale, Carr and Owen-DeSchryver (2007) reported higher rates of problem behavior across 12 individuals with NDs on days they were reportedly sick. Perhaps an even more concerning outcome of the study was they reported greater frequency and intensity of problem behavior the higher the level of pain the child was experiencing. In addition to allergies and illness, elevated levels of problem behavior also have been associated with otis media (deLissovoy, 1963), fatigue (Smith et al., 2016), sleep deficits (O'Reilly & Lancioni, 2000), constipation (Christensen et al., 2009), gastroesophageal reflux disease (GERD; Kennedy & Thompson, 2000), and menses (Taylor et al., 1993; Carr et al., 2007). Given the small number of studies that have evaluated the effect of pain and discomfort states on problem behavior compared to the commonality of medical comorbidities in children with NDs, it is likely that the prevalence of this phenomenon is greater than currently reported.

Another consideration related to pain sensitivity is that if, in fact, a particular individual is hypersensitive to pain it is likely that escape behavior would emerge in the context of social or instructional interaction involving physical contact. Although such interactions between hypersensitivity to pain and socially mediated negative reinforcement contingencies have not been clearly delineated through empirical research, combining what is known about pain sensitivity and negative reinforcement relations for severe behavior disorders is a direction for future research.

Pain as an Impediment to Assessment

Pain and discomfort also can hinder accurate functional behavioral assessments, skills assessments, and preference assessments. First, it has been demonstrated that pain and discomfort interact with socially mediated operant contingencies of reinforcement. Kennedy and Meyer (1996) revealed that the value of escape as negative reinforcement increased when Rudolfo was experiencing allergies. Escape may also increase in value solely due to the presence of pain. For example, O'Reilly (1997) demonstrated that back banging and ear poking (which occurred simultaneously) only occurred when a young child (Mary) was experiencing an ear infection. Problem behavior was further exacerbated when loud music was played, and increased response efficiency was observed when the researchers turned the radio off contingent on self-injury. This phenomenon was replicated in a later study (O'Reilly et al., 2000). Escape-maintained behavior, such as inappropriate mealtime behaviors, may persist even after the source of pain has been resolved (Ibañez et al., 2020). As described by Ibañez et al. (2020), children with medical comorbidities, like food allergies, may associate mealtime with pain and refuse food to avoid pain. Escape-maintained inappropriate mealtime behavior may generalize to other foods and result in persistent food refusal or picky eating even after the trigger foods are identified and removed (Ibañez et al., 2020). Although it has not been documented in the literature, to our knowledge, attention may also increase in value as a reinforcer. For example, a child seeking a caregiver's comfort when in a pain or discomfort state.

Second, it is unknown how often pain and discomfort manifest in the form of automatically reinforced behavior. Although automatic reinforcement subtype research by Hagopian and colleagues (Hagopian et al., 2015, 2017) has progressed our understanding of resistance to treatment based on patterns of responding during a functional analysis, behavior analysts are still largely unable to distinguish between positive (sensory) and negative (pain attenuation) automatic reinforcement. Furthermore, assessment methodology is lacking means of identifying specific sources of pain that contribute to severe behavior. For example, even when self-injury occurs at high levels in an "alone" or "no interaction" conditions (a test for automatic reinforcement), it is rarely known why the behavior persists in the absence of social reinforcement. As such, it is possible that pain and discomfort may serve as an establishing operation for automatic reinforcement, and then pain attenuation (counterintuitively) takes the form of self-injurious behavior (Cataldo & Harris, 1982). For example, a child may scratch or skin pick due to a rash, eye gouge due to seasonal allergies, or chin hit due to tooth pain (Breau et al., 2003). Much more research is needed on the relationship between pain location and response topography in the study of self-injury.

Finally, pain and discomfort may interfere with the accuracy of skills assessments and preference assessments. For example, a child experiencing a migraine or fatigue may not respond when asked to engage in a listener response task, resulting in poorer performance. Attention or highly preferred items may also increase in value in the context of pain and discomfort resulting in false positives during a preference assessment. As an alternative, a child may allocate away from food as a reinforcer and select leisure items if experiencing constipation (Ibañez et al., 2020). Children with a history of pain associated with food may also refuse to participate in a food-based preference assessment altogether (Zeleny et al., 2020). In sum, there are numerous ways pain and discomfort can affect the accuracy of behavioral assessments.

Pain as an Impediment to Treatment

Research suggests that pain from various health problems can adversely affect the efficacy of behavioral interventions for individuals with NDs (Carr & Owen-DeSchryver, 2007). Sometimes the effect of pain or discomfort on the efficacy of a behavioral intervention may be temporary until the ailment has been resolved. For example, Lichtblau et al. (2018) observed a temporary decrement in the efficacy of an intervention for a child's trichotillomania and trichophagia when the child was sick. In contrast, the failure to consider the occurrence of pain and discomfort also may result in long-term insufficient or ineffective treatment outcomes, especially if the root cause of the pain has not been addressed. For example, a commonly indicated treatment for escape-maintained problem behavior is escape extinction (Geiger et al., 2010); however, implementation of escape extinction for children experiencing pain and discomfort more than likely is a contraindicated treatment and poses an ethical challenge. That is, implementation of escape extinction for Rudolfo (Kennedy & Meyer, 1996) or Mary (O'Reilly, 1997) likely would result in increased rather than reduced rates of problematic behavior. Even if the behavior is extinguished, the root cause of the behavior (e.g., ear infection) is not addressed by an extinction-based treatment. As another example, consider a child with feeding difficulties. Similar to the treatment of severe problem behavior, the most efficacious treatment for feeding disorders is escape extinction (Volkert & Vaz, 2010). However, if the child experiences food allergies or GERD, then the implementation of escape extinction would not reverse the established aversive properties of food but instead may exacerbate it (Ibañez et al., 2020). A more ethical approach, which is required by our ethics code when a medical condition contributes to maintenance of the behavior, would be to identify and avoid presentation of the triggering foods and intervene with safe foods (Kennedy & Richman, 2019).

For automatically reinforced behavior, environmental enrichment is commonly recommended as a treatment, and, as a sole intervention, it is effective 41% of the time (Gover et al., 2019). When ineffective, more researchers evaluated the additive effects of punishment alone compared to reinforcement-based procedures or a combination of reinforcement and punishment-based procedures (Gover et al., 2019). Similar to the use of extinction, implementation of punishment procedures as an intervention would violate our ethics code when behavior is exacerbated or a result of the presence of pain or discomfort. Even if provision of highly preferred toys and other materials suppresses problem behavior, such an intervention potentially masks the root cause of the behavior, which may in turn go undetected. Finally, often functional analysis and behavior reduction studies do not fully describe the steps taken to rule out medical concerns prior to implementing treatment. Therefore, it may not be evident to clinicians (who rely on our literature base to develop intervention plans) that biological explanations for the behavior have been ruled out. In summary, the failure to address the pain state poses an ethical challenge when other interventions, even nonintrusive interventions like environmental enrichment, are used if the source of the pain is left untreated.

Next Steps and Considerations for Research and Practice

Coordination of Care

Given the high rates of comorbid health issues observed in individuals with NDs and given the hypothesis that the etiology of some cases of self-injury may be related to pain (Cataldo & Harris, 1982), it is imperative that behavior analysts coordinate care with physicians and other health professionals to consider the role of pain. Prior recommendations on effective collaboration have been largely limited to when the client is taking psychotropic medications (Li & Poling, 2018; Newhouse-Oisten et al., 2017), which means there is presently little guidance on how to effectively navigate collaboration with biobehavioral interventions. A full discussion of considerations and guidelines when coordinating care with physicians is out of the scope of this article; however, we aim to provide general recommendations for scientist-practitioners.

It cannot be denied that medical clearance prior to certain behavior analytic assessments and treatments is essential. One example of when it is necessary is prior to a functional assessment of a problem behavior in which pain could conceivably contribute to the maintenance of the behavior. This includes behaviors that appear to be automatically reinforced and behaviors maintained by social contingencies. For example, self-injurious behavior directed toward the eyes, ears, chin, and head may indicate the presence of allergies, infections, or headaches. Pica may be indicative of a nutritional deficiency (Fields et al., 2021) or necessity for dental intervention (Singh et al., 2015). Bruxism (teeth grinding or clenching) also may indicate a need for dental intervention (Lang et al., 2009). Aggression or inappropriate mealtime behaviors associated with food may be indicative of dental pain, swallowing problems, digestive problems, constipation, or many other sources of pain or discomfort (Ibañez et al., 2020). Thus, medical clearance also is essential prior to any treatment of food refusal or selectivity (Ibañez et al., 2020). This includes clearance from a physician, swallowing expert, and potentially an allergist. In addition, a scientist-practitioner may seek medical clearance, or at least inquire about wellness, prior to beginning toilet training (see Call et al., 2017, for a more in-depth rationale).

We pose two general recommendations when navigating clearance with the child's medical providers. First, we recommend obtaining and reviewing the child's medical records with their caregiver prior to beginning behavior analytic services. A thorough medical review will improve a behavior analyst's understanding of how some medical comorbidities may influence the child's problem behavior and development of adaptive behaviors. Second, we recommend the behavior analyst attempt to establish a collaborative relationship with the child's medical provider. However, if not feasible, we recommend the behavior analyst take special consideration in coaching caregivers prior to the medical appointment. This includes the behavior analyst developing specific, rather than general, questions to rule out a medical cause for the behavior. General questions like "Is there a medical explanation for this behavior?" or "Can we conduct a functional analysis for this behavior?" may not offer sufficient information for the medical provider to appropriately clear the patient. Therefore, more specific questions related to the child's comorbidity or a potential root cause of the behavior may produce a more thorough medical evaluation (e.g., allergy testing, sleep study). For example, consider a child with chronic constipation (as revealed by a review of the child's medical chart) who is demonstrating increased problem behaviors that seem to surround mealtime. The behavior analyst has the resources and training to collect and then disseminate rates of problem behavior prior, during, or after meals or even rates of problematic behaviors just before and after bowel movements. Detailing this information to the physician and asking about a potential biological cause for the behavior will likely greatly improve the efficacy of the consultation and access to accurate assessment and intervention. In general, the more description the behavior analyst can provide, or coach the caregiver to provide, the better. This includes describing the frequency, intensity, duration, quality, associated accompaniment behaviors (e.g., grimacing), or operant pain behaviors (e.g., aggression to get out of mealtime). In addition, we recommend providing a description of the location and topography of the behavior as those factors may also be important (Rooker et al., 2020; Symons & Thompson, 1997). Although there is some evidence suggesting that location and topography of the behavior may indicate a biological underpinning for the behavior (Breau et al., 2003), this does not negate the necessity for further behavioral assessment prior to developing behavioral interventions.

Collaboration with medical professionals also may be necessary when developing and implementing the child's behavior intervention plan (Cox, 2012). That is, collaboration with medical providers should not cease after initial clearance. Similar to how behavior analysts may continue to coordinate care with prescribing physicians (Newhouse-Oisten et al., 2017), behavior analysts may consider continuing to update physicians on the efficacy of medical interventions on behavioral interventions. Because behavior analysts have the capacity to take data on patterns of overt behaviors, they can assist the caregiver in advocating for their child and assist the physician in improving the quality of their patient's care. This type of coordination may be especially important when the child suffers from recurrent pain but does not have discriminable expressions of pain. For children with advanced verbal behavior, continued coordination with medical providers may be important when operant pain behaviors (e.g., avoidant or escape behaviors like skipping school) continue to persist despite presumed effective medical intervention (see Allen & Mathews, 1998, for a more in-depth discussion). It is also important to note that collaboration with the child's other providers (e.g., speech language pathologists, occupational therapists, physical therapist) may support programing and considering pain management. For example, physical therapists can assist with teaching behavior analysts how to incorporate stretches into play-based instruction to help an individual manage their pain (Peranich et al., 2010) or they may assist with guidelines for physical activity for individuals with physical disabilities. In sum, collaboration with other disciplines can ensure behavior analysts maintain a therapeutic environment.

When beginning the interdisciplinary collaborative process, it is essential that behavior analysts also confirm feasibility of medical collaboration with their clients and the client's caregivers. There are large disparities of access to health care in the United States. Location of the family's primary care provider, cost of an appointment, and the hospital or clinic's availability are all factors that tend to be controlled by, or at least highly correlated with an individual's identity. Wisniewski and Walker (2020) found that Black and Hispanic simulated callers were more frequently asked about their insurance status and offered appointments further in the future compared to their white counterparts. As such, behavior analysts should do their due diligence to confirm the necessity of the medical clearance through a caregiver interview and medical chart review in order to equitably support all of their clients in the face of potentially disparate health care access.

Collaboration with the Child's Caregiver

Prior to initiating a coordination of care, the behavior analyst should gather as much information as possible surrounding the child's pain states and related pain behavior. Who the behavior analyst interviews will be dependent on the child's current communication skills. That is, the behavior analyst may interview the child, the caregiver, or both. The child's caregivers are often relied upon for pain assessment by physicians (Genik et al., 2018) and are asked to distinguish between their child's pain experience and pain expression. As such, we recommend conducting an interview with the child's caregiver despite instances wherein the child demonstrates a strong communication repertoire. Through the interview, the scientist-practitioner could assess how the caregiver can identify if their child is in pain. These variables may include asking about particular past or current illnesses, increases or suppressions in behavior, or changes in body language (Parsons et al., 2012). Perhaps identifying variables when the caregiver knows the child is happy or pain-free may also be beneficial (e.g., Parsons et al., 2012).

For caregivers, ensuring they can identify when their child is in pain is essential. If they are unable to identify common pain variables, perhaps a training similar to Delgado and Lutzker (1988), who taught young parents to identify and appropriately respond to their children's illness, would be an appropriate first step. Training components should first focus on teaching a child's caregivers strategies to monitor their child's current pain states. This may include monitoring the intensity of pain experienced across the day while measuring the timing and dosage of pain alleviation strategies or examining common antecedents and consequences after the pain behavior. Training content also may include teaching a caregiver to implement environmental enrichment (Ringdahl et al., 1997). Environmental enrichment may serve as a mechanism for the caregiver to rule out other environmental causes of problematic or interfering behavior. In other words, caregivers can be taught that if interfering behavior, like crying, continues despite a dense schedule of delivery of the child's reinforcers other biological variables may be the antecedent for the behavior.

Measurement of Pain States and Perception

Appropriate selection of measurement systems to identify pain states in children with NDs is essential. Pain perception is most often measured using measurement tools that rely on self-report from the person experiencing pain. However, self-reports usually do not accurately reflect current or past pain experiences (Shinde et al., 2014; Jensen & Karoly, 2011). An alternative is to measure nonverbal expressions (e.g., facial expressions; wincing) of pain. Physicians commonly rely on the NCCPC-R (McGrath et al., 1998) to measure their patient's pain (Courtemanche et al., 2016). Although the NCCPC-R has been validated with children with NDs, it has only been validated for children with NDs post-operation. As called for by Barney et al. (2020), measures of pain need to be validated for samples and settings under study. At present, it is unknown if outcomes of the NCCPC-R have been properly operationalized for verbal and nonverbal children. As an alternative, the Pain and Discomfort Scale (PADS; Phan et al., 2005) has convergent validity with the Facial Action Coding System (FACS), which is the most validated measurement system for children with NDs (Shinde et al., 2014). These are two potential options for researcher, clinicians, and caregivers interested in measuring pain in children with NDs. Careful selection of a measurement system is important so we may identify valid outcome measures for use in interventions.

Of late, there have been major advances in the physiological and neurological measurement of pain perception in children with NDs. Symons et al. (2015) investigated epidermal innervation in young children (9- to 12-years-old) diagnosed with NDs who engaged in self-injurious behavior. They tested nondamaged skin (i.e., areas wherein the children had not engaged in self-injury), and found that their two male patients with NDs were significantly more likely to have increased epidermal nerve fiber densities and mast cell degranulation compared to their neurotypical counterparts. This work by Symons et al. is early evidence suggesting that this population may perceive sensations differently and experience an increased immune response. The authors suggest this approach offers a new potential treatment avenue for treating self-injurious behavior through disruption of the inflammatory-nociceptive cycle. This is especially important given that Symons et al. (2019) found similar results when evaluating tissue from four children diagnosed with Rett Syndrome.

Improving Behavioral Assessment

Behavior analytic methodology related to data collection and assessment can vastly improve our considerations of pediatric pain. Instead of being reliant on indirect measures of pain (e.g., NCCPC-R; McGrath et al., 1998), behavior analysts have the methodology to assess common collateral responses to pain. That is, in addition to surveying the caregiver, perhaps a descriptive analysis may be informative. The use of conditional probability (the probability of a collateral response given pain) and background probability (the probability of the collateral response independent of pain; Pence et al., 2009), which are commonly identified in precursor assessments (e.g., Schmidt et al., 2020), can confirm that the collateral response is predictive of the child experiencing a pain state. Other common data collection methodologies may benefit a behavior analysis of pediatric pain. This may include monitoring increases in rates of problem behavior, measuring changes in attending to instructional activity (including latency or accuracy of responding), and measuring changes in reinforcer consumption during reinforcement periods. The implementation of scatterplot methodology, which allows for tracking changes in behavior within and across days, may be particularly useful when tracking acute or cyclical pain states such as constipation or menses.

Improved assessment surrounding the location and topography of the behavior may indicate the occurrence of pain. Rooker et al. (2020) conducted archival reviews of 23 functional analyses and found that the location, severity, and topography of self-injurious behavior were correlated with later determinations of the behavior being maintained by automatic or social reinforcement. Across the 23 cases, Rooker et al. found a higher correlation with individuals with automatically reinforced behavior repeatedly targeting a single area compared to multiple areas as observed with individuals who displayed socially reinforced behavior. Related to this, the location the child targets (e.g., ears, mouth, head, stomach) also could be indicative of specific locations of pain or discomfort states. Extending our understanding of potential relationships between location and response topography could result in earlier detections of pain-related responding (Symons & Thompson, 1997; Symons et al., 1999) and prevent pain-related responding from coming under the control of operant contingencies.

Finally, it is crucial that behavior analysts adapt functional behavior assessment methodology to illuminate the effect of pain and discomfort states on problem behavior. This may include adapting methodology used by Kennedy and Meyer (1996) by conducting trial-based functional assessments or structured descriptive assessments to detect changes in rate and possibly function during the presence and absence of known pain or discomfort states. Further analysis of periods where the establishing operation (EO) is present versus absent also may clarify controlling variables. That is, the delivery of the matched reinforcer (an EO absent period) should produce relatively quick suppression of the behavior; however, if behavior continues to occur then perhaps another variable like pain or discomfort may be influencing behavior. Embedding a concurrent-chains arrangement within the assessment, specifically contingent on problem behavior, may be beneficial because it may illuminate more potent reinforcers for the child's behavior. For example, consider a child with sleep difficulties whose behavior seems to be evoked by demands (potentially escape-maintained); however, escape alone does not suppress behavior during the EO absent periods. A clinician may consider a concurrent chains arrangement wherein the child could select receiving a denser schedule of positive reinforcement, like contingent tangibles rather than praise, or to lay down and turn off the lights. This may suggest that the root cause of behavior is due to insufficient positive reinforcement or a biological variable, like lack of sleep, or (perhaps most likely) some combination.

Incorporating Pain Alleviation into Behavioral Interventions

It is essential that behavior analysts consider the role of pain and discomfort when developing behavioral interventions. In cases, like Mary's (O'Reilly, 1997), wherein pain and discomfort were the direct establishing operation for problem behavior, the only ethical solution is to resolve the source of pain when possible. In cases wherein pain or discomfort exacerbates the establishing operation, not only should the behavior analyst assist with directly addressing the source of pain or discomfort but adapt the environment to accommodate the presence of pain and discomfort. That is, behavioral approaches to interventions are not necessarily contraindicated when an individual is experiencing pain, instead they should be considered as ancillary to medical intervention (Allen & Mathews, 1998). Potential ancillary interventions may include adapting the environment such that the behavior analyst embeds in denser schedules of differential reinforcement. This may include providing longer breaks or longer access to preferred items (Kennedy & Itkonen, 1993) or embedding noncontingent reinforcement (or environmental enrichment) more frequently when the individual is not feeling well (Falcomata & Gainey, 2014). Behavior analysts may also consider restructuring the therapy or school day so that there is a denser schedule of natural environmental teaching, such as during free play, at the end of the day if the child is fatigued (Bacotti et al., 2022). It is important to emphasize that these environmental manipulations are only temporary solutions until the root cause of the behavior (i.e., pain) is identified and resolved.

Given the probability that there are multiple interventions that can alleviate the child's pain (see Rosen & Dower, 2011, for a review on pharmacological and nonpharmacological approaches to pain management), behavior analysts can assist physicians by evaluating which interventions is or are most preferred by the child and caregiver. We recommend clinicians consider the child's preference for pain alleviation tactics through a concurrent-chains assessment (Hanley, 2010). For example, under situations wherein the child is experiencing pain, the scientist practitioner should provide a choice opportunity for the child to pick between the previously identified efficacious, nonpharmacological, pain alleviation strategies. For more detail regarding how to set up and when to end the assessment, we recommend the tutorial outlined by Hanley (2010).

Benefits of a Verbal Behavior Approach

In addition to assisting with temporary pain management when the individual is experiencing acute or undiagnosed pain ailments, behavior analysts may also assist with self-management strategies associated with recurrent and chronic pain. Allen and Mathews (1998) offered an approach for ancillary behavioral strategies for children with recurrent pain. These strategies include (1) prevention of antecedents or triggers that exacerbate pain-related behaviors, including elimination of those variables all together (when feasible); (2) assisting the child in developing self-regulation strategies; and (3) considering and modifying caregiver responses to pain behaviors when appropriate. We refer scientist-practitioners to the Allen and Mathews (1998) chapter for these considerations on pain management for children with advanced verbal behavior. However, for children who display minimal verbal skills, behavior analysts may consider strengthening the child's communication skills by using Skinner's (1945) verbal behavior approach as a base. There are now hundreds of studies supporting the use of Skinner's framework in teaching verbal skills to individuals with NDs (Sautter & Leblanc, 2006). Imperative after initial steps are taken to navigate the biological impact of pain on behavioral assessment and treatment, the behavior analyst should work toward teaching the child verbal skills to begin advocating for themselves. This includes teaching children to tact the presence of pain and mand for pain alleviation.

Teaching a child to state that they are in pain and where they are in pain is the first essential step in improving immediacy of pain management strategies. At present, research on teaching children with NDs to tact pain states is limited, so this represents an area of both great need and powerful potential impact. As one model for this type of work, Fitzpatrick et al. (2022) taught children with NDs to tact the presence and location of pain states through four intervention components. First, they taught the children to label body parts on others. Second, they taught the children to label body parts on themselves. Third, they taught the children to label picture flashcards of how another child was feeling. Fourth, they taught the children to label four pain relief strategies used through picture flashcards. Although they saw mastery-level responding within the four intervention components described above, observed generalization to labeling their own pain sensations and requesting relief was limited to a few instances. As an alternative, scientist-practitioners may consider teaching the child to respond to alternative private events first. For example, Rajagopal et al. (2021) used public accompaniment to teach children with ASD to tact sensations (e.g., prickly, soft) across different body parts. Although not directly targeted or addressed during their generalization tests, Rajagopal et al. reported that two out of three participants began tacting pain across numerous body parts both independently and when asked, "What hurts?" It is currently unknown why the tacts generalized to pain states for two children and not the third child. In sum, there are only a few empirical examples of efficacious procedures to teach children to tact the presence and intensity of pain. Furthermore, examples have been limited to children with language. It is imperative that behavior analyst evaluate additional strategies to teach children, especially those that are not vocal-verbal at baseline, how to tact pain sensations.

After teaching children to tact the occurrence of pain, the next step is to investigate procedures to teach children to mand for pain alleviation. As demonstrated by Balandin et al. (2007), the best predicator of pain relief is the ability to request pain relief. However, strategies on teaching these skills are limited. Perhaps behavior analysts can rely on previously published mand training procedures to teach children to mand for pain alleviation. For example, similar to how a missing item during a task evokes requests for help or access to the item (Rosales & Rehfeldt, 2007), conceivably the presence of a known pain source (perhaps with a public accompaniment, such as a sunburn) could have discriminative effects on behavior and increase the value of engaging in the next step of the behavior chain: to mand for alleviation (e.g., applying soothing ointment). Although these approaches are conceptually consistent with evidence-based behavior analytic approaches, it is clear that additional empirical support and comprehensive research programs are necessary.

Summary

Applied behavior analysis is one of the two evidence-based practices encompassing multiple interventions for individuals with NDs (Hyman et al., 2020). Over the past 4 years, the number of board certified behavior analysts has doubled (BACB, 2022), which suggests that applied behavior analysts are serving more individuals with NDs than ever before. Given the widespread occurrence and effects of pain in individuals with NDs, it is essential that behavior analysts practice compassionate care by considering the effect pain has across domains with the individual and their family. For example, conducting a functional analysis of self-injury without exploring the contributing variables, such as pain or discomfort states, almost certainly affects how caregivers perceive behavior analysis. And ethical practice requires not only consideration of such variables, but intensive examination of such variables. Imagine, for example, if a child is consistently pointing, pulling, and hitting their teeth. Unbeknownst to the behavior analyst, the child has infected gums and damaged teeth, causing pain. Imagine next that the child's behavior analyst conducts a functional analysis and concludes "your child's mouth hitting is maintained by automatic reinforcement." Imagine further that the behavior analyst then provides alternative activities that do in fact suppress the rate of mouth hitting (but do not eliminate it). This sequence of events raises two serious ethical quandaries. First, the actual source of the behavior (tooth pain) is not cured, and the infection remains. Second, the behavior analyst's (and possibly behavior analysis as a field) relationship with the caregiver is likely tarnished because any reasonable caregiver is likely thinking (if not saying) "but what about my child's teeth?" Without considering the effect of pain states, behavior analysts can disrupt efficient relationship-building and treatment outcomes with the client and their family.

Groups like the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT, n.d.) have been created to improve the design, execution, and interpretation of clinical trials of treatments for pain. We believe that behavior analysts also should establish a community of their client's service providers to help with the development of treatment plans to evaluate and teach their client to label and request help with pain. This includes establishing better coordination and collaboration of care with the child's medical providers, speech therapists, occupational therapist, and others. Each team member would almost certainly play a vital role in considering and managing the child's pain and discomfort states.

We have argued that behavior analysts are crucial to the assessment and management of pediatric pain as we have the methodology to help. This includes evidence-based procedures on improving social communication, strong measurement systems, operational definitions of observable and measurable behavior, and assessment methodology to manipulate environmental variables to assess for functions of behavior. Furthermore, if the etiology of self-injurious behavior may be related to pain (Cataldo & Harris, 1982), a behavior analyst is best suited to attempt to minimize the likelihood that the behavior comes under operant contingencies (Allen & Mathews, 1998). That is, early identification and consideration of pain states may prevent the development of self-injurious behavior (Schroeder et al., 2014). In sum, the paucity of research related to understanding pain suggests the difficulty in tackling this area of research; however, we believe behavior analysts are well poised to greatly affect the assessment and treatment of pediatric pain. The special considerations related to a client's health will not only greatly improve the client's quality of life but likely advance our field to new levels of understanding our clients in a thoroughgoing manner.

Declarations

Conflict of Interests/Competing Interests The authors have no potential conflicts of interests to disclose.

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