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INTELLECTUAL DISABILITIES (M FELDMAN AND R CONDILLAC, SECTION EDITORS)

Preventing Challenging Behaviors in People with Neurodevelopmental Disabilities

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Abstract

Purpose of Review We review the current literature on preventing challenging behaviors in people with neurodevelopmental disabilities. The goal of the review is to identify existing best practices shown to prevent or reduce challenging behaviors. We then review emerging areas of innovation that may help contribute to a more robust approach to prevent the development of these behaviors.

Recent Findings Preventative interventions that include family-based protective factors, communication skills, social competence, and/or functional skills show evidence of reducing or preventing challenging behaviors. Research on the emergence of challenging behaviors from stereotypy suggests an additional avenue for prevention, as does the diagnosis and treatment of health conditions that can contribute to challenging behaviors. There is also a growing literature suggesting that biological factors such as behavioral phenotypes and gene variants associated with aggression may be viable avenues for prevention research.

Summary This paper shows that the prevention of challenging behaviors is a tangible possibility and raises areas for future research to more robustly develop a prevention science focused on pre-empting the development of challenging behaviors in people with neurodevelopmental disabilities.

Keywords Neurodevelopmental disabilities · Challenging behavior · Prevention

Introduction

Children with neurodevelopmental disabilities (NDD) are at increased risk for developing chronic challenging behaviors meeting Diagnostic and Statistical Manual-5 (DSM-5) criteria for Behavioral Disorder. The most common topographies of challenging behaviors include mild disruptive behaviors (e.g., screaming), physical aggression, property destruction, and self-injury (e.g., head banging). The risk for developing challenging behavior in NDD typically increases with (a) intellectual disability severity and (b) decreased communication skills and other adaptive behaviors [1•, 2••].

Severe challenging behaviors are now classified as "Impulse-Control Disorders Not Otherwise Specified" and draws attention to the bidirectional influence of an individual's phylogenic characteristics (e.g., biologically-based individual strengths and weaknesses) with ontogenic selection of behaviors that are efficient for contacting environmental reinforcers (e.g., escaping demands). That is, phylogenic selection is the process by which characteristics are transferred across generations of offspring, while ontogenic selection is the process that leads to specific behaviors being maintained by contingencies of reinforcement [3].

There is an extensive empirical research base on early identification and treatment of cognitive, communication, and social-emotional development for young children at-risk for NDD, but most of these studies did not include children with the most severe developmental delays or other high-risk predisposing conditions (e.g., specific genetic disorders). Another difficulty with consuming this literature is that studies are spread across several disciplines: (a) medical (e.g., pediatrics, psychiatry, and genetics), (b) psychology (e.g., behavior

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analysis and child development), (c) and life sciences (e.g., neuroscience). Recently, several NDD scientists have called for increased empirical research on preventing challenging behavior, but most of this research specific to NDD is conceptual or descriptive in nature [4–6]. However, there is a substantial body of experimental research on children at-risk for developing challenging behavior due to sociocultural variables, and this literature consistently indicates the need to increase levels (I–III) of screening that progresses from all children (e.g., 1- to 24-month baby well-child checkups) to increased frequency and intensity of screening and monitoring as children exhibit increased early signs of challenging behavior or risk factors and markers [7, 8]. This increasing level of screening allows for the earliest detection of challenging behavior and prescription of early intervention treatment components that may prevent more severe forms of challenging behavior.

In this review article, we discuss the current state of the literature on preventing challenging behaviors in people with NDD. We will make the case that there are existing strategies that may prevent challenging behaviors from occurring and note emerging areas that may allow for a more robust approach to the prevention of problematic behaviors. We will begin with a review of proactive interventions and how they can preclude or reduce challenging behaviors. We then discuss the emerging literature on how challenging behaviors emerge from precursor behaviors such as stereotypy and how this may guide prevention efforts. Next, we review the evidence for how health conditions contribute to challenging behaviors and then finish with a review of biological factors that predispose individuals to developing behavioral problems.

Proactive Interventions

Evidence-based interventions have long been considered an important strategy for preventing the development of challenging behaviors [9•, 10••]. The logic for using intervention strategies with proven efficacy is based on the logic that effective practices can obviate the motivation for children to develop an extensive repertoire of challenging behaviors. Since intervention research has been a fertile area for discovery since the 1960s in NDD, there is a rich literature of effective practices to choose from [11, 12]. In this article, we will limit ourselves to four broad categories of interventions that follow the logic previously noted: family-based protective factors, increasing (a) socially appropriate communication, (b) social competence, and (c) functional skills.

Family-based Protective Factors

A range of factors mediated by the family environment can influence the development of challenging behaviors [13]. The presence of certain factors can place the child at less risk for the emergence of challenging behaviors (or, obversely, their absence can be associated with greater risk). Identified family-based protective factors include responsive proactive parenting practices, social support networks, reducing parental stress, access to intervention services, and care coordination [14]. In general, these protective factors provide children and families with resources to meet the demands of raising a child with NDD.

Communication Skills

Communication skills encompass verbal and nonverbal aspects of information exchange between two or more individuals. Over the past several decades, research on communication skills has yielded abundant evidence regarding its importance, as well as intervention strategies for teaching these skills to individuals with NDD [15]. In fact, the most common early interventions to reduce challenging behavior are communication-based interventions, such as "functional communication training" [16]. However, communication interventions can also be used to preclude the development of challenging behaviors by teaching more socially normative forms of communication before severe challenging behavior develops. These latter strategies have shown efficacy in preventing challenging behaviors from emerging in children with NDD [17].

Social Competence

Similar to communications skills, teaching children to be more socially competent has a distinguished history of intervention efficacy research. Social competence interventions were initially developed in the 1970s to teach children social skills (e.g., appropriate social greetings with eye contact) when interacting with others [18]. This area of research has grown to encompass broader social domains such as social networks, friendships, and social reciprocity [19, 20]. Recent reviews of the research literature suggest that social competence interventions, like communication skills interventions, can preclude the development of challenging behaviors [21••, 22].

Functional Skills

The fourth area of proactive intervention mentioned in this review is teaching functional skills to individuals with NDD. This area focuses on developing useful and meaningful skills to individuals that enable them to more effectively and independently engage with their environments. Examples of functional skills include toothbrushing, cooking, and grocery shopping [23]. In addition, the notion of functional skills has been extended to the use of meaningful curricula for students

with NDD so that instruction focuses on developing useable skills often needed to navigate the most basic daily life activities [24]. Research has shown that emphasizing functional skills instruction can reduce the frequency of individuals engaging in challenging behaviors. Evidence, however, is less compelling that this approach precludes the occurrence of challenging behaviors although it is often accepted prima facie, and more research remains to be conducted [25].

Summary

The proactive factors just reviewed show efficacy in reducing challenging behavior and can have preventative effects on these responses. The interventions are essentially "best practices" in educational intervention and build skills and social contexts to facilitate children's development. In this sense, these proactive interventions can be viewed as first-line interventions for preventing challenging behavior. However, the full extent to which these interventions can prevent challenging behavior when used in a comprehensive support model has yet to receive wide-scale efficacy testing thus definitive statements about their preventative effects remain to be established. In the remainder of the review, we will discuss emerging areas of research that promise to increase the field's understanding of how challenging behaviors develop and offer new approaches to treatment and intervention to prevent their occurrence.

Stereotypical and Self-Injurious Behaviors

Children with the most severe or profound intellectual disability are not only at higher risk for developing challenging behavior, but they are also more likely to spend the vast majority of their waking hours engaged in nonfunctional repetitive motor behaviors termed "stereotypy" [26]. Stereotypy is a difficult behavior to treat because these behaviors often—but not always [27]—are maintained by automatic reinforcement where the stimulus is directly produced the behavior [28]. Unlike socially mediated reinforcers, the individual can produce the reinforcer for behavior maintained by automatic reinforcement (e.g., sensory induction or reduction) without interacting with another person; thus, reinforcement-based treatments often produce transient treatment effects. Another difficulty with treating stereotypy is that there is a growing body of research suggesting that some forms of early and chronic motor stereotypies exhibited by infants and toddlers with the most severe developmental delays are at risk for developing into self-injurious behavior (SIB [29•, 30, 31, 32, 33••]). Of all the topographies of challenging behavior in NDD, SIB is the most costly to manage [31]. However, proactive interventions for challenging behavior do not necessarily focus on stereotypy as a possible source of SIB. Early intervention and prevention of more severe topographies of SIB is a promising line of future research that might be informed by parallel attempts at increasing levels (I–III) of screening for early detection of "proto-SIBs" that could lead to proactive interventions highly specific to preventing the development of SIB.

Health Conditions

People with NDD have a higher prevalence of many health conditions when compared with the general population. Recent studies have suggested increased rates of between 1.5 and 10 times normative levels [34, 35]. Examples include gastrointestinal conditions, chronic allergies, diabetes, and many other common health problems. The higher rate of health conditions appears to be associated with the developmental disability and sometimes represent an underlying genomic effect of the disability (e.g., congenital heart problems in Down syndrome) or a side-effect of the disability (e.g., diabetes in Prader-Willi syndrome). The impact of these health conditions on the development of children with NDD is only beginning to be studied [36].

Of particular interest in the prevention of challenging behaviors is the comorbidity of health conditions and problematic behavior in people with NDD. Research has shown that people with challenging behaviors have higher rates of health conditions when compared with matched controls without behavioral disorders [37]. Thus, not only do people with NDD have higher rates of health conditions than the general population but also people with NDD, and challenging behaviors have even higher rates of health conditions than others with only NDD. An emerging literature suggests that these health conditions are less likely to be diagnosed or treated in this population than in other groups, suggesting an understudied instance of health disparities [38].

Health conditions associated with challenging behaviors include: (a) Gastroesophageal reflux disease (GERD), (b) constipation, (c) dysmenorrhea, (d) sleep problems, (e) allergies, (f) asthma, (g) headaches, and (h) otitis media [39••]. The current literature suggests that many of the health conditions associated with challenging behavior are painful to the person experiencing the condition [40•, 41•]. For example, individuals with GERD often experience severe chest pain 20 to 40 min after consuming a meal. In people with NDD and challenging behavior this can result in problem behaviors occurring after meals in a highly predictable sequence [42]. In such cases, treatment of the health condition can be the primary form of intervention for challenging behavior. Treating challenging behavior associated with health conditions requires an interdisciplinary approach. Many challenges exist in the diagnosis of health conditions for people with NDD, particularly when individuals have limited verbal repertoires

[36]. New approaches to interprofessional education and case management need to be developed and studied to address complex cases of challenging behavior associated with health conditions. If challenging behaviors result from painful health conditions, then identifying and treating the health condition early in its course of development may preclude the emergence of challenging behaviors associated with the health condition.

Biological Factors

The past several decades have seen unparalleled growth in research on molecular approaches in the life sciences [43, 44]. Areas such as genomics, molecular medicine, gene editing, neuroscience, and epigenetics—all of which have relevance to NDD—have seen robust innovation and discovery. Some of these developments have the potential to assist in preventing challenging behavior [45•, 46••]. In this section, we will discuss the potential of biological factors for preventing challenging behaviors with a focus on (a) behavioral phenotypes and (b) gene association studies.

Behavioral Phenotypes

Behavioral phenotypes represent the expression of a person's genetic makeup in the development and maintenance of response-environment relations [47, 48]. In some instances, the known genetic mutation associated with a particular syndrome is highly predictive of challenging behavior as part of its phenotypic expression. For example, chronic lip and/or finger biting is observed in 85% of cases of Lesch-Nyhan syndrome [49]. Thus, the diagnosis of this syndrome in infancy could lead to the use of proactive interventions (see previous section) and evidence-based practices specific to this syndrome [50]. It is possible that other syndromes with a high rate of self-injurious, aggressive, and/or stereotypical behaviors similarly could be targeted with first-line interventions when the diagnosis is made. Researchers have only begun to consider syndromes as indicators for proactive interventions in cases where rates of challenging behavior are predictably high (e.g., Cornelia de Lange syndrome, Down syndrome, Fragile X syndrome, Prader Willi syndrome [51]).

Along with biomarkers that are syndrome specific, there are other gene variants associated with challenging behaviors. These biomarkers occur at similar rates across the human population and, with some notable environmental interactions, are predictive of increased rates of aggression and antisocial behavior [52, 53]. These biological factors represent naturally occurring gene mutations within the general population that have been linked to increased rates of challenging behavior and may assist in identifying individuals with NDD who are at enhanced risk of developing problem behaviors.

Gene Association Studies

The prototypical instance of gene mutations associated with increased rates of challenging behavior is the promoter gene for monoamine oxidase A (MAOA). Initially identified using a gene knockout model system of neural development in which aggression was noted as a behavioral phenotype [54], functional polymorphisms in the MAOA promoter gene were associated with an increased probability of antisocial behavior in adults if individuals were exposed to stressful environments as children [55]. These findings have been replicated in adults with NDD and suggest a possible association between MAOA polymorphisms and an increased likelihood of developing challenging behavior [56, 57]. Other gene mutations may also exist, such as other genes related to monoaminergic brain circuits, that await further discovery [58].

More controversial than for syndrome-specific gene mutations, is the identification of children with NDD who are at-risk for higher rates of challenging behavior associated with gene variants to receive preventative interventions [59, 60]. Although an appealing opportunity for preventing challenging behavior, genetic screening also carries risks of moderate prediction accuracy, false positives, and possible care provider reactivity [61, 62]. More ethics and policy discussions, as well as additional research, are needed to better situate the susceptibility of this early identification approach to the prevention of challenging behavior in children with NDD.

A Future Agenda for Preventing Challenging Behaviors

A substantial proportion of infants and toddlers with severe NDD eventually develop challenging behaviors, with some cases becoming chronic conditions requiring ongoing care management across a team of healthcare, behavioral, and educational providers. The American Academy of Pediatrics recommends that pediatricians conduct frequent developmental screenings from 1 to 30 months of chronological age due to research demonstrating the beneficial effects of early intervention, and the need for repeated screening and early identification of developmental delays [63]. We propose that one critical research need is the development of a risk and protective factors/markers algorithm that will guide healthcare providers through a decision tree that will potentially lead to: (a) increased or decreased frequency of screening for challenging behavior, (b) referral to appropriate diagnostic experts, (c) earlier treatment of emerging challenging behavior, and/or (d) access to support services that can have positive outcomes on family functioning. As described previously, some very powerful risk variables for developing challenging behavior have been identified, but we lack data on protective factors that may counteract the deleterious effects of risk variables. Although protective factors specific to challenging behavior in NDD are

understudied, protective factors in neurotypical children contributing to resilient development include (a) individual strengths and weaknesses, (b) familial resources, and (c) social resources such as support outside of the nuclear family [64].

We encourage NDD investigators to learn from our colleagues in epidemiology, social sciences (e.g., positive psychology), and life sciences that have not traditionally played an extensive role on NDD research teams. If an accurate risk and protective factor algorithm can be developed, it may potentially guide healthcare professionals through the difficult process of knowing when to make a sensitive clinical decision ranging from (a) continued surveillance and screening to (b) referral to specialists for assessment and treatment of emerging challenging behavior in an attempt to prevent the development of chronic challenging behaviors. After this goal is achieved, large-scale multisite studies could begin allowing for selection of subjects that are at the greatest risk for developing chronic challenging behaviors that warrant relatively intensive early intervention in an attempt to prevent children from learning an advanced repertoire of different topographies of challenging behavior that may evolve to serve several social functions for the child. If we can prevent some forms and functions of challenging behavior in NDD, we will need to carefully analyze the cost-benefit implications of preventing the development of challenging behavior or halting the trajectory of developing more severe topographies. That is, successful early intervention and prevention of challenging behavior will need to benefit the child, family, and society more than the cost (broadly defined) to the child, family, and society.

In 2015, the US President's Council of Economic Advisers completed a report entitled The Economics of Early Childhood Investments and concluded that the existing research literature suggests that early learning initiatives provide benefits to society of a multiple of eight dollars for every dollar spent on early intervention. This is a very powerful statement that augments the personal and familial benefits of early learning initiatives that help to justify the extensive financial costs of these initiatives to expand access to high quality early childhood care and education. Fortunately, NDD investigators can use early childhood educational program outcomes as a model for developing a comprehensive cost-benefit analysis of early intervention and prevention attempts for challenging behavior. For example, Barnett [65••] and Barnett and Masse [66] have carefully studied the long-term benefits and costs associated with intensive education within preschool programs termed the Abecedarian Program and the associated policy implications for high quality preschool programs during full-day childcare. A review of the benefit-cost methodologies is beyond the scope of the current review article, but future investigators will likely benefit from reviewing their methods before attempting to document and justify the costs associated early intervention and prevention of challenging behavior in NDD.

Conclusion

The prevention of challenging behaviors has begun to emerge as a realizable goal over the past decade. Evidence-based foundations now exist to support the use of proactive interventions to reduce challenging behaviors that also hold promise for pre-empting their development. Parallel efforts have also identified proto-behaviors and health conditions that can contribute to the development of challenging behavior that could result in additional preventative approaches to reducing behavioral problems. There is also an emerging opportunity to examine the biological substrates that contribute to challenging behavior and develop a research agenda incorporating this new information. Overall, the preventative science of challenging behavior in NDD has a strong base upon which to develop and a bright future of possible new accomplishments ahead.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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