

REVIEW ON MULTI-COMPONENT TRAINING PROGRAMS FOR PARENTS OF CHILDREN WITH NEURODEVELOPMENTAL DISABILITIES AND DIRECT-CARE STAFF

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Abstract

Families of children with neurodevelopmental disabilities (NDDs) face specific challenges including limited social support, financial burdens, and elevated risks of psychological distress, notably anxiety and depression. These challenges extend to the well-being of both parents and children. On the positive side, contemporary early behavioral interventions have demonstrated their effectiveness in developing positive outcomes in children with developmental disabilities. This review examines the effectiveness of behavioral interventions, focusing on the role of parental involvement in treatment outcomes for children with DD, including autism spectrum disorder. Review analyzes studies on behavioral parent training (BPT) that emphasize extending parental involvement, considering implementing relationship-building and self-help strategies to mitigate parental stress. Additionally, the review addresses the parallel challenges faced by direct-care staff, highlighting the necessity for integrated training approaches that cater to both parental and staff needs to maintain treatment integrity. This integrative approach is crucial for fostering a supportive environment, enhancing treatment efficacy, and improving outcomes for children with NDD. Findings suggest that multi-component training programs, addressing self-help skills, stress reduction, and parenting skills, are beneficial for both parents and staff, promoting effective collaboration and treatment adherence. The review advocates for continued research and application of combined training methods, including Acceptance and Commitment Therapy (ACT) and Applied Behavior Analysis (ABA), to support families and caregivers of children with NDD."

Keywords: parental stress, multicomponent treatment, neurodevelopmental disabilities, behavioral parent training, direct-care staff training, ACT, ABA

Introduction

Neurodevelopmental disorders (NDDs) are a group of conditions that are related to brain development and can be noticed in a child's early years. Due to a mix of genetic and environmental influences skill development is often challenging, especially because it influences social skills, executive functions, communication, adaptive behavior, and learning capabilities. These disorders persist throughout life and can be challenging for individuals to participate in independent life, which influences personal, social, academic, or occupational functioning (Morris-Rosendahl & Crocq, 2020; Roccella & Vetri, 2021). As for the prevalence of pervasive developmental disorders in Europe, systematic reviews of studies show a wide range of rates, from 30 to 116 in every 10,000 people; similarly, with autism spectrum disorder, the range is from 2 to 73 in every 10,000. The average rate is increasing, suggesting more cases are being identified (Elsabbagh et al., 2012). Parents have a lot of responsibilities while caring for a child or adolescent with NDDs often face a lot of stressful situations, and have a higher chance of mental health problems such as depression or anxiety (García et al., 2021). Raising a child with NDD is often associated with higher stress levels (Alamdarloo & Majidi, 2021; Reed, 2020; García et al., 2021; Craig et al., 2016).

This article asks what factors influence the quality and involvement of parents in parenting behavioral training, and what methods are used to support parental well-being.

Current Challenges in Support

High levels of stress and burnout are also experienced by staff providing direct care to people with NDD (Leoni et al., 2020; Ryan et al., 2019;). Similar to the parent, direct care workers have a higher stress reaction if they are exposed to the challenging behavior of the people they care for. In both cases, for staff and parents, there are mediating factors that influence the likelihood of burnout, most commonly socio-economic factors, level of education (understanding the causes of behavior), interpersonal factors (self-esteem and sense of efficacy), and emotional factors (response to behavior) (Weiss et al., 2012; Dovgan & Mazurek, 2017; Ryan et al., 2019; Klaver et al., 2020).

In addition to the above factors, Osborne, et al (2007) in the context of the effectiveness of the early intensive behavioral intervention, which usually requires more time input to achieve an effective and sustainable result - the effectiveness of the intervention is significantly reduced if parents have high levels of stress.

Behavioral parent training, which is often mentioned in these studies, is a practice of applied behavior analysis, where a practitioner teaches parents to understand the nature of the behavior, behavior management, and how to use these principles to teach their child in order to address more skills and extend training to the child home, meaning that it is a parent-mediated intervention that is technique-based and utilizes the parent as a primary change facilitator for a child.

Besides the quality of the parent intervention, the health of the parents is affected by chronic high-stress levels. Elevated stress levels can lead to an imbalance in cortisol, a key stress hormone. This dysregulation can have far-reaching effects on parents' health. Physically, it can impair immune function, disrupt sleep patterns, and cause metabolic disturbances, including weight gain and insulin resistance. Additionally, mental health can be affected, impacting cognitive functions and memory. These comprehensive health implications underline the importance of managing stress effectively in parent interventions (Roberts et al., 2019).

Research (Allen & Warzak (2000) and meta-analysis (Singer et al., 2007) suggest that including educational components that focus on managing parents' emotions, cognitions, and behavior as part of a parenting program can help increase parents' sense of competence and lower stress. Allen and Warzak (2000) also note that parents often struggle to apply skills learned in clinical settings to their everyday environment. They suggest two solutions: training in naturalistic settings and teaching parents to generalize skills using rules learned during training. Simplifying behavioral terminology for parents is also recommended.

Establishing and sustaining relationships with families plays an important role in collaborative work with parents. Research indicates that clients place significant emphasis on the manner in which specialists conduct their work. If specialists fail to effectively practice and apply essential skills, it can adversely impact the treatment process. This deficiency can lead from a client's lack of support and implementation of programming skills to a complete withdrawal from treatment, among other consequences (Taylor et al., 2018).

For a child, parents are the people who play the most important role in the child's development. There is a need for more coherent and quality-of-life-oriented interventions for families. To achieve the best possible outcome of interventions and ensure the overall well-being of individuals with NDDs, it is important that carers and family members have access to resources for their own well-being. They should also have the skills to analyze situations and be flexible and adaptive to the demands of caring for a child.

Bearss et al. (2015) described the most common scenarios of support for parents of children with ASD - separate parental support programs and separate programs for the child, parent training focused on parental technical skills, where parents work directly with their child, or

parental support programs through psychoeducation and support management, where the child is an indirect beneficiary of support.

According to observations, the most common support methods described in publications are parenting styles education, community support groups, psychoeducation on NDDs, cognitive-behavioral approaches, and mindfulness training.

Methods

Studies were identified through research conducted in EBSCO, Scopus, Web of science, Medline, APA PsycArticles, APA PsycInfo MEDLINE Complete and SocINDEX databases up to December of 2023, using the following keywords: "acceptance and commitment therapy or act or acceptance and commitment training) AND (applied behavior analysis or aba or applied behavior analysis) AND (parents or staff or caregiver training) AND neurodevelopmental disorders".

Inclusion criteria:

Studies included met the following criteria: a) an intervention was grounded in theoretical and conceptual framework of Applied Behavioral Analysis and Acceptation and Commitment Therapy, b) studies utilized parents as a main change facilitator for the child behavior (parent-led intervention), c) the study provided empirical results (quantitative or qualitative) for parents, d) the publication date ranged from 2010 to 2023, e) the study was peer-reviewed f) the article was published in English g) the full text is available.

Exclusion criteria:

Studies were excluded based on the following: a) publication not available in open access, b) studies that focuses on one component of the intervention, c) study is focused only on child outcomes, d) studies where parents are not involved child intervention, e) studies without parent support component f) studies that do not provide measurable results, and do not use empirical methods.

Results. Scope of existing literature.

Mindfulness-based third-wave interventions, including Acceptance and Commitment Therapy (ACT), are becoming more popular in aiding people with neurodevelopmental disorders as well as in supporting the wellness of parents, caregivers, and professionals (Garcia et al., 2022). Regarding ACT itself, it combines proven behavioral methods with mindfulness practices to help improve behavior regulation and psychological flexibility. Twohig et al. (2019) emphasize that Acceptance and Commitment Therapy (ACT) assists clients in cultivating a set of behaviors that enable them to adaptively pursue their values, despite the presence of unavoidable internal and external obstacles. This ability is known as psychological flexibility. In ACT, a crucial function is the identification of personal values, which then shape the objectives of the treatment.

As outlined by Hayes et al. (2006), it is grounded in a contextualistic philosophy of science, that includes a foundation theory of language and cognition, known as Relational Frame Theory (RFT), and an applied model for understanding and addressing psychopathology and psychological change. The six core processes of ACT include Acceptance, an alternative to experiential avoidance; Cognitive Defusion, changing the unwanted function of thoughts; Being Present, experiencing the world more directly; Self as a Context, being aware of experiences

without attachment; Values, chosen life directions; and Committed Action, actions linked to chosen values. These aspects are nurtured in ACT through mindfulness exercises, metaphors, and experiential processes (Hayes et al., 2006).

Several studies have explored the integration of Acceptance and Commitment Therapy (ACT) with behavioral training for parents, aiming to determine how effective these combined approaches are. Research was conducted on combining therapeutic strategies with behavioral training for parents and staff to determine how this might affect parental involvement and the fidelity of procedures for professionals in training and delivering therapy.

In their brief report, Pennefather et al. (2018) described an online program designed to enhance the well-being of parents and their children with Autism Spectrum Disorder (ASD). Similarly, Yi & Dixon (2020) detailed the refinement of an online Parent Training Program (PTP) incorporating brief ACT training and mindfulness exercises throughout the program. Andrews et al. (2021) evaluated the effectiveness of combining ACT, a mindfulness-based approach, with behavior-parent training (BPT), delivered online for parents of autistic children. This study investigated whether this training could enable parents to use behavioral strategies more effectively and reduce their stress. Further advancing this field, Little et al. (2020) and Bethay et al. (2012) focused on examining whether adding Acceptance and Commitment Training (ACT) to Behavioral Skills Training (BST) improves the effectiveness of training staff trainers and if ACT, combined with ABA, can be effective stress-reducing intervention for staff working with individuals with intellectual disabilities, accordingly.

These studies contribute to our understanding of how acceptance and commitment strategies can be effectively combined with applied behavioral analysis techniques, not only concerning family well-being but also as a tool for professional development and well-being among practitioners, which undoubtedly affects the quality of the relationship between parents and practitioners.

Discussion and conclusions

The review of multi-component training programs aimed at supporting parents, caregivers, and professionals who raise or work directly with children with neurodevelopmental disorders using applied behavior analysis and acceptance and responsibility therapy draws attention to the challenges and effective strategies for dealing with these situations. Families of children with developmental disabilities encounter diverse challenges, and an increased risk of psychological issues like anxiety, depression, and burnout. These factors profoundly impact both the parent's and children's well-being through multiple factors as they influence treatment integrity and efficiency. It emphasizes the need for interventions that address this stress alongside technical skills. Discussing the use and effectiveness of Acceptance and Commitment Therapy in integration with behavioral training for parents and staff is a promising area for development, enhancing psychological flexibility and behavior regulation.

In emerging research fields, such as the topic presented above, reproducibility of research is a very important consideration, and to provide comprehensive evidence of effectiveness, researchers should provide a detailed and transparent description of the research process. For this purpose, researchers should have a detailed clarity of the definition of the key terms, expand on provided steps for generalization, use supplementary materials, robust description of the research methods and data analysis, and discuss potential biases, ethical considerations, and limits of research. To further develop this scientific idea, a combination of training based on the principles of applied behavior analysis and psychological support based on training using acceptance and commitment therapy.

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