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A video parent-training program for families of children with autism spectrum disorder in Albania

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ABSTRACT

Background: Behavioral intervention with parent participation is effective in reducing symptoms of Autism Spectrum Disorder (ASD), but access to intervention is limited. The current study explored whether a video-enriched parent-training program would (a) be comprehensible and acceptable to parents in the Republic of Albania, (b) increase parental knowledge of behavioral strategies, and (c) increase parental self-efficacy.

Methods: Twenty-nine parents of children with ASD aged 18–70 months completed the Early Intervention Parenting Self-Efficacy Scale (EIPSES, Guimond et al., 2008) and a quiz to assess their knowledge of behavioral strategies. Parents in the Treatment Group then received access to a parent-training (PT) program on evidence-based teaching and behavior management techniques. The program was based on empirical research, but considered Albanian cultural norms and included topics Albanian parents requested. Parents in the Treatment Group rated the program using the Treatment Evaluation Inventory Short Form (TEI-SF; Kelley et al., 1989). Change in parents' quiz scores and EIPSES ratings from baseline to post-treatment were compared by group.

Results: Parents rated this video training program as comprehensible and valuable. The program modestly increased aspects of self-efficacy as well as parents' knowledge of effective teaching strategies.

Conclusion: Remote PT may be useful in low-resource settings to help parents develop techniques for teaching skills and forestalling problem behavior in children with ASD. Additional research, with a larger sample size, that observes the effect of the program on child behavior is warranted.

1. Introduction

Although ASD is generally considered a lifelong disorder, symptoms can diminish and individuals with ASD can demonstrate life-

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enhancing improvements in their communication skills and adaptive behavior (e.g., Anderson, Liang, & Lord, 2014; Bal, Kim, Cheong, & Lord, 2015; Rogers & Vismara, 2008). Yet owing to sociodemographic and logistical factors, access to early intervention programs that can improve outcome remains limited for many families (Chiri & Warfield, 2012; Sharpe & Baker, 2007; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007).

Intensive intervention that takes advantage of the plasticity in early development (Dawson, 2008) is one of the most important predictors of progress in communication and in reductions of restricted, repetitive behaviors (e.g., Anderson et al., 2014; MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014; Orinstein et al., 2014; Rogers & Vismara, 2008). Participation in early intervention also predicts increases in skills of daily living, which are necessary for independent living (Bal et al., 2015). There are a variety of interventions for children with ASD, but behaviorally based teaching is the most evidence-based method for optimizing outcome (Rogers & Vismara, 2008), especially when parents participate in delivery of the intervention (Ozonoff & Cathcart, 1998; Rogers & Vismara, 2008; Tonge, Brereton, Kiomall, Mackinnon, & Rinehart, 2014). Indeed, reviews of early intervention for ASD have cited family involvement as one of the crucial elements of effective treatment (Hurtb, Shaw, Izeman, Whaley, & Rogers, 1999; Rogers & Vismara, 2008). For example, children's joint attention, joint engagement, intellectual development, adaptive behavior, compliance, and dyadic communication with parents have all been shown to increase in response to parent training (Bahadourian & Greer, 2005; Bal et al., 2015; Green et al., 2010; Kasari, Gulsrud, Paparella, Hellemann, & Berry, 2015; Rocha, Schreibman, & Stahmer, 2007; Vismara, Young, & Rogers, 2012). Some treatment for very young children, as in the Infant Start Denver Model (Rogers et al., 2014), relies entirely on parent training.

Parents also experience personal advantages as a result of participation in their children's treatment. For example, parents reported reduced stress levels after they were taught how they could participate in their children's intervention (Kasari et al., 2015; Keen, Couzens, Muspratt, & Rodger, 2010). In another study that provided parents of young children with ASD with access to a telehealth-based parent-mediated intervention, parents demonstrated reduced stress and greater self-efficacy post-intervention, in comparison to their baseline assessments (Ingersoll, Wainer, Berger, Pickard, & Bonter, 2016). Indeed, Hume, Bellini, and Pratt (2005) found that parents judged their own training to confer the greatest impact on their children's growth of all the services they received.

Parents are especially appropriate agents for helping their children with ASD learn new skills and reduce maladaptive behaviors. Parents are usually children's earliest teachers and are often in a unique position to notice the emergence of the skill deficits and maladaptive behaviors that signal developmental delay (CDC, 2017; Glascoe, 1999). Parents are also able to practice skills with their children across a variety of contexts, thereby enhancing generalization (Sachse & Von Suchodoletz, 2008). Moreover, children may be more motivated to interact with parents than with intervention providers. Finally, teaching parents to provide intervention can dramatically increase the hours of intervention a child receives.

1.1. Barriers to intervention

Taken together, the literature on ASD suggests that children should ideally receive between 25 and 40 hours of intervention per week (AAP, 2007), and some portion of the intervention should involve parent participation. However, multiple barriers prohibit many children and families from obtaining this level of services. First, parental perceptions of some interventions as not being of high quality diminish their enthusiasm about participation; indeed, some families judge providers' inability to adequately treat their child as a major obstacle (Chiri & Warfield, 2012).

Second, even if families are enthusiastic about intervention, practical barriers can limit access to services. Intervention can be expensive and geographical locations vary in the amount of free or subsidized support offered for children with ASD (Latifi et al., 2015; Sharpe & Baker, 2007). Accordingly, poverty and being uninsured are significantly associated with greater unmet need for medical and psychological services (Chiri & Warfield, 2012). Additionally, transportation to and from intervention may be costly and time-consuming. Given the inequitable geographic distribution of health-related resources, this is particularly the case for families living in rural areas (Latifi et al., 2015; Thomas et al., 2007). Moreover, intervention services are frequently offered during standard business hours that overlap with working parents' schedules. Therefore, bringing a child to a facility to receive intervention, or clearing their schedule in order to participate in their children's intervention, presents challenges for working parents. If the child with ASD has siblings, parents must arrange for alternative childcare while they travel to a treatment facility and if the older sibling is also affected with ASD, parents may be using resources to facilitate this treatment. In the event that parents are able to overcome these challenges, they often continue to face additional barriers to services due to a scarcity of providers. Specifically variable waitlists in different regions often prevent timely access to intervention, a particularly frustrating limitation for eager parents who have been encouraged to begin treatment as early as possible (Mansell & Morris, 2004; Young, Ruble, & McGrew, 2009).

All of these impediments coalesce to create a substantial gap between available evidence-based ASD intervention services and their utilization. Intervention access is particularly disproportionate across families of different sociodemographic backgrounds, including race/ethnicity, education, and occupation (Kohler, 1999; Liptak et al., 2008; Thomas et al., 2007; Zablotsky et al., 2015). Survey-based studies in the United States suggest that approximately one-third of children with ASD have problems accessing desired services (Kohler, 1999; Krauss, Gulley, Sciegaj, & Wells, 2003; Zablotsky et al., 2015). Twenty-nine percent of parents of children with comorbid ASD, intellectual disability, and an additional psychiatric disorder reported unmet needs for their children's treatment (Zablotsky et al., 2015).

In addition to the discrepancy within countries, access to intervention varies among countries. While therapists are lacking in developed countries, they are even scarcer in low-resource countries (Fairburn & Patel, 2014). Indeed, over 90% of global mental health resources are located in wealthy countries (Fairburn & Patel, 2014). Accordingly, between 76 and 85% of people with mental