Research in Autism Spectrum Disorders 3 (2009) 528–537

Contents lists available at ScienceDirect

Research in Autism Spectrum Disorders

Journal homepage: http://ees.elsevier.com/RASD/default.asp

Parental reports on the efficacy of treatments and therapies for their children with autism spectrum disorders

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ARTICLE INFO

Article history:
Received 13 November 2008
Accepted 24 November 2008

Keywords:
Asperger's syndrome
PDD-NOS
Intervention
Efficacy
Pharmacotherapy
Medication
Placebo
Parent report

ABSTRACT

Parents of children with autism spectrum disorders (ASD) try many and varied interventions and therapies in the hopes of improving their children's outcomes; however, empirical evidence supporting (or opposing) the vast majority of treatments is limited or nonexistent. This study examined caregiver efficacy ratings for a wide range of biological and educational/behavioral treatments commonly used for children with ASD. A web-based questionnaire regarding the development of children with ASD was distributed nationally and internationally through more than 200 autism-support organizations; results were analyzed from 479 parents (91% mothers) who reported on their children with autism, Asperger's syndrome, or PDD-NOS (*M* age = 8.3 years, 80.2% male). Improvement – whether small or dramatic – was rated for 50–80% of children in each of 9 drug categories, while ratings of "child became worse" were reported for 15–20.3%. Approximately half of children were said to improve while on a special diet; 51% of those on a gluten-free and/or casein-free (GF/CF) diet were reportedly improved, while no observable effects of the GF/CF diet were indicated for about one quarter of participating children. For 10 of the 16 educational/behavioral therapies, parents reported improvement for approximately 70% of children. The most common rating was "child improved somewhat" followed by "child improved dramatically." Results are discussed relative to the meaning of "improvement" in ASD and in light of both placebo effects and cost of treatments/therapies.

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doi:10.1016/j.rasd.2008.11.001

A great many treatments and therapies are being used for children with autism spectrum disorders (ASD; Goin-Kochel, Myers, & Mackintosh, 2006; Green et al., 2006). However, the empirical evidence in support of these regimens is most often limited or nonexistent (Frances, 2005; Kasari, 2002; Lord et al., 2005; Rogers & Vismara, 2008; Scahill & Martin, 2005; Volkmar, Lord, Bailey, Schultz, & Klin, 2004). Autism spectrum disorders do not have a clear etiology or course of therapy. While treatments for other illnesses and disorders can focus on a limited number of symptoms, treatment for ASD needs to address virtually every area of development and adaptive behavior (Rogers & Vismara, 2008). Even for treatments that work well for some children on the spectrum, other individuals show little or no improvement (Goin-Kochel, Myers, Hendricks, Carr, & Wiley, 2007; Lovaas, 1987; Sallows & Graupner, 2005; Smith, Groen, & Wynn, 2000). Doctors and therapists are unable to prescribe the ‘‘standard of care’’ because there is no universally accepted regimen that will help a specific child.

Without a clear path of treatment, parents assume a major role in deciding which therapies to use with their children. They consider a myriad of possibilities, some that are easily available and others that entail great costs in money and effort. Parents look for guidance from their children's doctors and teachers, for sure, but a higher percentage reported to us that they seek information on their own—from other parents of children with autism, websites, books, and autism groups and newsletters (Mackintosh, Goin-Kochel, & Myers, 2005). This search is complicated by outpourings of new treatments, many of which have only anecdotal support from one or a few children and have not been evaluated objectively. In the absence of empirical evidence regarding the effectiveness of treatments, parents are continuously trying to decide whether or not a particular treatment has been or would be effective for their own child. Many try a variety of complimentary and alternative medical (CAM) treatments, some of which are safe and possibly helpful, and some of which are based on implausible theories and are potentially harmful (Herbert, Sharp, & Gaudiano, 2003; Levy & Hyman, 2003, 2005; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003).

1. Challenges in determining the efficacy of ASD interventions

There are qualities inherent to ASD that make it difficult to determine efficacy of treatments. Children with ASD have highly variable symptoms and show uneven development across skills (Lord et al., 2005; Marcus, Kunce, & Schopler, 2005). Furthermore, children show fluctuations in behaviors from one day to the next, independent of any treatments (Herbert et al., 2003; Sandler, 2005). For example, a child might sleep poorly, be agitated, and have meltdowns on one day, and the next day be calm and cooperative. These fluctuations make it difficult to assess what changes – if any – are the result of a given intervention. Children are also highly variable in their responses to intervention. We are currently unable to predict which children will respond to particular treatments, what intensity of treatment might make a difference, and what behaviors the treatments might affect (Kasari, 2002).

Further complicating the assessment of treatment efficacy is the fact that children with ASD are most often involved in multiple treatments simultaneously. In two separate Internet studies, parents reported that their children were currently enrolled in an average of 5–7 different treatments (Goin-Kochel et al., 2006; Green et al., 2006); in the Green et al. study, one child was reportedly using 47 treatments. Therefore, it is not unusual for a child to start a new diet in the midst of receiving intensive behavioral intervention at school, several sessions of speech therapy per week, visits from an occupational therapist who encourages a sensory-rich diet, social skills training activities in the afternoons—all while continuing the natural process of growing, maturing, and interacting with family. And then we ask parents to gauge the impact of the diet.

It is well accepted that the ideal method for determining whether an intervention has the postulated effect is the randomized, double-blind, placebo-controlled trial (Friedman, Furberg, & DeMets, 1998). Rogers and Vismara (2008) report that, as of 2008, there are just five randomized clinical trials (RCTs) of comprehensive behavioral and educational treatments for young children with autism. RCTs are costly and time-consuming to conduct, and it would take years to determine the efficacy of the many treatments that are currently available for children with ASD. Some treatments would be difficult or impossible to evaluate in a double-blind fashion (e.g., animal therapies,