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Interventions used with an Australian sample of preschool children with autism spectrum disorders

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ABSTRACT

This study examined the previous and current range of educational, therapy, medical and CAM interventions used by a clearly described Australian sample of 84 families of preschool-aged children with autism spectrum disorders who were enrolled in a controlled trial of early intervention services. With regard to educational and therapy interventions, the most frequently used services were speech–language pathology, preschool and childcare, generic early intervention, and occupational therapy. With the exception of preschool and childcare, the access frequency for most of these services indicated they were used at relatively low intensity. Exclusion diets, oils/fatty acids and vitamin and mineral supplements were the primary CAM interventions used by families. There was no clear evidence of a relationship between the number of interventions used by families and developmental status although this may have been due to the relatively recent diagnoses. Implications of these findings and directions for future research are discussed.

1. Introduction

There has been substantial interest in autism spectrum disorders (ASDs) over recent years, probably associated with reports of increase in prevalence (Thomas, Morrissey, & McLaurin, 2007). The development of the Internet over the past decade and a half has provided parents with unprecedented access to largely unfiltered information on ASD and a wide array of treatments. These include conventional education, therapy, medical and complementary and alternative medicine (CAM) interventions. These treatments range from theoretically plausible interventions with supporting empirical evidence to implausible interventions that have been substantively disproved or may even be dangerous (Metz, Mulick, & Butter, 2005). Further, some interventions entail substantial financial and time costs to families. Consequently, there has been interest in the treatment options selected by families of children with ASD.

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Green et al. (2006) conducted an Internet survey of interventions used by parents of children with ASD. Information about the survey was distributed through autism associations and colleagues of the researchers. A total of 552 usable responses were obtained and 80% of these were from the USA. Approximately one-third of the children were of preschool age, a further third were 6–10 years, 18% were 11–14 years and 12% were 15 years or older. Parents reported they were currently using a mean of seven treatments compared with a mean of eight treatments in the past (i.e., those that were not currently used). Younger children used a greater number of interventions, as did those with more severe autistic symptomatology. Interventions were analyzed according to type/severity of disability and there were large and significant differences in several broad classes of intervention but no such analysis was conducted for age. A number of limitations of the Green et al. (2006) study should be noted. Given the methodology employed, both the response rate and representativeness of the sample remain unknown. The researchers noted that occupational and physical therapies were mistakenly left off the survey and they may have been under-reported. In addition, information regarding the diagnosis of ASD and the level of disability was necessarily based on parent report.

Goin-Kochel, Myers, and Mackintosh (2007) extended the study of Green et al. (2006) with an Internet survey of drug, diet and behavioral/educational/alternative interventions that parents of children with ASD, including pervasive developmental disability-not otherwise specified (PDD-NOS), had tried or were currently using. A range of interventions was listed and respondents were given a limited option of adding treatments. The survey was advertised through autism support organizations. Responses were obtained worldwide although 77.5% of the 479 usable responses were from the USA. Again, given the methodology employed, both the response rate and representativeness of the sample remain unknown. Results were analyzed in terms of parent reported diagnosis as well as age.

On average, children were currently receiving between four and six treatments and had received between seven and nine in the past. There were a number of distinctive and significant age-related patterns in treatment usage. Younger children tended to use more dietary and behavioral/educational/alternative interventions, while pharmacological intervention was most prominent for adolescents. These differences may have reflected both a changing pattern in parent preferences over time (e.g., exhausting educational treatments before considering medication) as well as cohort effects as some types of services were not available when adolescents were younger (Goin-Kochel et al., 2007). Nevertheless, the study does illustrate that patterns of service access may change very considerably over time.

A number of earlier studies have focused on younger children. Kohler (1999) conducted telephone surveys of 25 families with children aged 3–9 years who were diagnosed with autism or pervasive developmental disabilities, although it was unclear how these diagnoses were obtained and confirmed. The children were serviced by four organizations in Pennsylvania and the response rate to invitation to participate in the study was 83%. Parents were asked to provide information on types and amounts of services they had received in the past 6 months. School or preschool placements were used most frequently (all children) while speech therapy (88%) and occupational therapy (56%) were also ranked highly. For preschool children, a mean of approximately six services were received and these children received a mean of 33 h of service per week but, presumably, much of this was associated with the preschool placements.

Smith and Antolovich (2000) surveyed 290 families enrolled in a consultation-based intervention service based on the UCLA behavior analytic program. Families were asked about non-behavioral supplementary interventions they were receiving or had received in the past. Families self-referred to the program and children were under 5 years of age at the point of program commencement. The response rate was 42% and all children were reported as having a diagnosis of autism from an unaffiliated psychologist or physician although further detail of diagnostic protocols was not provided. Parents were provided with a list of therapies, which the researchers regarded as "unvalidated", and had the option of adding additional interventions. Parents were asked to identify the interventions they had used with their child at any point and reported an average of seven interventions (range 0–15) in addition to the behavior analytic program. Smith and Antolovich (2000) noted that, given the nature of the program they provided, participating parents were likely to be atypical in both their level of motivation to provide assistance and family income.

Thomas et al. (2007) used a combined telephone and self-administered survey on a self-selected sample of families living in North Carolina who had a child with ASD under 9 years of age. Participants were obtained from both a subject registry and through direct recruitment in 2003–4. Information on diagnosis and presence of intellectual disability was provided via parental report and not verified. No specific information was provided about the developmental status of children. Overall, families were using a mean of seven services.

The use of CAM interventions by families of children with ASD has been examined in several recent studies (Hanson et al., 2007; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Wong & Smith, 2006; Wong, 2009) in Canada, the United States and Hong Kong, using clearly described samples and diagnostic verification. While the details varied considerably across study (and geographical region), there was evidence that a substantial proportion of parents of children with ASD use at least one CAM intervention.

Thus, there is an increasing amount of information on the types of educational and CAM interventions employed by parents of children with ASD. While studies of CAM intervention have typically used well defined and described samples, studies of educational interventions have been hampered by uncertain representativeness, low response rate for defined samples and a lack of verification of diagnoses and developmental level. In addition, few studies have provided extractable data on preschool aged children and there is no specific information on children in Australia. The present study examined the previous and current range of educational, therapy, medical and CAM interventions used by families of preschool aged children with ASD who were enrolled in a controlled trial of educational interventions.