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Prevalence and predictors of complementary and alternative medicine use in a large insured sample of children with Autism Spectrum Disorders

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ABSTRACT

Purpose: The purpose of the present study was to examine the prevalence and predictors of complementary and alternative medicine (CAM) use as well as parental perceptions of CAM efficacy in a large, geographically diverse sample of children with Autism Spectrum Disorders (ASD).
Methodology: Data were obtained from a web-based survey administered to parents of children with ASD at four sites participating in the Mental Health Research Network (MHRN). The web survey obtained information about services and treatments received by children with ASD as well as the caregivers' experiences with having a child with ASD.
Results: Approximately 88% of the sample had either used CAM in the past or had recently used some type of CAM. The following characteristics were associated with CAM use: greater parental education, younger child age, a mix of regular and special classroom settings and prescription drug use in the past three months.
Conclusions: The use of CAM was very prevalent in this large, geographically diverse sample of children with ASD. It is critical that providers be prepared to discuss the advantages and potential side effects with families to help them make well-informed health care decisions and prevent possible CAM-drug interactions.

1. Introduction

Autism spectrum disorders (ASDs) – including Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified – are neurodevelopmental disorders typically detected in early childhood and are characterized by impairments in social interaction and communication. Recent data suggest that the overall prevalence of

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ASD is 14.7 per 1000 (one in 68) children aged 8 years (Centers for Disease Control and Prevention (CDC, 2014). Caring for children with ASD can be challenging and costly, with an estimated lifetime cost per affected child of $2.4 million in the US (Buescher, Cidav, Knapp, & Mandell, 2014).

The mainstay of treatment for ASD is behavioral intervention, which focuses on improving daily functioning, communication and social skills (Copeland & Buch, 2013; Dawson et al., 2010; Shattuck & Grosse, 2007). Although behavioral interventions can improve outcomes in some children with ASD, there is a great deal of variability with respect to treatment response and it is difficult to predict which children will respond (Howlin, Magiati, & Charman, 2009). Only two medications are approved by the Federal Food and Drug Administration (FDA) for the treatment of ASD – the antipsychotics Risperidone and Aripiprazole – and both drugs target problem behavior (irritability) rather than the ASD core symptoms (Hendren, 2013; McPheeters et al., 2011).

Consequently, many parents may turn to complementary and alternative medicine (CAM) therapies, defined as systems, practices and products that are currently not part of mainstream medicine (National Center for Complementary and Integrative Health, 2015). Prior research suggests that CAM is widely used among families of children with chronic health conditions (Kemper, Vohra, & Walls, 2008; McDonagh, Morgan, Carson, & Russman, 2007; Myers & Johnson, 2007), especially families of children with ASD, with reported use as high as 95% (Christon, Mackintosh, & Myers, 2010; Hanson et al., 2007; Harrington, Rosen, Garnecho, & Patrick, 2006; Perrin et al., 2012; Wong & Smith, 2006). Most families with children with ASD report that they use CAM therapies for general health maintenance, though some indicate they also use CAM to treat specific ASD symptoms such as irritability, hyperactivity, GI symptoms and sleep problems (Akins, Krakowiak, Angkustsiri, Hertz-Picciotto, & Hansen, 2014; Wong & Smith, 2006). Sociodemographic and clinical predictors of CAM use by children with ASD include: higher socioeconomic status (Akins et al., 2014; Hall & Riccio, 2012; Hanson et al., 2007; Valicenti-McDermott et al., 2013; Wong & Smith, 2006), non-Hispanic white race/ethnicity (Perrin et al., 2012; Valicenti-McDermott et al., 2013), more time elapsed since initial diagnosis (Hanson et al., 2007), more serious ASD diagnosis (Hanson et al., 2007; Perrin et al., 2012), multiple comorbid diagnoses (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Perrin et al., 2012) and more severe symptoms (Hall & Riccio, 2012).

Although many prior studies have explored the prevalence and predictors of CAM use among children with ASD, much of this research has significant methodological limitations including small sample sizes (Hanson et al., 2007; Harrington et al., 2006; Huang, Seshadri, Matthews, & Ostfeld, 2013; Senel, 2010; Valicenti-McDermott et al., 2013; Wong & Smith, 2006; Wong, 2009), unknown survey response rates (Bowker, D'Angelo, Hicks, & Wells, 2011; Christon et al., 2010; Goin-Kochel, Mackintosh, & Myers, 2009; Green et al., 2006; Hall & Riccio, 2012; Valicenti-McDermott et al., 2013) and lack of geographic diversity (Akins et al., 2014; Hanson et al., 2007; Harrington et al., 2006; Huang et al., 2013; Levy & Hyman, 2003; Senel, 2010; Valicenti-McDermott et al., 2013; Wong & Smith, 2006; Wong, 2009). Further, some of these studies have only asked respondents about which CAM therapies they have *ever* used with their child and have not also asked about recent or current use (Goin-Kochel et al., 2009; Harrington et al., 2006; Levy & Hyman, 2003; Senel, 2010), which does not allow for a nuanced assessment of CAM use in this population. Some of these studies have also not asked parents about their perceptions of the efficacy of various CAM therapies (Akins et al., 2014; Green et al., 2006; Hall & Riccio, 2012; Harrington et al., 2006; Levy et al., 2003; Perrin et al., 2012). Finally, several of these studies have only assessed CAM use not respondents' concurrent use of conventional therapies such as pharmacological medications (Christon et al., 2010; Hall & Riccio, 2012; Levy & Hyman, 2003; Wong & Smith, 2006; Wong, 2009). There can be significant interactions between herbal/dietary supplements and common psychotropic medications (Fugh-Berman, 2000; Miller, 1998; Sood et al., 2008; Van Strater & Bogers, 2012; Zablocka-Slowinska, Kawna, & Biernat, 2013), making it critical to evaluate the concurrent use of these treatments.

The purpose of the present analysis was to begin to address these limitations from prior research by examining the prevalence and predictors of CAM use as well as parental perceptions of efficacy in a large, geographically diverse sample of children with ASD.

2. Materials and methods

2.1. Setting

Data were obtained from a web-based survey administered to parents of children with ASD at four sites participating in the Mental Health Research Network (MHRN), a consortium of 11 research centers affiliated with large integrated health care systems within the HMO Research Network (HMORN). These sites were all regions of Kaiser Permanente (KP), a health maintenance organization providing comprehensive, prepaid care for its members. The four regions, Kaiser Permanente Northern California (KPNC), Kaiser Permanente Southern California (KPSC), Kaiser Permanente Northwest (KPNW), and Kaiser Permanente Georgia (KPGA), collectively serve a population of approximately 7 million members. The Institutional Review Boards at each site reviewed and approved the study.

2.2. Eligibility and recruitment

All children $\leq$17 years old as of April 2012 who were KP members between February and April 2012 and who had at least two ASD diagnoses recorded in their KP medical record were identified for outreach based upon our previous work that at