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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

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potential side effects with families to help them make well-informed health care decisions and prevent possible CAM-drug interactions.

Keywords

complementary and alternative medicine; autism spectrum disorders

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 ASD is 14.7 per 1,000 (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 et al., 2008; McDonagh, Morgan, Carson, & Russman, 2007; Myers, Johnson, & The American Academy of Pediatrics Council on Children With Disabilities, 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; H. H. 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 (R.S. Akins, Krakowiak, Angkustsiri, Hertz-Picciotto, & Hansen, 2014; H. H. Wong & Smith, 2006). Sociodemographic and clinical predictors of CAM use by children with ASD include: higher socioeconomic status (R.S. Akins et al., 2014; Hall & Riccio, 2012; Hanson et al., 2007; Valicenti-McDermott et al., 2013; H. H. 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; H. H. Wong & Smith, 2006; V. C. 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 (R.S. 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; H. H. Wong & Smith, 2006; V. C. 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 (R.S. 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; H. H. Wong & Smith, 2006; V. C. 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 ≤ 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 least two diagnoses were needed to obtain accurate ASD cases from electronic medical records (Coleman et al., 2015). English speakers and Spanish speakers at one site only were eligible to participate. All parents of eligible children were mailed a packet containing a recruitment letter and a fact sheet explaining the study. The recruitment letter included a link to the Web survey and instructions for logging in as well as a telephone number to call if a parent had questions and/or wanted to complete the survey by telephone.

2.3 Web Survey

Overview—The web survey comprised 231 questions about services and treatments received by children with ASD as well parents' experiences with having a child with ASD. Topics covered by the survey included: 1) the child's ASD diagnosis, 2) parent satisfaction with the care provided in the previous year, 3) services and treatments received in the child's lifetime and in the prior three months, 4) the Caregiver Strain Questionnaire (Brannan, Athay, & de Andrade, 2012), 5) the Pediatric Quality of Life Inventory (Varni, Katz, Seid, Quiggins, & Friedman-Bender, 1998), 6) the effect of the child's ASD on parent's employment, 7) demographic information, 8) educational resources of interest to the family, and 9) willingness to participate in future research. Various follow up activities implemented across sites to increase responses included: additional mailings, phone and email reminders and over the phone assistance to complete the survey. Participants received incentives for survey completion. Additional details about the development and administration of the survey can be found elsewhere (Massolo et al.).

2.3.1. Sociodemographic Questions—Child's age, sex and race/ethnicity were reported by the parent as well as their own education level, total household income and marital status. Parents were also asked about the type of classroom setting in which their child spent the majority of the school day (a regular classroom all day, a mix of regular classrooms and special education classrooms, or a special classroom all day).

2.3.2. Clinical Questions—Respondents were asked about the specific type of ASD diagnosis their child had received (ASD, Asperger's Syndrome, Autistic Disorder or Pervasive Developmental Disorder Not Otherwise Specified), whether they believed their child's ASD had improved, not changed or worsened since the initial diagnosis and whether their child had been seen in an urgent care center or emergency room for any reason in the past three months. Respondents were also asked about their child's past and recent (prior 3 months) psychotropic medication use including their use of the following: stimulants, antipsychotics, antidepressants, mood stabilizers and antianxiety medications.

2.3.3. CAM Use Questions—CAM treatments and services were categorized as follows: (1) CAM products, (2) CAM providers, and (3) CAM practices. These three categories of CAM were drawn from prior literature which has categorized CAM therapies based on how the potential users gain access to them (Fouladbakhsh & Stommel, 2007). For example,

CAM products are those that are often ingested (such as herbs and dietary supplements); CAM providers are therapies provided by CAM practitioners (such as acupuncturists, massage therapists and chiropractors); CAM practices are both individual and communal activities that are not provided by a CAM practitioner but are instead typically practiced in the home (such as at-home yoga/tai chi/qi gong, at-home massage, special diets). The specific therapies included in each category were based on the literature available on types of CAM (Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006; Hanson et al., 2007; Levy & Hyman, 2003; Senel, 2010; H. H. Wong & Smith, 2006); however, respondents could also add their own if they were using a modality not listed. Within each category, a list of CAM therapies were provided and the respondent was asked to indicate whether the service or treatment was ever used specifically for ASD-related symptoms and, if so, whether it was used in the past three months (recent use). If the therapy was ever used, the respondent was also asked about whether he/she believed that the therapy was: (1) very harmful, (2) moderately harmful, (3) moderately helpful, (4) very helpful or (6) had no effect.

2.4 Analyses

The statistical analysis proceeded in several phases. First, we compared individuals who reported never using CAM to those who reported ever or recently using CAM (within the last 3 months) by the sociodemographic and clinical characteristics described above using t-tests for comparisons of means of continuous variables, Pearson chi-square tests for comparing unordered categorical data and Mantel-Haenszel chi-square tests for comparing ordered categorical data. Next, we examined the frequency of CAM use (ever use and recent use) and perceived efficacy of each therapy by CAM domain (products, providers and practices). Finally, we examined whether any of the sociodemographic and clinical characteristics were associated with recent use of CAM product. Variables identified as associated with CAM use in bivariate analyses at $p \leq 0.20$ were retained in the subsequent multivariable logistic regression model to assess predictors of recent CAM use. Adjusted odds ratios, 95% confidence intervals, and their corresponding p-values were calculated; a conservative alpha value of .01 was used due to the multiple comparisons in the analysis. Analyses were conducted using SPSS version 22.0.

3. RESULTS

3.1 Survey Response Rate

Parents of 9,109 eligible children were invited to participate in the study and 1,155 parents completed the web survey (response rate=12.7%). Of those completing the survey, 1,084 respondents (94%) answered all CAM use questions and were subsequently included in the present analyses.

3.2 Sample

The majority of respondents were college educated (66.1%) and were married/living with a partner (81.3%). The majority of respondents' children were male (82.9%), White (64.9%) and Non-Hispanic (75.8%). Approximately 40.0% of the study population reported that their child had taken psychotropic medication in the past three months (Table 1). Approximately

20.0% reported that their child had taken a stimulant, 12.5% had taken an antipsychotic, 11.0% had taken an antidepressant, 2.3% had taken a mood stabilizer and 1% had taken an antianxiety medication.

3.3 Prevalence of CAM Use

Approximately 88% of the sample had either used CAM in the past or had recently used some type of CAM: 19.3% of parents had used CAM in the past (but had not used it recently) while 68.8% reported using CAM recently (in the past three months). There was no significant variation in CAM use by child sex, Hispanic ethnicity, total household income, region of the U.S, type of ASD diagnosis, progression of ASD since diagnosis, number of ER/urgent care visits or classroom setting. We did find some variation in CAM use by child age, child race, parental education, parental marital status and recent prescription drug use. Specifically, recent CAM users were younger and had parents who were more highly educated and married (Table 1).

Past and recent use of specific types of CAM are shown in Table 2. CAM products were the most commonly reported types of CAM used, with 18.8% of parents reporting past use and 55.7% reporting recent use. The majority of CAM product users (43.7%) indicated they had used multivitamins recently. Other commonly used products included fish oil/omega 3s, melatonin, vitamins C, D and B12 and probiotics. In contrast with CAM product use, there was more variability in the types of CAM providers used. Though yoga/tai chi/qi gong was the most commonly used therapy in this domain, only 6.7% reported past use and 2.9% reported recent use. Other commonly used CAM providers included chiropractors, naturopaths and massage therapists. Approximately 26.3% and 28.4% of respondents indicated any past and recent CAM practice use, respectively, with parents most often reporting use of special diets, massage at home and yoga/tai chi/qi gong at home.

The average number of CAM therapies used recently was 2.06 (SD=2.80). Within the CAM product domain, approximately 48% of users reported recently using only 1 product, approximately 23% reported recently using 2 products and approximately 29% reported using >3 products. Within the CAM provider domain, approximately 72% of users reported recently using only 1 provider; 28% reported recently using >1 provider. Within the CAM practice domain, approximately 61% of users reported recently using only 1 practice; 39% reported recently using >1 practice. The majority of respondents (76.9%) reported recently using 1 CAM domain; approximately 19% reported recently using 2 domains and approximately 3% reported using all 3 domains. In general, the sociodemographic profile of individuals who used only 1 domain was similar to those who used more than 1 domain (data not shown).

Recent CAM product, provider and practice use varied modestly by study site. For example, 66.5% of participants from the Northwest used CAM products, compared to 60.2% of participants from the Southeast, 29.6% of participants from Northern California and 53.0% of participants from Southern California. Approximately 12% of participants from Southern California used CAM providers, compared to 9% of participants from the Northwest, 8.1% of participants from Northern California and 3.5% of participants from the Southeast. Approximately 33% of participants from Southern California used CAM practices,

compared to 30% of participants from Northern California, 29.8% of participants from the Northwest and 28.9% of participants from the Southeast.

3.4 Perceived Efficacy of CAM

Perceived efficacy of CAM therapies ranged from 20%–84.2% (Table 2). Among CAM products used most often, melatonin (78.8%) and probiotics (65.1%) were perceived as helpful by the majority of parents while only a third of parents reported multivitamins (34%) and vitamin C (38.3%) as helpful. Among the quarter of parents who had used CAM providers, the majority reported that yoga/tai chi/qi gong providers (73.1%), chiropractors (66.3%), naturopaths (68.1%) and massage therapists (77.9%) were helpful. Among CAM practices, at-home massage was seen as helpful by most parents (84.2%), followed by at-home yoga/tai chi/qi gong (80.1%) and special diets (71.6%).

3.5 Predictors of CAM Use

Results from the multivariate regression analysis indicated that the following characteristics were associated with both (1) any recent CAM use and (2) recent CAM product use: greater parental education, younger child age, a mix of regular and special classroom settings and prescription drug use in the past three months. Compared to parents who had a high school diploma or less, parents with some graduate education or a graduate degree were 2.27 times more likely to use any type of CAM with their children [95% CI=1.30–3.96, $p<0.05$].

Compared to children age 15–18 years, children four years of age or younger were 3.20 times more likely to use any type of CAM [95% CI=1.59–6.43, $p<0.05$] and children age five to nine years old were 1.97 times more likely to use any type of CAM [95% CI=1.31–2.95, $p<0.05$]. Compared to children who were in a special classroom all day, children who had a mix of regular and special classrooms were 1.70 more likely to use any type of CAM [95% CI=1.22–2.37, $p<0.05$]. Children who were currently using psychotropic medications were 2.16 times more likely to use any type of CAM compared to children not taking these medications [95% CI=1.58–2.94, $p<0.05$; Table 3).

Compared to parents who had a high school diploma or less, parents with some graduate education or a graduate degree were 2.19 times more likely to use CAM products with their children [95% CI=1.27–3.79, $p<0.05$]. Compared to children age 15–18 years, children four years of age or younger were 3.57 times more likely to use CAM products [95% CI=1.81–7.02, $p<0.05$] and children age five to nine years old were 1.93 times more likely to use CAM products [95% CI=1.30–2.87, $p<0.05$]. Compared to children who were in a special classroom all day, children who had a mix of regular and special classrooms were 1.82 times more likely to use CAM products [95% CI=1.32–2.50, $p<0.05$]. Children who were currently using psychotropic medications were 2.08 times more likely to use CAM products than children not taking these medications [95% CI=1.54–2.81, $p<0.05$; Table 4).

4. DISCUSSION

Findings from the present study suggest that CAM use is very common in this population and that, specifically, CAM products including multivitamins, fish oil/omega 3s, melatonin, vitamins C, D and B12 and probiotics were the most frequently used types of CAM

therapies. Parents/caregivers in our study generally felt that melatonin and probiotics were the most helpful types of CAM products for their children with ASD. Respondents used CAM providers and practices less often but, within these categories, yoga/tai chi/qi gong, chiropractic care, special diets and massage were the mostly commonly used and the majority of parents using these therapies indicated that they were helpful. We also found that greater parental education, younger child age, a mix of regular and special classroom settings and prescription drug use in the past three months predicted both recent use of any CAM modality as well as recent CAM product use.

The finding that CAM use was very common in this population is consistent with prior reports (Christon et al., 2010; Hanson et al., 2007; Harrington et al., 2006; Huang et al., 2013), as is finding that CAM products were the most commonly used types of CAM therapies (K. A. Brown & Patel, 2005). Unfortunately, there are limited data available about the efficacy (and the possible harms) of CAM products for children with ASD (Huffman, Sutcliffe, Tanner, & Feldman, 2011). For example, while there are a few preliminary studies that suggest that vitamin and herb supplementation may be reasonable to consider for children with ASD (Levy & Hyman, 2008), there are some important limitations to these data. First, dietary supplements are often vitamin fortified and many families provide multiple supplements to their children (R. S. Akins, Angkustsiri, & Hansen, 2010). Data from the present study supports this, as over half of CAM product users reported using more than 1 vitamin or supplement with their child. Additionally, the purity and quality of the preparation of these supplements is unknown (Bent, Bertoglio, & Hendren, 2009; Nickel, 1996). Thus, caution must be exercised to avoid inadvertent excessive intake of individual vitamins which can result in vitamin toxicity (e.g., excessive intake of vitamin C can result in diarrhea and kidney stones (Schechtman, 2007).

Second, the efficacy studies that have been conducted have generally had small sample sizes. For example, though there have been several randomized, double-blind crossover studies of melatonin in the ASD population, the sample sizes range from 5–20 children (Garstang & Wallis, 2006; Wasdell et al., 2008; Wirojanan et al., 2009). Similarly, one study reported gains in verbal IQ for children receiving a vitamin B-magnesium combination compared to those in the placebo group; however, there were only four participants in each group (Kuriyama et al., 2002). Other studies that have examined the efficacy of essential fatty acids have also had small sample sizes and have reported no statistically significant reduction in symptomatology in the treatment verses control groups (Bent et al., 2009). Therefore, it is difficult to draw any clear conclusions from these data.

Third, many of these studies have only evaluated the safety and efficacy of a product at relatively low doses; thus we have few data available about the risk of adverse events at higher doses. For example, though melatonin appears to be well tolerated up to 10 mg dose (R. S. Akins et al., 2010; Anagnostou & Hansen, 2011; Whitehouse, 2013) and Omega 3 fatty acids appear to be well tolerated up to 1.54 grams per day (Bent et al., 2009), we do not yet know about the safety of these supplements for children at higher doses (Bent et al., 2009). Given that fewer than 50% of families talk with their children's doctors about their CAM use (Sibinga, Ottolini, Duggan, & Wilson, 2000), many providers may not be aware of the specific products and doses parents are using with their children.

Finally, we also have very limited data available about possible interactions between vitamins/supplements and other prescription medications commonly used by children with ASD including stimulants, antipsychotics, antidepressants, mood stabilizers and antianxiety medications. Some preliminary evidence suggests that St. John's wort, Echinacea, valerian, garlic, ginseng, kava and ginkgo can all have significant interactions with antipsychotics, antidepressants and/or sedatives (Chen et al., 2011; Fugh-Berman, 2000; Miller, 1998; Sood et al., 2008; Van Strater & Bogers, 2012; Zablocka-Slowinska et al., 2013). Therefore, it is concerning that our findings indicate that recent psychotropic medication use was predictive of recent CAM product use, as it suggests that many children with ASD may be concurrently taking both vitamins/supplements and prescription psychotropic medications and thus may be at risk for possible interactions.

Prior research that has examined the association between CAM and prescription medication use among individuals with ASD has been mixed. One study reported that children who were currently using psychotropic medications were less likely to be on special diets (Perrin et al., 2012) and a second reported a non-significant trend toward more CAM therapy use by the children who did not use prescription medications (Huang et al., 2013). By contrast, another study suggests that pediatric CAM users are *more* likely to take prescription medications (Birdee, Phillips, Davis, & Gardiner, 2010). Evidence suggests that parents of children with ASD may differ with respect to what factors influence their decision making to seek out additional treatments/therapies. For example, while some studies suggest that parents do not seek new treatments because they are already using treatments that they believe are effective (Birkin, Anderson, Seymour, & Moore, 2008), others indicate that the perceived effectiveness of one type of therapy may lead parents to try additional therapies (Loomis, 2007). Other parents may seek out new treatments when they believe that progress is slow or that the current therapies they are using are ineffective (Smith & Antolovich, 2000; Valentine, 2010). Clearly, further studies are needed to better understand the reasons why parents of children with ASD decide to use both CAM *and* prescription medications.

Our finding that greater parental education was associated with CAM use is consistent with several prior studies (R.S. Akins et al., 2014; Hall & Riccio, 2012; Hanson et al., 2007; H. H. Wong & Smith, 2006). The use of most CAM therapies, excluding some home remedies, often requires the user to identify how and where to seek out information about the therapy, understand the information, evaluate its credibility and then make use of that information. Though this process may also be common among individuals seeking additional conventional health information (Friedman, Hoffman-Goetz, & Arocha, 2006; Vallance, Taylor, & Lavallee, 2008), it may be even more likely among CAM users as the Internet and print materials may be the only sources of information about CAM therapies. Given the complexity and poor readability of many Internet and print health materials (Cotugna, Vickery, & Carpenter-Haefele, 2005; Wilson, 2009), it is reasonable to conclude that higher educational attainment may be needed for more extensive CAM use. Additionally, socioeconomic resources may also facilitate individuals' ability to pay for CAM (Chao & Wade, 2008) which has not historically been covered by Medicaid, Medicare or private insurers.

We found that younger children were more likely to use CAM compared to their older counterparts, which is inconsistent with two prior studies that did not report any association between child age and CAM use (H. H. Wong & Smith, 2006; V. C. Wong, 2009). Older children may be less willing to take CAM products or engage with a CAM provider or in CAM practices compared to younger children. It may also be the case that, because older children have generally had an ASD diagnosis for a longer period of time compared to younger children, parents could have used CAM products with their children many years ago but have since turned to other therapies (and thus would not report using these products in the past 3 months). Future research is needed to explore the ways in which parents' choices about treatment may evolve over time.

Our finding that children who had a mix of regular and special classrooms were more likely to use CAM compared to children who were in a special classroom all day has not been reported in prior literature, to the best of our knowledge. There is some evidence that children with more severe impairment are more likely to use CAM (Christon et al., 2010; Hanson et al., 2007); thus, if classroom type is a marker for ASD severity, our finding is not consistent with these studies. Additional research is needed to examine the ways in which symptom severity may impact parents' choices about CAM therapies.

The present study has several limitations. First, the survey response rate was fairly low (~13%); however, this response rates is similar to that observed in other Web surveys (Cook, Heath, & Thompson, 2000) and evidence suggest web-based data collection is considered a valid and reliable technique when compared with mailed or in-person approaches (Gosling, Vazire, Srivastava, & John, 2004) and is a frequently-used tool in survey research (Granello & Wheaton, 2004). Survey respondents were more likely to be White and Non-Hispanic and less likely to be Black or Asian when compared to non-respondents. Prior research suggests that Non-Hispanic Whites are more likely than their African-American and Asian counterparts to use most types of CAM modalities including vitamins/nutritional supplements, chiropractic care, mind/body practices, manual therapies and homeopathy. However, Mexican-Americans are more likely to use medicinal herbs and teas and Asians are more likely to use acupuncture and prepackaged Chinese medicines compared to Non-Hispanic Whites (Kronenberg, Cushman, Wade, Kalmuss, & Chao, 2006). Therefore, while children's gender, ASD diagnosis type and age were similar for respondents and non-respondents, we may not have fully captured the patterns and predictors of CAM use among all children with ASD in the patient population.

Second, though we were able to assess whether parents had used CAM products and/or prescription psychotropic medications with their children within the past three months, we were not able to inquire about the dose and frequency with which these therapies were taken nor were we able to explore the association between CAM products and other, non-psychotropic medications. Future studies could ask participants about CAM product dose and frequency as well as obtain more in-depth information about dose and frequency of all prescription medications from the electronic medical record. Third, though we did ask respondents about CAM therapies that they were specifically using for their child's ASD, respondents did not have an opportunity to state which ASD symptoms they hoped that therapy might impact. Future studies could examine parents'/caregivers' expectations of the

ways in which a *particular* CAM modality might improve their child's ASD. Fourth, depending on the condition being treated, some therapies may be considered standard Western allopathic treatments and thus should not be defined as CAM (Wieland, Manheimer, & Berman, 2011). For example, there is growing evidence to support the use of probiotics among children with gastrointestinal problems (Korterink et al., 2013) and, due to the fact that these problems are particularly common among children with ASD (Chaidez, Hansen, & Hertz-Picciotto, 2014), probiotics may be becoming a more mainstream practice. According to the National Center for Complementary and Integrative Health, "CAM" practices are those that are developed and used outside of mainstream, Western practice (National Center for Complementary and Integrative Health, 2015). Therefore, we may have overestimated CAM use if this definition of CAM is considered. Finally, all sites participating in the study were integrated health care organizations and thus findings may not be generalizable to other healthcare settings, particularly those that serve uninsured populations.

In spite of these limitations, this study has a number of important strengths. We were able to address some of the limitations of prior research on CAM use among individuals with ASD, namely that our sample was large and geographically diverse, we assessed recent CAM use in addition to past use, and we asked respondents about concurrent use of CAM and prescription therapies.

5. CONCLUSION

As CAM use is common in this population and there are limited data published about the safety and efficacy of CAM treatments for children with ASD, it is critical that providers be aware of the high use of CAM, understand these therapies and be prepared to discuss the possibility of negative side effects and CAM-drug interactions. Future studies are needed that specifically evaluate the safety of concurrent CAM and prescription medication use among children with ASD. Providers should also be prepared to help families think about other possible disadvantages to using some types of CAM, namely that many of these therapies can be expensive and can involve a great deal of time and energy (Christon et al., 2010). Some therapies may even be harmful to children. For example, there is some evidence that gluten-free/casein-free diets may be associated with nutritional deficiencies (Arnold, Hyman, Mooney, & Kirby, 2003) and suboptimal bone development (Hediger et al., 2008); there are also serious adverse side effects associated with chelation treatment including fever, vomiting, diarrhea, cardiovascular problems and even death (Beachamp et al., 2006; M. J. Brown, Willis, Omalu, & Leiker, 2006; Moel & Kumar, 1982). Thus, given these risks as well as the biologic implausibility of some CAM therapies such as homeopathy and chiropractic (R. S. Akins et al., 2010), families' time and money might be better spent on evidence-based interventions such as social skills groups and early intensive behavioral interventions (Reichow, 2012; Reichow, Barton, Boyd, & Hume, 2012; Reichow, Steiner, & Volkmar, 2012). Providers and families need to have ongoing and open dialogues about both the advantages and disadvantages of CAM for children with ASD so that parents of children with ASD can make well-informed health care decisions.

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HIGHLIGHTS

- We examined the prevalence and predictors of complementary and alternative medicine (CAM) use among children with ASD
- We administered a web-based survey to parents of children with ASD to obtain information about services and treatments received by children with ASD
- The majority of participants had either used CAM in the past or had recently used some type of CAM
- Greater parental education, younger child age, a mix of regular and special classroom settings and prescription drug use in the past three months were associated with CAM use

Table 1

Sociodemographic and clinical characteristics of the study population, overall and by CAM use.

Characteristic	Sample Size N (%)	CAM Use (%)			Sig
		Never Used (N=129)	Past Use (N=209)	Recent Use (N=746)	
Overall Sample	**N=1,084**	**11.9%**	**19.3%**	**68.8%**	
Age (in years)					
0–4 years	100 (9.2)	12.4	3.3	10.3	$\chi2=23.91$, $p<0.01$
5–9 years	371 (34.2)	32.6	26.8	36.6	
10–14 years	411 (37.9)	36.4	45.0	36.2	
15–18 years	202 (18.6)	18.6	24.9	16.9	
Sex					
Male	899 (82.9)	82.9	86.1	82.0	$\chi2=1.93$, $p=0.38$
Female	185 (17.1)	17.1	13.9	18.0	
Race					
White	691 (64.9)	55.2	67.8	65.7	$\chi2=22.20$, $p=0.08$
Black/African-American	66 (6.2)	8.0	5.4	6.1	
Asian	67 (6.3)	12.0	2.5	6.4	
American Indian/Native American	25 (2.3)	2.4	4.0	1.9	
Native Hawaiian/Pacific Islander	41 (3.8)	4.8	5.4	3.3	
Other	92 (8.6)	8.8	6.9	9.1	
Multi-Racial	26 (2.4)	1.6	2.0	2.7	
Prefer not to answer	57 (5.4)	7.2	5.9	4.9	
Hispanic	254 (23.8)	32.0	24.8	22.2	$\chi2=6.29$, $p=0.18$
Parental Education					
High school or less	89 (8.4)	13.0	10.0	7.2	$\chi2=11.60$, $p=0.02$
Some college/college deg	698 (66.1)	68.3	69.7	64.8	
Some grad/grad deg	269 (25.5)	18.7	20.4	28.0	
Total Household Income					

Characteristic	Sample Size N (%)	CAM Use (%)			Sig
		Never Used (N=129)	Past Use (N=209)	Recent Use (N=746)	
Overall Sample	**N=1,084**	**11.9%**	**19.3%**	**68.8%**	
<$20,000	35 (3.3)	1.6	3.0	3.7	$\chi2$=13.93, p=0.31
$20,000–39,999	114 (10.7)	9.6	7.4	11.8	
$40,000–59,999	164 (15.4)	19.2	12.4	15.6	
$60,000–79,999	191 (17.9)	22.4	20.3	16.5	
$80,000–99,999	132 (12.4)	12.8	15.3	11.5	
≥$100,000	324 (30.4)	28.0	32.2	30.4	
Prefer not to answer	105 (9.9)	6.4	9.4	10.6	
Parent Marital Status					
Married/Living with Partner	866 (81.3)	78.4	76.2	83.2	$\chi2$=16.64, p=0.03
Single	45 (4.2)	5.6	5.9	3.5	
Separated/Divorced	135 (12.7)	11.2	16.8	11.8	
Widowed	12 (1.1)	2.4	1.0	0.9	
Prefer not to answer	7 (0.7)	2.4	0.0	0.5	
Study Site					
Northwest	279 (25.7)	20.2	25.4	26.8	$\chi2$=7.44, p=0.28
Northern CA	471 (43.5)	44.2	41.1	44.0	
Southern CA	249 (23.0)	28.7	26.8	20.9	
Southeast	85 (7.8)	7.0	6.7	8.3	
Type of ASD diagnosis					
ASD	370 (34.8)	36.1	33.2	35.1	$\chi2$=7.86, p=0.25
Asperger’s Syndrome	288 (27.1)	26.2	32.2	25.8	
Autistic Disorder	214 (20.1)	21.3	22.0	19.4	
PDD-NOS	191 (18.0)	16.4	12.7	19.7	
Progression of ASD					
No Change	53 (4.9)	5.4	4.3	5.0	$\chi2$=10.43, p=0.11
Improved	967 (90.0)	87.6	90.0	89.3	

Characteristic	Sample Size N (%)	CAM Use (%)			Sig
		Never Used (N=129)	Past Use (N=209)	Recent Use (N=746)	
Overall Sample	**N=1,084**	**11.9%**	**19.3%**	**68.8%**	
Worse	54 (5.0)	3.9	4.3	5.4	
Any psychotropic drug use in past 3 months	415 (38.9)	29.0	32.8	42.2	$\chi 2=11.66$, $p<0.01$
Any ER/urgent care visits in last 3 months	65 (6.0)	3.9	6.7	6.2	$\chi 2=1.25$, $p=0.54$
By Classroom Setting					
Special classroom all day	371 (37.6)	40.2	38.5	36.8	$\chi 2=6.31$, $p=0.18$
Mix of regular and special classrooms	366 (37.0)	30.8	32.3	39.5	
Regular classroom all day	251 (25.4)	29.1	29.2	23.7	

Table 2

Types of, frequency and perceived efficacy of CAM use.

CAM Domain	Frequency of CAM Use		Perceived Helpful[1] N (%)
	Past Use N (%)	Recent Use N (%)	
Products			
Any Product Use	218 (18.8)	644 (55.7)	
By Therapy			
Multivitamin	259 (22.4)	506 (43.7)	261 (34.0)
Fish Oil/Omega 3s	149 (12.9)	181 (15.6)	158 (47.9)
Melatonin	109 (9.4)	186 (16.1)	231 (78.8)
Vitamin C	151 (13.1)	98 (8.5)	95 (38.3)
Probiotics	101 (8.7)	89 (7.7)	123 (65.1)
Vitamin D	84 (7.3)	96 (8.3)	78 (43.6)
Vitamin B12	97 (8.4)	63 (5.4)	86 (53.8)
Vitamin B6	97 (8.4)	41 (3.5)	66 (47.8)
Magnesium	72 (6.2)	50 (4.3)	64 (52.5)
Zinc	66 (5.7)	34 (2.9)	40 (40.0)
Digestive Enzymes	60 (5.2)	24 (2.1)	49 (58.3)
Vitamin A	61 (5.3)	23 (2.0)	36 (42.9)
Chamomile	48 (4.1)	16 (1.4)	35 (54.7)
Homeopathic supplement	40 (3.5)	17 (1.5)	34 (59.6)
Echinacea	43 (3.7)	10 (0.9)	20 (37.7)
Garlic	24 (2.1)	17 (1.5)	14 (34.1)
Valerian	19 (1.6)	3 (0.3)	5 (22.7)
Chinese Herbs	12 (1.0)	3 (0.3)	3 (20.0)
Evening Primrose	9 (0.8)	3 (0.3)	6 (50.0)
Gingko Biloba	9 (0.8)	3 (0.3)	4 (33.3)
Algae	9 (0.8)	2 (0.2)	4 (36.4)
St. John’s Wort	5 (0.4)	4 (0.3)	3 (33.3)
Kava	6 (0.5)	1 (0.1)	3 (42.9)
Providers			
Any Provider Use	205 (17.7)	97 (8.4)	
By Therapy			
Yoga/Tai Chi/Qi Gong	78 (6.7)	33 (2.9)	79 (73.1)
Chiropractor	61 (5.3)	26 (2.2)	57 (66.3)
Naturopath	55 (4.8)	17 (1.5)	47 (68.1)
Massage	51 (4.4)	18 (1.6)	53 (77.9)
Homeopath	42 (3.6)	12 (1.0)	33 (64.7)
Meditation	46 (4.0)	23 (2.0)	21 (67.7)
Acupuncture	23 (2.0)	3 (0.3)	12 (50.0)
Chelation	25 (2.2)	3 (0.3)	14 (51.9)
Biofeedback	21 (1.8)	3 (0.3)	11 (47.8)

CAM Domain	Frequency of CAM Use		Perceived Helpful[1] N (%)
	Past Use N (%)	Recent Use N (%)	
Energy Therapy	15 (1.3)	0 (0.0)	8 (57.1)
Hypnotist	11 (1.0)	3 (0.3)	7 (53.8)
Traditional Chinese Medicine	12 (1.0)	2 (0.2)	6 (46.2)
Secretin Provider	10 (0.9)	1 (0.1)	2 (20.0)
Practices			
Any Practice Use	304 (26.3)	329 (28.4)	
By Therapy			
Special Diets	251 (21.7)	182 (15.7)	310 (71.6)
Massage	141 (12.2)	124 (10.7)	223 (84.2)
Yoga/Tai Chi/Qi Gong	87 (7.5)	59 (5.1)	117 (80.1)
Meditation	42 (3.6)	12 (1.0)	48 (69.6)
Acupressure	26 (2.2)	9 (0.8)	24 (68.6)
Energy Therapy	15 (1.3)	4 (0.3)	8 (42.1)

[1] N and % of individuals indicating that the therapy was ‘moderately’ or ‘very’ helpful.

Table 3

Factors associated with any recent CAM use.

Factor	aOR[+]	95% CI
Parental Education		
High school or less	Referent	Referent
Some college/college degree	1.46	0.89–2.40
Some grad/grad degree	2.27**	1.30–3.96
Parent Marital Status		
Married/Living with Partner	Referent	Referent
Single	0.49	0.25–1.95
Separated/Divorced	0.68	0.46–1.02
Widowed	1.44	0.34–5.99
Prefer not to answer	0.60	0.11–3.46
Child Age (in years)		
15–18 years	Referent	Referent
10–14 years	1.21	0.83–1.76
5–9 years	1.97***	1.31–2.95
0–4 years	3.20***	1.59–6.43
Child Race		
White	Referent	Referent
Black/African-American	0.99	0.56–1.76
American Indian/Native American	0.45	0.19–1.11
Asian	1.36	0.74–2.50
Native Hawaiian/Pacific Islander	0.58	0.29–1.18
Other	1.16	0.70–1.91
Prefer not to answer	0.61	0.33–1.15
Multi-Racial	1.22	0.48–3.10
Classroom setting		
Special classroom all day	Referent	Referent
Mix of regular and special classrooms	1.70**	1.22–2.37
Regular classroom all day	1.15	0.81–1.65
Prescription drug use in past 3 months		
No	Referent	Referent
Yes	2.16***	1.58–2.94

[+] Adjusted for all other variables in the model

** $p<0.01$

*** $p<0.001$

Table 4

Factors associated with recent CAM product use.

Factor	aOR[+]	95% CI
Parental Education		
High school or less	Referent	Referent
Some college/college degree	1.42	0.87–2.32
Some grad/grad degree	2.19**	1.27–3.79
Parent Marital Status		
Married/Living with Partner	Referent	Referent
Single	0.65	0.34–1.26
Separated/Divorced	0.70	0.47–1.04
Widowed	1.87	0.45–7.71
Prefer not to answer	0.81	0.14–4.60
Child Age (in years)		
15–18 years	Referent	Referent
10–14 years	1.32	0.91–1.91
5–9 years	1.93**	1.30–2.87
0–4 years	3.57***	1.81–7.02
Child Race		
White	Referent	Referent
Black/African-American	0.98	0.56–1.72
American Indian/Native American	0.56	0.23–1.36
Asian	1.24	0.69–2.21
Native Hawaiian/Pacific Islander	0.57	0.29–1.15
Other	0.94	0.58–1.52
Prefer not to answer	0.58	0.32–1.08
Multi-Racial	1.19	0.48–2.94
Classroom setting		
Special classroom all day	Referent	Referent
Mix of regular and special classrooms	1.82**	1.32–2.50
Regular classroom all day	1.36	0.96–1.94
Prescription drug use in past 3 months		
No	Referent	Referent
Yes	2.08***	1.54–2.81

[+] Adjusted for all other variables in the model

** $p<0.01$

*** $p<0.001$