



Published in final edited form as:

J Autism Dev Disord. 2018 May ; 48(5): 1803–1818. doi:10.1007/s10803-017-3432-6.

Parents' Use of Complementary Health Approaches for Young Children with Autism Spectrum Disorder

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Abstract

Knowledge of why parents use complementary health approaches (CHA) for children with autism spectrum disorder (ASD) is limited. We conducted a mixed methods study to better understand factors influencing parents' decision to use CHA for ASD. Parent-reported data about CHA use were collected on a probability sample of 352 young children with ASD in Denver, Colorado; Los Angeles, California; or Portland, Oregon. Follow-back interviews were conducted with 31 parents. CHA use was negatively associated with older child age and positively associated with parents' belief ASD has major consequences, living in Portland or Denver, and medication use. Nine

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Conflict of Interest: All authors declare they have no conflicts of interest.

Compliance with Ethical Standards

Ethical approval: All procedures performed in the study involving human participants were in accordance with the ethical standards of the institutional committees and with the 1964 Helsinki declaration and its later amendments.

Informed consent: Informed consent was obtained from all individual participants included in the study.

themes help explain these results. Study findings may have utility for healthcare providers working with children with ASD and their families regarding CHA.

Keywords

autism spectrum disorder; complementary and alternative medicine; complementary health approaches; mixed methods research

Autism spectrum disorder (ASD) is a complex and chronic neurodevelopmental disorder characterized by impairment in social interaction and behavioral functioning (American Psychiatric Association, 2013). ASD is often diagnosed in early childhood (Zuckerman, Lindly, & Sinche, 2015), and ASD has become increasingly prevalent among children in the United States (Christensen et al., 2016) and in other countries (Baron-Cohen et al., 2009). Certain treatments, such as early intensive behavioral intervention, are efficacious for ASD symptoms and are, therefore, often recommended by conventional healthcare providers (Myers & Johnson, 2007; Weitlauf et al., 2014; Williamson et al., 2017). Yet conventionally recommended treatments typically incur costs for families, both in terms of the time and out-of-pocket expense required, and may also take time to show any noticeable and positive effects for children with ASD. By contrast, complementary health approaches (also referred to as complementary and alternative medicine [CAM]) may be perceived by parents as being more within their control to utilize and as having greater potential to show immediate and positive effects for their child with ASD (Cidav, Marcus, & Mandell, 2012; Ganz, 2007; Gupta, 2010; Hyman & Levy, 2005). Within this context, parents commonly pursue complementary health approaches for children with ASD.

Complementary health approaches (CHA) encompass a wide array of modalities developed outside of or parallel to mainstream medicine including those classified as natural products (e.g., vitamins, herbal supplements), mind and body practices (e.g., chiropractic manipulation, yoga), and other approaches (e.g., special diets, chelation therapy) (National Center for Complementary and Integrative Health, U.S. Department of Health and Human Services, 2015). Parental use of CHA for children with ASD in the United States and Europe ranges from 17.3% (Zuckerman, Lindly, Sinche, & Nicolaidis, 2015) to 47.0% (Salomone, Charman, McConachie, & Warreyn, 2015). In addition, CHA use is more common in children with ASD compared to other children, even those with other developmental disabilities (Akins, Krakowiak, Angkustsiri, Hertz-Picciotto, & Hansen, 2014; Valicenti-McDermott et al., 2013; H. Wong & Smith, 2006).

ASD symptomatology (Hall & Riccio, 2012; Hopf, Madren, & Santianni, 2016; Perrin et al., 2012; Salomone et al., 2015; Valicenti-McDermott et al., 2013), greater parent education (Akins et al., 2014; Hall & Riccio, 2012; Hanson et al., 2007; Owen-Smith et al., 2015; Salomone et al., 2015; H. Wong & Smith, 2006), and use of multiple health services (Akins et al., 2014; Owen-Smith et al., 2015; Salomone et al., 2015) are associated with an increased likelihood of parental CHA use for children with ASD. Discrepant findings have, however, emerged about the relationship of age, sex, and race/ethnicity with parental use of CHA for children with ASD (Akins et al., 2014; Hall & Riccio, 2012; Hanson et al., 2007; Hopf et al., 2016; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Owen-Smith et

al., 2015; Perrin et al., 2012; Salomone et al., 2015; Valicenti-McDermott et al., 2013; H. Wong & Smith, 2006; Zuckerman, Lindly, Sinche, et al., 2015). Moreover, little research has qualitatively explored how these factors, together, contribute to parental use of CHA for children with ASD. Methodological differences (e.g., definition and measurement of CHA use and correlates) and limitations (e.g., cross-sectional design, nonprobability sampling) across past studies also further constrain understanding of *why* parents use CHA for children with ASD.

Greater knowledge of factors motivating parental use of CHA for children with ASD is needed for several reasons. First, improving understanding of parental use of CHA for children with ASD is important because it is common (Hofer, Hoffman, & Bachman, 2017). Second, many CHA modalities have limited evidence of efficacy and safety for treating ASD symptoms (Anagnostou & Hansen, 2011; Cheuk, Wong, & Chen, 2011; Ghanizadeh, 2012; Hendren, 2013; Huffman, Sutcliffe, Tanner, & Feldman, 2011; James, Montgomery, & Williams, 2011; James, Stevenson, Silove, & Williams, 2015; Levy & Hyman, 2015; Nye & Brice, 2005; Whitehouse, 2013; Williams, Wray, & Wheeler, 2012). Third, parental use of CHA for children with ASD often incurs even greater out-of-pocket costs for families belonging to a subgroup that is already likely to experience high financial burden (Gupta, 2010; Nahin, Barnes, & Stussman, 2016).

For these reasons, additional research employing mixed quantitative and qualitative methods is needed to establish a more comprehensive understanding of why parents use CHA for children with ASD. This study was, therefore, intended to generate new knowledge on this topic. In specific, we aimed to: (1) identify what ecological factors at the child, family, and health system levels influence parental use of CHA for children with ASD; and (2) describe, from the parent perspective, *how* these factors may affect use of CHA for children with ASD. We adapted the Complementary and Alternative Medicine (CAM) Healthcare Model (Fouladbakhsh & Stommel, 2007), which is a modification to the Behavioral Model of Health Services Utilization (Andersen, 2008), as the conceptual framework to guide our study (Appendix). Based on the literature reviewed and the availability of related measures for this study, we hypothesized that greater ASD severity, higher parent education level, and higher number of health services utilized would have positive and statistically significant associations with parental use of CHA for children with ASD.

Method

This study was added to a larger study investigating barriers to autism care for Latino and non-Latino children. We used an embedded mixed methods design (Creswell, Klassen, Clark, & Smith, 2011), in which qualitative data were used to help explain quantitative results about associations of ecological (i.e., child, family, and health system) factors associated with parents' use of CHA for children with ASD. Integration of results occurred after both quantitative and qualitative data collection and analysis were completed. The Institutional Review Boards at the affiliated universities approved the study.

Quantitative Methods

Survey sampling and participants—Probability samples of Latino and non-Latino white children aged 2–10 years with an ASD diagnosis confirmed in the past five years were selected from three ASD clinics in Denver, Colorado; Los Angeles, California; and Portland, Oregon. Parents of the children selected were then recruited through mailings and follow-up telephone calls. The survey sampling and recruitment procedures are detailed in a previous article (Zuckerman, Lindly, Reyes, Chavez, Marcias, Smith, et al., 2017). The final survey sample included 352 children with ASD aged 2–10 years across the three sites.

At the time of the survey, the median age of children with ASD was six years. As shown in Table 1, most children with ASD were male, and more than half had parent-reported moderate or severe ASD. A plurality of parents reported English-speaking proficiency, always having lived in the United States, and being married or partnered. In terms of their beliefs regarding ASD, most parents agreed ASD is lifelong, challenges of ASD can be reduced with treatment, and ASD has major consequences on the child's life. On average, some stigma of ASD was perceived in the child's community, a diagnostic delay of more than a year occurred, seven or more barriers to accessing ASD care were experienced, and more than two conventional therapy services were utilized for the child's ASD. Most children also received more than one hour of therapy per week, and nearly half reported unmet need for therapy services.

Survey development and administration—The survey instrument included 34 items. Whenever possible, previously used and/or validated measures were included. Measures of child and family characteristics were primarily adapted from the U.S. Census American Community Survey (U.S. Census Bureau, 2015) and the 2009–2010 National Survey of Children with Special Health Care Needs (National Center for Health Statistics, 2014). For instance, parent belief measures (e.g., ASD has major consequences on the child's life) were adapted from the previously validated Illness Perception Questionnaire Revised for Autism (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010). Measures of ASD services use were largely adapted from the 2011 Survey of Pathways to Diagnosis and Services (National Center for Health Statistics, 2015). Because validated and previously used measures for certain concepts such as barriers to ASD care and ASD stigma did not exist, new measures were developed. The initial survey instrument was refined based on feedback from Autism Parent Advisory Committees at two sites and pilot testing with 20 parents of children with ASD.

Most participants completed the survey by mail ($n = 322$). For those participants who did not complete the survey by mail, but agreed to complete the survey by telephone ($n = 30$), a trained interviewer administered the survey in English or Spanish. The survey was administered from March 2014 to October 2015. The survey response rate was 76.2%.

Child, family, and health system factors examined—For this study, the conceptual framework (Appendix) guided our selection of variables indicative of factors at the child, family, or health system levels potentially associated with CHA use among children with ASD. As displayed in Table 1, child level factors included child age, age of initial ASD

diagnosis, sex, health insurance coverage, and parent-reported ASD severity (i.e., mild versus moderate or severe). Family level factors included ethnicity and primary language, number of children per household, number of children with ASD per household, parent nativity, family structure, years of parent education, parent employment, and delay between when parent was first concerned about the child's development and when the parent talked about concerns with a healthcare provider. Family level factors also included parent beliefs about ASD (i.e., ASD is lifelong versus temporary, challenges of ASD can be decreased with treatment, parent has the power to change child's ASD, ASD is a mystery, parent becomes upset when thinking about child's ASD, and ASD has major consequences on the child's life). Parent belief measures were rated on a four-point Likert scale, ranging from 1=strongly disagree to 4=strongly agree. Due to response distributions, we subsequently dichotomized responses into disagree (i.e., strongly disagree or disagree) or agree (i.e., strongly agree or agree). Health system factors included perceived ASD stigma in the community (Zuckerman, Lindly, Reyes, Chavez, Marcias, Cobian, et al., 2017), study site, delay between when parent first talked with a healthcare provider about concerns regarding their child's development and initial ASD diagnosis (i.e., diagnostic delay) (Zuckerman, Lindly, & Sinche, 2015), number of barriers experienced when accessing ASD care (Zuckerman, Lindly, Reyes, Chavez, Marcias, Smith, et al., 2017), number of conventional therapy services used (i.e., speech and language therapy, social skills training, occupational therapy, psychological counseling, applied behavioral analysis, other behavioral therapy, other therapy), total hours of home or school therapy services the child usually received per week, special education receipt, applied behavioral analysis (ABA) use, prescription and/or over-the-counter (OTC) medication use for the child's ASD symptoms, and perceived unmet need for therapy services.

Assessment of complementary health approaches used—In the survey, parents were asked “Does your child currently use any of these medications or treatments for his or her ASD symptoms?” If respondents indicated any of the following treatment types, the child was determined to use CHA: (1) vitamins; (2) herbal supplements; (3) dietary treatments, such as gluten-free or low sugar diet; (4) chiropractic, acupuncture, or massage therapy; (5) traditional healers; or (6) other CHA. Other CHA included equestrian, music, hydro, and sensory integration therapy.

Analysis—We computed descriptive univariate and bivariate statistics for all variables of interest. Characteristics of CHA used were also descriptively examined. Chi-square, t-tests, and odds ratios were used to examine unadjusted associations of child, family, and health system factors with CHA use. To determine a parsimonious model, we used a stepwise model selection process in which variables initially determined to be associated with CHA use from bivariate analysis results ($p < .15$) were included as independent variables in a multivariable logistic regression model (Bursac, Gauss, Williams, & Hosmer, 2008). The same alpha level was used to exclude variables from subsequent models. Goodness of model fit to the data was examined using the Hosmer-Lemeshow chi-square statistic and the Bayesian Information Criterion. A generalized linear mixed model was additionally fit to account for potential clustering by site; however, the correlation within each site related to CHA use did not necessitate this approach (results not shown), so the original modeling

approach was retained. All quantitative analyses were performed in Stata 14.2 (StataCorp, 2015).

Qualitative Methods

Sampling and recruitment for interviews—To be eligible for the qualitative component of this study, survey participants had to have indicated any use of CHA and English-speaking proficiency. Parents who met these criteria were recruited from the sites in Portland, Oregon and Denver, Colorado using an advance mailing and follow-up by telephone. Eligible parents interested in participating were re-screened over the telephone to determine if (1) their child was still diagnosed with ASD and (2) they had used CHA for their child in the past year. Of the 89 parents re-contacted, 31 agreed to participate and completed interviews.

Interview participants.—Of the 31 parents who participated in interviews, 18 were from Portland and 13 were from Denver. A majority of participants were the mother of the child with ASD, identified as being white and non-Latino, and were employed (Table 2). In addition, all parents interviewed reported having 12 or more years of education and that they were 25 years or older. When the interviews were conducted, the median age of children with ASD was eight years.

Data collection—Three trained interviewers conducted in-depth telephone interviews in English with parents from March 2016 to January 2017. All parents provided verbal informed consent prior to being interviewed. Interviews, which lasted 35–120 minutes, were audio recorded and then transcribed verbatim by a professional transcription firm. Each parent received a \$20 gift card after the interview.

Interview guide—The semi-structured interview guide was comprised of predominately open-ended questions and probes about parents' experiences using CHA for their child with ASD. The guide also included questions about parents' experiences disclosing CHA used to their child's healthcare provider(s), as well as ways in which they felt communication with healthcare providers about CHA could be improved for other families of children with ASD. An initial version of the interview guide was pilot tested with two parents of a child with ASD who had used CHA, and the feedback was used to revise the guide. The interview guide was further modified after the first seven interviews.

Analysis—A directed content analysis approach, intended to validate and extend the conceptual framework and relevant past research, was used to analyze interview data (Hsieh & Shannon, 2005). A coding scheme was initially generated after two authors independently reviewed transcripts from four interviews. The authors then independently coded the interview transcripts, met to discuss and resolve coding discrepancies with another author, and revised the coding scheme accordingly. This process continued until all transcripts were coded by the two authors. Elemental coding methods were primarily used including descriptive, in vivo, and structural coding (Saldaña, 2013). After coding was completed, research team members met several times with a parent advocate who had used CHA for her child with ASD to extrapolate broader themes from the coded data and to identify illustrative

quotes regarding factors promoting or impeding the use of CHA. Qualitative data analysis was performed in QSR NVivo 11.3.2 (QSR International Pty Ltd., 2014).

Results

Survey Results

Nearly half (44.9%) of children with ASD used one or more CHA. The majority used only one modality (Figure 1). Vitamins, herbal supplements, and special diets were the most frequently used modalities (Figure 2).

Bivariate results demonstrated statistically significant unadjusted associations of CHA use with multiple factors at the child, family, and health system levels (Table 1). Results from the final multivariable model are presented in Table 3. The only factors that retained statistically significant adjusted associations with use of CHA were child age, the belief that ASD has major consequences on the child's life, study site, and medication use. Specifically, for each year older a child with ASD was, the adjusted odds of CHA use decreased by approximately 15 percent. At the family level, parents who agreed ASD has major life consequences had higher adjusted odds of CHA use. At the health system level, children with ASD from Denver or Portland had higher adjusted odds of CHA use relative to children with ASD from Los Angeles. Prescription and/or over-the-OTC medication use was additionally associated with higher adjusted odds of CHA use.

Interview Results

Parents reported ever or currently using many different CHA for their child with ASD (Table 4). The most frequently used type of CHA was natural products (e.g., herbal supplements). Special diets, primarily gluten and/or casein free diets, was the single most frequently used modality. Massage therapy, yoga, and qigong were the most common mind and body practices used. Many parents also reported that some of the CHA used were directed by a healthcare provider (e.g., general pediatrician, naturopath). Most parents reported CHA were used with conventional healthcare; however, some reported they used CHA as an alternative to conventional healthcare. All parents reported their child with ASD used some conventional healthcare, with the most common services being preventive care (e.g., well child visits), school-based services (e.g., special education, speech and language therapy), other therapy services (e.g., ABA), and prescription and/or OTC medication (data not shown). Thirteen parents did, however, elaborate that they used or were currently using CHA as an alternative to conventional healthcare. Most of these parents were recruited from Portland, Oregon and described CHA as an alternative to conventional healthcare (e.g., ABA) for their child's core ASD symptoms.

Nine themes emerged in relationship to the four factors significantly associated with CHA use in the final multivariable model (i.e., child age, parent belief ASD has major consequences on the child's life, study site, and medication use). For each of the four factors, relevant themes are subsequently described to provide greater understanding of how each factor may contribute to CHA use among children with ASD.

The role of child age—Nineteen parents discussed how their child’s age had influenced their decision to use CHA. Three themes emerged in relationship to the quantitative result that the adjusted odds of CHA use decreased as age increased.

CHA use may be viewed as no longer necessary when ASD symptoms change with age: Most parents described change in their child’s ASD symptomatology over time. Parents typically characterized this change as an improvement or worsening in their child’s ASD symptoms. Related to CHA use, some parents described how fewer treatments including CHA were needed as their child grew older because his or her symptoms had improved or had become better managed. As one parent explained, “I mean we’re doing less of [CHA] now that he’s getting older...I mean because some of this stuff we’ve either tackled it or he’s grown out of it...”

By contrast, parents described CHA as less effective relative to certain conventional treatment options when their child’s ASD symptoms—particularly externalizing behaviors—became more severe with age. Psychotropic medication (e.g., stimulant medication) was generally described as the form of conventional treatment with the greatest potential for adverse side effects. Still, several parents explained the necessity of moving from solely using CHA to using CHA in combination with psychotropic medication to manage worsening symptoms as their child aged. For example, one parent said:

When he started getting bigger and older...to the point where it was a little bit harder for me to handle it from a physical standpoint. And, the alternative medicines weren’t exactly working to the degree that I hoped they would be. We started turning more towards the conventional medication to control behaviors.

There is a perceived critical period to act by using CHA when children with ASD are young: In discussing the influence of their child’s age on CHA use, several parents described how, once their child was diagnosed with ASD, they had a finite period to promote their child’s healthy development. Parents commonly described this period as occurring in early childhood. Related to this belief, parents often recounted their tireless search for ASD treatment options to aide their child. For many, this process led them to use CHA. As one parent explained,

I felt like I was in a race sometimes to get him to make progress before he reached six years old. I don’t know how accurate that statistic is, but I heard it from multiple people and sources. That had an impact on me. I don’t think we rushed any treatment because of that, but I was real anxious for him to [make] progress.

CHA are viewed as safe for young children: Most parents described how they believed CHA were safe or safer than conventional healthcare treatments available for ASD, particularly medication. In relationship to their child’s age, some parents further explained how their perceived safety of CHA was a determining factor in their decision to use it for their child because their child was young and was, therefore, more susceptible to adverse health impacts. This theme is illustrated in the following exchange:

Interviewer: Did [child's] age influence your use of complementary and alternative medicine for him at all? Parent: Probably. He was four, five, and six, and the thought of medication or ABA or other kinds of therapy seemed scarier, I guess, because he seemed so young and more fragile, perhaps.

The role of believing that ASD has major consequences on the child's life—

Three themes related to the relationship between the belief ASD has major consequences on the child's life and CHA use were identified.

Parents can reduce the impact of ASD on their child's life by using CHA: Twenty-three parents described how they were initially compelled to use CHA for their child because they wanted to ameliorate their child's ASD symptoms or, in a few cases, completely cure their child's ASD. For example, one parent shared:

Qigong was just something that came about during the timeframe that my daughter still was non-verbal and had been diagnosed already. I said, "Well, what else could we do to help her? I want to get her everything I can." That was an option.

Conventional healthcare is viewed as ineffective for ASD: Twenty-five parents expressed concerns about the efficacy and/or safety (i.e., effectiveness) of conventional healthcare to treat their child's ASD. For some parents these concerns were based on their past experiences using conventional healthcare, while for others their concerns were hypothetical. Regardless, parents' perceptions that conventional healthcare is ineffective for ASD was often ascribed to their decision to use CHA, as illustrated in the following quote:

I think I've sought [CHA] out more because it—traditional medicine—does not have any options for autism specifically. They tend to throw a lot at you that's very generic....I mean, it's basically just anti-depressants and anti-anxiety medication that's used to treat a lot of stuff that has nothing to do with autism. I mean, although anxiety is a component of autism, a kid that totally doesn't have autism is using the same medication that they're treating a lot of kids with [who have] autism. So, I don't really think that the medical community—because they don't have the research and knowledge yet to do so, really offers a lot of interventions that are [effective]. I mean, behavioral, yes. Therapy, yes. But in terms of true medical medicinal options, they really... offer you very little. In that way, it steers people more towards alternative medicines because those at least seem like they are addressing the symptoms of autism more directly. For instance, a probiotic with gut inflammation. I do think there's something to that. While I don't think it's the entire key, or they would've already cured autism, I definitely think it is a component that has to be considered.

CHA are viewed as effective for ASD: Twenty-nine parents described how they used CHA for their child with ASD because they believed it could improve or had improved their child's ASD symptoms. For some parents, the effectiveness of CHA for their child's ASD symptoms was described relative to their experiences with conventional healthcare. One parent described the preference for CHA in this way:

[N]obody could help us and nobody knew where to send us. The pediatrician didn't. They just wanted to keep giving him shots and I didn't want to do that because I believe that's what made him sick in the beginning. And so, then when we saw [a naturopath] and started seeing results with [CHA], and I didn't want to medicate him either. That scared me because I didn't want to create dependency. I wanted to fix the problem. I believe that now with everything, there's a root cause of everything and I want to fix the root. I don't want to stick a medicine band aid over the symptoms, I want to fix the root and heal him.

The role of geographic location—Quantitative results showed children with ASD from Denver, Colorado or Portland, Oregon had higher adjusted odds of using CHA than those from Los Angeles, California. All parents interviewed mentioned how where they lived had facilitated their use of CHA. Two key themes emerged around this topic.

CHA is widely accepted in the family's community, which facilitates use: When asked if their family's use of CHA was similar or different from the use of CHA in their community, many parents discussed how it was difficult to compare but that they generally thought their use of CHA was similar or less than use by others in their community. Most parents made these comparisons between themselves and other family members, co-workers, or other parents of children with ASD whom they associated with through support groups or educational classes. Often parents anchored these comparisons to where they currently lived; however, some parents compared the acceptability of CHA where they currently lived to places they had previously lived or visited.

I think [our use of CHA] is frankly to a minimum compared to where we live [...]. I see a lot of my neighbors, and we have a couple of families around us that do a lot of alternative medicine. We live close to [city name], so I don't know if that matters. But I almost feel like, you know, they're a little more holistic.

CHA accessibility in certain geographic locations makes use easy: Many parents also described how being easily able to access CHA in their community had facilitated use of CHA for their child with ASD. As one parent surmised: "We have easy access in [location name]. There's all sorts of places."

The role of medication use—Regarding the quantitative result that medication use was associated with greater use of CHA, the following theme emerged: ASD may necessitate multiple treatment approaches, including the concurrent use of medication and CHA. Although many parents discussed how they opted for more "natural" CHA instead of certain conventional healthcare, particularly medication, 16 parents reported using medication for their child with ASD. Some parents described how medication was or might be necessary for optimizing their child's health; however, parents often couched this by elaborating that medication is their last resort for treatment. As one parent described,

My philosophy is basically to try to treat it naturally, in a more natural way first, especially if it's something small like that. You don't just go to a pill right away that may have side effects and other problems that come with it. You try to treat it naturally first. But then if it's a huge problem and if it's something that needs more

traditional work, then fine we do that, but my philosophy is you try something else first and I feel like that's been good for him.

Discussion

Our study's findings provide new knowledge of why parents use CHA for children with ASD. This study is novel in that it is one of the first to show what and how different ecological factors at the child, family, and health system levels may influence parents' use of CHA among young children with ASD. Past research on this topic has generally relied on quantitative methodology, primarily cross-sectional surveys of nonprobability parent samples (Christon, Mackintosh, & Myers, 2010; Hall & Riccio, 2012; Hanson et al., 2007; Harrington, Rosen, & Garnecho, 2006; Hopf et al., 2016; Huang, Seshadri, Matthews, & Ostfield, 2013; Owen-Smith et al., 2015; Perrin et al., 2012; Valicenti-McDermott et al., 2013; H. Wong & Smith, 2006). By using qualitative results to help explain quantitative results, this study's findings contribute unique insights into why many parents use CHA for children with ASD.

Contrary to our hypotheses, which did not specify age would be correlated with use of CHA, study results demonstrated that parent use of CHA was more likely when children with ASD were younger. This finding aligns with some (Owen-Smith et al., 2015) but not all past research (Perrin et al., 2012; Valicenti-McDermott et al., 2013; H. Wong & Smith, 2006; V. C. N. Wong, 2009; Zuckerman, Lindly, Sinche, et al., 2015). Most studies have not shown a statistically significant association between age and use of CHA for children with ASD. Past research showing use of CHA is more likely in younger children with ASD than older children with ASD suggests older children may not want to use CHA and/or their parents may turn to other therapies after trying CHA when the child was first diagnosed with ASD (Owen-Smith et al., 2015). Our study's qualitative findings lend some support for the latter explanation because many parents interviewed described the cyclical nature of trying different treatments over time for their child with ASD. Parents described this cycle primarily in relationship to changes in their child's ASD symptoms, as well as feeling compelled to use CHA when children were younger to promote their healthy development and minimize health risks and because they viewed CHA as being relatively safe. Several parents who were interviewed did describe the ease of using CHA as decreasing with child age; however, this decrease in use was mainly regarding certain mind and body practices (e.g., qigong, massage therapy) rather than natural products (e.g., vitamins) or other approaches (e.g., special diets). To more fully understand how ease of use and the child's treatment preferences contribute to use of CHA, additional research capturing the perspectives of children with ASD using CHA is needed.

Past research shows parents of children with greater ASD severity or medical complexity (e.g., comorbid gastrointestinal problems, hyperactivity) (Hall & Riccio, 2012; Perrin et al., 2012; Salomone et al., 2015; Valicenti-McDermott et al., 2013) are more likely to use CHA for their child. We accordingly hypothesized that parent-reported ASD severity (i.e., mild vs. moderate or severe) would be associated with use of CHA; however, our study's results did not show a statistically significant association of parent-reported ASD severity with CHA use. Rather parents' belief that ASD has major consequences on the child's life—a variable

not examined in prior research on CHA use—was associated with being more likely to use CHA. Parent perceptions of their child’s ASD severity are related to ASD’s impact on their family (Zablotsky, Bramlett, & Blumberg, 2015). For this reason, the belief that ASD has major consequences on the child’s life may be more salient to parents than the somewhat arbitrary rating of ASD as being mild, moderate or severe. Therefore, this belief may also be more predictive of CHA use than ASD severity or medical complexity. Our qualitative findings further illuminate that parents may believe they can reduce ASD’s impact on their child’s life by using CHA, and relatedly, that they view CHA as being effective and conventional healthcare as being ineffective for treating ASD. Past research shows that parents commonly view CHA as efficacious for treating ASD (Christon et al., 2010; Hopf et al., 2016; Huang et al., 2013; H. Wong & Smith, 2006). Future research is, however, needed to determine how parents’ evolving beliefs regarding their child’s ASD in addition to their perceptions of the relative effectiveness of CHA and routinely recommended conventional therapies for their child’s ASD may influence parents’ decisions to continue or cease the use of CHA for their child over time. In addition, future research should examine how parent views regarding the safety of CHA (e.g., “it is natural”), as part of its effectiveness, are formed and what can be done to correct any erroneous views of safety that parents may have for potentially harmful modalities (e.g., chelation and hyperbaric oxygen therapy).

Little research has examined how place may affect parents’ use of CHA for children with ASD. One study did find U.S. school-aged children with ASD in the South were less likely than those in the West to use CHA (Zuckerman, Lindly, Sinche, et al., 2015). Our study showed parents of children with ASD in Denver or Portland may be more likely to use CHA for their child than those in Los Angeles. Qualitative findings suggest that the acceptability and accessibility of CHA in the family’s geographic location may contribute to such variation. Future research should determine how geography including rurality may deter parents’ use of CHA for their child’s ASD.

Our study’s finding that parents’ use of CHA is more likely for children with ASD who also use medication is consistent with some past research (Owen-Smith et al., 2015; Salomone et al., 2015) and lends some support for our hypothesis that higher services use is correlated with use of CHA. Earlier investigations have, indeed, suggested certain prescription medications (e.g., risperidone) may be efficacious for treating core and associated ASD symptoms (Huffman et al., 2011). Still, as demonstrated by our qualitative findings, parents may be reluctant to pursue medication—particularly psychotropic medication—until they have exhausted other treatment options they view as “safer.” That is, parents’ willingness to use medication may increase when they do not see improvement in their child’s ASD symptoms or when symptoms become more severe while using other treatment options. In this scenario, medication use may also reflect greater ASD severity or medical complexity, for which continued use and/or concurrent use of CHA may be viewed as necessary by parents in their efforts to optimize their child’s health.

Unlike past research (Akins et al., 2014; Hall & Riccio, 2012; Hanson et al., 2007; Owen-Smith et al., 2015; Salomone et al., 2015; H. Wong & Smith, 2006), our study’s results did not show a statistically significant association of parent education with use of CHA for their child’s ASD. This may be due in part to how education was measured in the survey (i.e.,

years of education rather than receipt of terminal degrees such as a high school diploma were asked about). In addition, the study sample surveyed was relatively homogeneous in terms of having an average of 13 or more years of education. Another plausible explanation is that education could have less bearing on parents' awareness of CHA and their decision to use it because information about CHA has become more widely accessible through sources like the Internet and CHA is more broadly available.

Limitations

This study has important limitations. First, we cannot generalize the quantitative results beyond the population from which the study sample was drawn. Nevertheless, probability sampling was used for the survey, and the survey sample included children who each had a verified ASD diagnosis. Much of the relevant past research has used nonprobability sampling and has not confirmed child ASD status. Also, regarding our study's quantitative component, post-hoc analysis results suggest that the use of CHA for ASD may have been reported to a lesser extent among most parents who completed the survey by mail versus the minority of parents who completed the survey by telephone. For this reason, additional research is needed to better understand parents' reporting biases about the use of CHA for children with ASD in relation to data collection mode and may be useful to best facilitate accurate reporting in future studies. Because we were only able to recruit parents from Denver or Portland for interviews, our qualitative findings are even more limited with respect to generalizability. Moreover, interviews were conducted with a purposive sample of parents who used CHA for their child with ASD, and consequently perspectives of those who were not recruited (e.g., parents who were unreachable, parents who did not elect to use CHA for their child with ASD) were not captured. Because the survey was not originally intended to focus on CHA, it did not measure certain factors such as household income that have been correlated with use of CHA in previous research. Relatedly, in the survey, parents may have reported CHA used for their child's ASD that was medically indicated (e.g., iron or vitamin D supplementation). For this reason, estimates of CHA use from the survey data may have been biased because it was not possible to determine if the various modalities reported were medically indicated or were considered by parents to be CHA. All interviews were conducted by telephone to maximize the convenience of participation for parents; however, this mode of data collection could have reduced the comfort level and/or rapport between the interviewer and participants. More broadly, this study only included data from parents of children with ASD, an important but singular information source. Consequently, further research is needed to elucidate the mechanism through which use of CHA occurs for ASD by incorporating child and provider perspectives.

Conclusions

Findings from our mixed methods study show that parents' decision to use CHA for their child with ASD is often multifactorial. Quantitative study results demonstrate child age, parent beliefs about the consequences of ASD for their child's life, geographic location, and medication use are each associated with parents' use of CHA for their child's ASD. Qualitative study results provide further insights into why and how these factors contribute to parents' use of CHA for children with ASD. Parents generally have the best intentions when deciding to use CHA for their child with ASD, that is, to optimize the child's health.

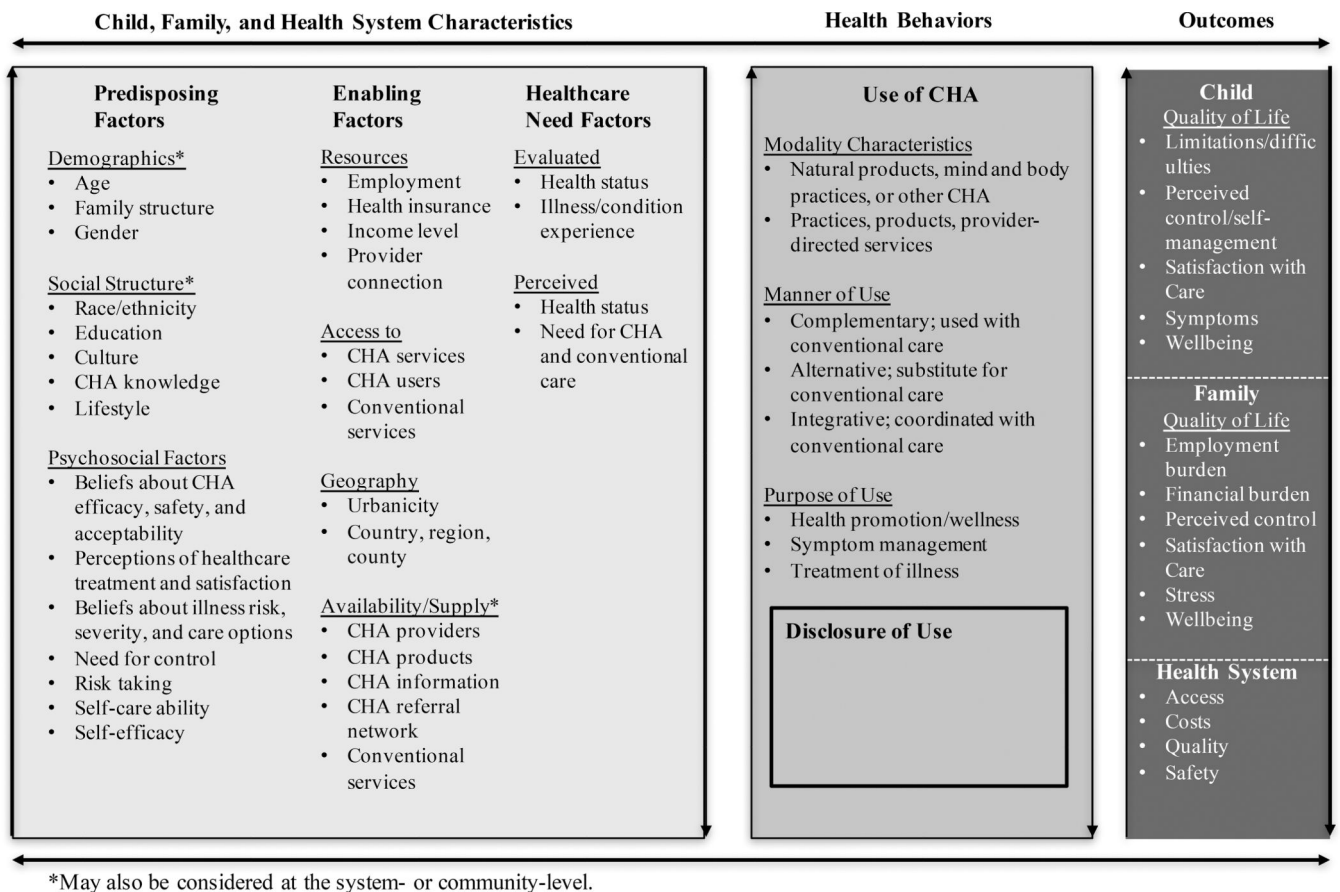
Yet these intentions may be misinformed contributing to the use of ineffective, unsafe, and/or costly CHA for children with ASD, in some cases at the exclusion of potentially efficacious behavioral or educational interventions for ASD. Efforts to increase parents' understanding of viable ASD treatment options and resources during or directly following the diagnostic process may enable parents to make better informed treatment decisions, which may include the use of CHA, for their child. Ensuring that conventional healthcare providers understand the context within which families often make treatment decisions for a child's ASD, and more specifically the factors likely to influence a parent's use of CHA for their child with ASD, may also help families and providers better partner in optimizing the treatment for and health of children with ASD.

Acknowledgments

This study was supported by the Agency for Healthcare Research and Quality grant # 5T32HS000063–24, by the Ruth Warnke Graduate Fellowship from Oregon State University, and by the National Institute of Mental Health grant # K23MH095828. We thank Lorraine Ball, Adam Branscum, Joseph Catania, Kari-Lyn Sakuma, and Emily Ho for their feedback on the research reported. We also thank Ann Reynolds and Kathryn Smith for their assistance with the submission of research protocol materials to their respective Institutional Review Boards.

Funding: This study was supported by the Agency for Healthcare Research and Quality grant # T32HS000063, by the Ruth Warnke Graduate Fellowship from Oregon State University, and by the National Institute of Mental Health grant # K23MH095828.

Appendix



Conceptual framework (adapted from Fouladbakhsh & Stommel, 2007)

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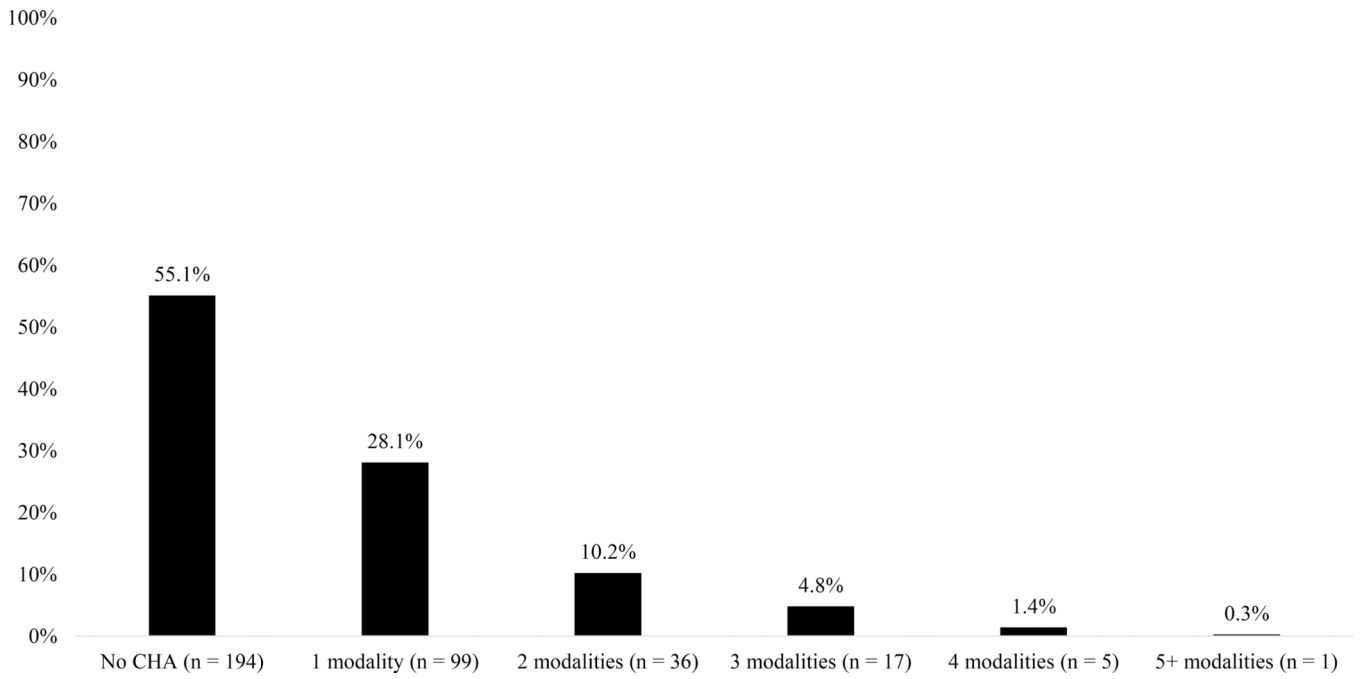


Figure 1. Percentage of children with autism spectrum disorder aged 2–10 years who used no, one, two, three, four, or five or more complementary health approaches as reported in the survey.

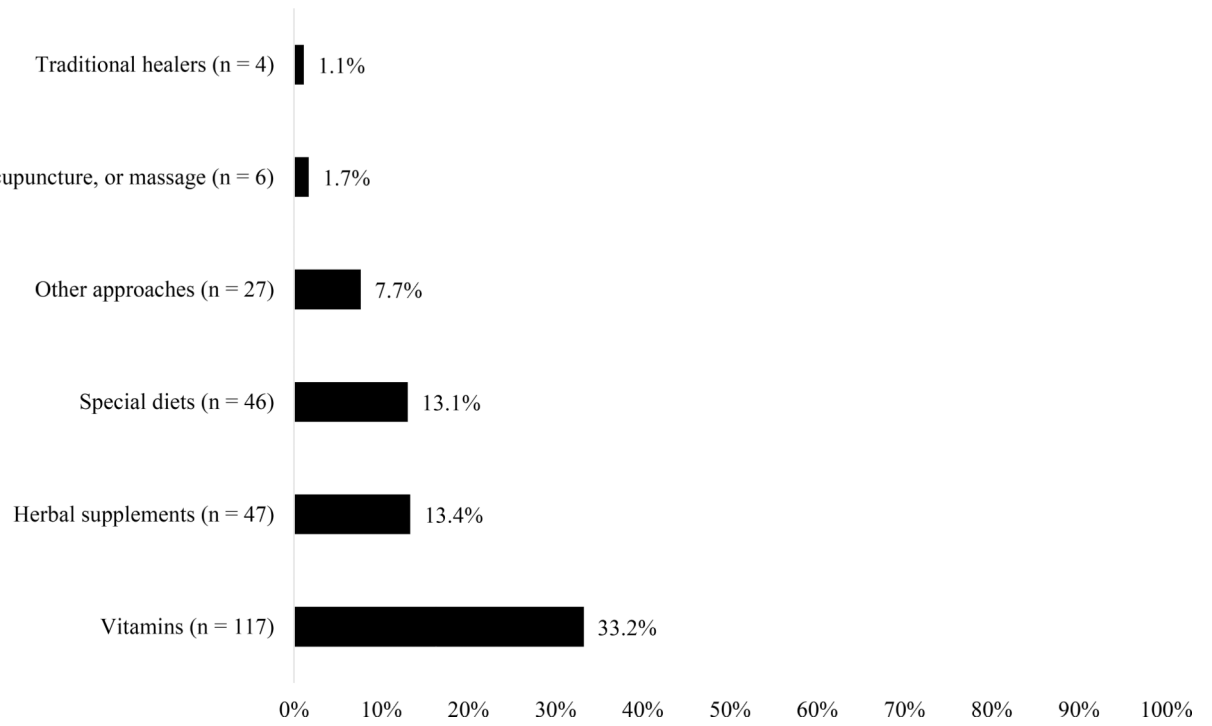


Figure 2. Type of complementary health approaches used by children with autism spectrum disorder aged 2–10 years, as reported in the survey.

Table 1

Child, Family, and Health System Factors among a Probability Sample of Children with ASD aged 2–10 years, Overall and by Any Use of Complementary Health Approaches

	Overall ^a	No CHA	Any CHA	No vs. Any CHA OR (95% CI)
<i>N</i> (%)	352 (100%)	194 (55.1%)	158 (44.9%)	—
<u>Child level</u>				
Age, years (<i>n</i>=343)				
<i>M</i> (<i>SD</i>)	6.17 (2.00)	6.33 (2.04)	5.99 (1.93)	0.92 [0.82, 1.02]
<i>p</i> -value			0.11	
Age when ASD diagnosed (<i>n</i>=346)				
Mean (<i>SD</i>)	3.47 (1.42)	3.64 (1.47)	3.28 (1.35)	0.83 [0.71, 0.97]
<i>p</i> -value			0.02	
Sex (<i>n</i> =348)				
Male (<i>n</i> =291)	83.6%	56.4%	43.6%	1.00
Female (<i>n</i> =57)	16.4%	49.1%	50.9%	1.34 [0.76, 2.36]
<i>p</i> -value			0.32	
Health insurance coverage (<i>n</i> =347)				
Public health insurance only (<i>n</i> =210)	60.5%	53.3%	46.7%	1.00
Any private health insurance (<i>n</i> =137)	39.5%	56.9%	43.1%	0.86 [0.56, 1.33]
<i>p</i> -value			0.51	
Child ASD severity (<i>n</i>=344)				
Mild (<i>n</i> =162)	47.1%	64.2%	35.8%	1.00
Moderate or severe (<i>n</i> =182)	52.9%	47.3%	52.8%	2.00 [1.30, 3.09]
<i>p</i> -value			0.002	
<u>Family level</u>				
Family ethnicity and language (<i>n</i>=352)				
Non-Latino, white, English proficient (<i>n</i> =163)	46.3%	49.7%	50.3%	1.00
Latino, English proficient (<i>n</i> =95)	27.0%	57.9%	42.1%	0.72 [0.43, 1.20]
Latino, limited English proficiency (<i>n</i> =94)	26.7%	61.7%	38.3%	0.61 [0.37, 1.03]
<i>p</i> -value			0.14	
Children per household (<i>n</i> =346)				
<i>M</i> (<i>SD</i>)	2.14 (1.09)	2.18 (1.08)	2.07 (1.10)	0.91 [0.74, 1.10]
<i>p</i> -value			0.32	
Children with ASD per household (<i>n</i> =342)				
Mean (<i>SD</i>)	1.14 (0.44)	1.12 (0.43)	1.17 (0.46)	1.29 [0.79, 2.11]
<i>p</i> -value			0.3	
Parent nativity (<i>n</i> =352)				
Always lived in U.S. (<i>n</i> = 228)	64.8%	53.5%	46.5%	1.00
Lived outside the U.S. (<i>n</i> =124)	35.2%	58.1%	41.9%	0.83 [0.53, 1.29]
<i>p</i> -value			0.41	
Family structure (<i>n</i> =351)				
Married or living with partner (<i>n</i> =278)	79.2%	55.8%	44.2%	1.00

	Overall ^a	No CHA	Any CHA	No vs. Any CHA OR (95% CI)
Single (<i>n</i> =32)	9.1%	50.0%	50.0%	1.26 [0.61, 2.62]
Other (<i>n</i> =41)	11.7%	53.7%	46.3%	1.09 [0.56, 2.10]
<i>p</i> -value			0.81	
Parent education, years (<i>n</i> =345)				
<i>M</i> (<i>SD</i>)	13.65 (3.91)	13.44 (4.13)	13.91 (3.62)	1.03 [0.98, 1.09]
<i>p</i> -value			0.26	
Parent employment (<i>n</i>=352)				
Employed (<i>n</i> =174)	49.4%	50.0%	50.0%	1.00
Unemployed (<i>n</i> =178)	50.6%	60.1%	39.9%	0.66 [0.44, 1.01]
<i>p</i> -value			0.06	
Delay in parent concern and talking w/provider (<i>n</i> =343)				
<i>M</i> (<i>SD</i>)	0.40 (0.75)	0.40 (0.73)	0.41 (0.78)	1.02 [0.77, 1.36]
<i>p</i> -value			0.87	
Belief ASD is lifelong vs. temporary (<i>n</i> =350)				
Disagree (<i>n</i> =68)	19.4%	55.4%	44.6%	1.00
Agree (<i>n</i> =282)	80.6%	55.0%	44.0%	0.98 [0.57, 1.66]
<i>p</i> -value			0.93	
Belief that challenges of ASD can be decreased with treatment (<i>n</i> =349)				
Disagree (<i>n</i> =35)	10.0%	57.1%	42.9%	1.00
Agree (<i>n</i> =314)	90.0%	54.5%	45.5%	1.12 [0.55, 2.26]
<i>p</i> -value			0.76	
Belief about having the power to change child's ASD (<i>n</i> =346)				
Disagree (<i>n</i> =182)	52.6%	58.2%	41.8%	1.00
Agree (<i>n</i> =164)	47.4%	51.2%	48.8%	1.33 [0.87, 2.03]
<i>p</i> -value			0.19	
Belief child's ASD is a mystery (<i>n</i> =347)				
Disagree (<i>n</i> =205)	59.1%	54.6%	45.4%	1.00
Agree (<i>n</i> =142)	40.9%	54.9%	45.1%	0.99 [0.64, 1.52]
<i>p</i> -value			0.96	
Being upset when thinking about child's ASD (<i>n</i> =345)				
Disagree (<i>n</i> =187)	54.2%	55.6%	44.4%	1.00
Agree (<i>n</i> =158)	45.8%	53.8%	46.2%	1.08 [0.70, 1.65]
<i>p</i> -value			0.74	
Belief ASD has major consequences on child's life (<i>n</i>=344)				
Disagree (<i>n</i> =97)	28.2%	68.0%	32.0%	1.00
Agree (<i>n</i> =247)	71.8%	49.4%	50.6%	2.18 [1.33, 3.58]
<i>p</i> -value			0.002	
<u>Health system level</u>				
Perceived ASD stigma (<i>n</i>=349)				
<i>M</i> (<i>SD</i>)	2.31 (0.60)	2.27 (0.65)	2.37 (0.54)	1.35 [0.95, 1.92]
<i>p</i> -value			0.09	

	Overall ^a	No CHA	Any CHA	No vs. Any CHA OR (95% CI)
Site (n=352)				
Los Angeles, California (n=114)	32.4%	63.2%	36.8%	1.00
Denver, Colorado (n=110)	31.3%	52.7%	47.3%	1.54 [0.90, 2.62]
Portland, Oregon (n=128)	36.4%	50.0%	50.0%	1.71 [1.02, 2.87]
<i>p</i> -value		0.10		
ASD diagnostic delay, years (n=345)				
<i>M</i> (<i>SD</i>)	1.35 (1.19)	1.39 (1.29)	1.31 (1.06)	0.95 [0.79, 1.13]
<i>p</i> -value		0.54		
Number of barriers experienced to ASD care (n=352)				
<i>M</i> (<i>SD</i>)	7.56 (2.70)	7.48 (2.79)	7.66 (2.59)	1.03 [0.95, 1.11]
<i>p</i> -value		0.52		
Conventional therapy services^b used (n=352)				
Mean (<i>SD</i>)	2.73 (1.44)	2.56 (1.33)	2.94 (1.55)	1.20 [1.04, 1.40]
<i>p</i> -value		0.02		
Weekly dose of therapy services (n=344)				
<1 or no hours per week (n=56)	16.3%	60.7%	39.3%	1.00
1–10 hours per week (n=215)	62.5%	57.7%	42.3%	1.13 [0.62, 2.07]
> 10 hours per week (n=73)	21.2%	42.5%	57.5%	2.09 [1.03, 4.26]
<i>p</i> -value		0.05		
Receipt of special education services (n=352)				
No (n=186)	52.8%	59.7%	40.3%	1.00
Yes (n=166)	47.2%	50.0%	50.0%	1.48 [0.97, 2.56]
<i>p</i> -value		0.07		
Use of Applied Behavioral Analysis (n=352)				
No (n=275)	78.1%	58.6%	41.5%	1.00
Yes (n=77)	21.9%	42.9%	57.1%	1.88 [1.13, 3.14]
<i>p</i> -value		0.01		
Medication use (n=352)				
No (n=263)	74.7%	61.6%	38.4%	1.00
Yes (n=89)	25.3%	36.0%	64.0%	2.86 [1.73, 4.71]
<i>p</i> -value		< .001		
Unmet need for therapy services (n=345)				
No (n=176)	51.0%	55.1%	44.9%	1.00
Yes (n=169)	49.0%	54.4%	45.6%	1.03 [0.67, 1.57]
<i>p</i> -value		0.90		

^aNot all percentages sum to 100% due to rounding.

^bThe following conventional treatment services for ASD were included: speech and language therapy, social skills training, occupational therapy, psychological counseling, applied behavioral analysis, other behavioral therapy, and other therapy). Does not include any CHA.

Note. ASD = autism spectrum disorder; CHA = complementary health approaches; CI = confidence interval; *M* = mean; *SD* = standard deviation. Differences in distributions of binary or nominal variables by use of CHA were determined using Pearson chi-square tests, and with two-sample *t*-tests adjusted for unequal variances for continuous or count variables. Bolded variables had statistically significant associations at a *p* < .15 level.

Table 2

Characteristics of Parents Interviewed and their Children with ASD

	<i>n</i>	%
<u>Parent</u>		
Relationship to child with ASD		
Mother	29	94%
Father	1	3%
Grandmother	1	3%
Age, years		
Median (Range)	36 (25–51)	
Ethnicity		
Non-Latino	19	61%
Latino	12	39%
Lived in the U.S. entire life	26	84%
Years of education		
Median (Range)	14.5 (12–20)	
Currently employed at a paid job	25	81%
<u>Child</u>		
Age at time of interview, years		
Median (Range)	8 (6–12)	
Ethnicity		
Non-Latino	19	61%
Latino	12	39%
Sex		
Male	25	81%
Female	6	19%

Note. ASD = autism spectrum disorder. Parent and child characteristics were based on the quantitative survey data gathered, unless otherwise indicated.

Table 3

Final Multivariable Logistic Regression Model Results (n = 351)

	aOR (95% CI): <u>Any Use of CHA</u>
<u>Child level</u>	
Age, years	0.85 [0.76, 0.96]
<i>p</i> -value	0.008
<u>Family level</u>	
Belief ASD has major consequences on the child's life	
Disagree	1.00
Agree	1.77 [1.08, 2.92]
<i>p</i> -value	0.03
<u>Health system level</u>	
Location	
Los Angeles, California	1.00
Denver, Colorado	1.99 [1.13, 2.92]
<i>p</i> -value	0.017
Portland, Oregon	2.03 [1.18, 3.50]
<i>p</i> -value	0.010
Use of medication	
No	1.00
Yes	3.27 [1.91, 5.61]
<i>p</i> -value	< .001
<u>Model Fit</u>	
Hosmer-Lemeshow chi2 (<i>df</i>)	10.31 (8)
Prob > chi2	0.24

Note. aOR = adjusted odds ratio; CHA = complementary health approaches; CI = confidence interval. Variables that did not have a statistically significant association with use of CHA at the $p < .15$ level in the initial multivariable model were excluded from the final model and are not included in the table.

Table 4

Use of Complementary Health Approaches Reported by Parents Interviewed

	<i>n</i>	%
<u>Modalities used</u>		
<i>Natural products overall</i>	29	94%
Herbal or non-vitamin supplements	19	61%
Specific vitamins and/or minerals	18	58%
Multivitamins/minerals	17	55%
Essential oils	7	23%
Herbal teas	3	10%
Cannabis	1	3%
<i>Mind and body practices overall</i>	25	81%
Massage therapy	11	35%
Yoga	8	26%
Qigong	8	26%
Meditation	6	19%
Biofeedback	5	16%
Music therapy	3	10%
Equestrian therapy	3	10%
Movement therapy	2	6%
Progressive relaxation	2	6%
Chiropractic or osteopathic manipulation	2	6%
Skin brushing	2	6%
Acupuncture	1	3%
Hydrotherapy	1	3%
Deep breathing exercises	1	3%
<i>Other modalities overall</i>	25	81%
Special diets	23	74%
Naturopathy	8	26%
Homeopathy	5	16%
Nebulizer or Vaporizer	3	10%
Chelation	2	6%
Hyperbaric oxygen therapy	2	6%
Books	1	3%
<i>Provider-directed use of CHA</i>	20	65%
<u>Manner of use</u>		
Complementary to conventional healthcare	22	71%
Alternative to conventional healthcare	13	42%
Integrative with conventional healthcare	10	32%

Note. CHA = complementary health approaches. Modalities were reported as being ever or currently used.