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Published in final edited form as:

Child Care Health Dev. 2018 November ; 44(6): 916–925. doi:10.1111/cch.12612.

Comparison of maternal beliefs about causes of autism spectrum disorder and association with utilization of services and treatments

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Abstract

Background: This study aimed to describe parental perceptions of the causes of autism spectrum disorder (ASD) in an ethnically diverse sample and explore whether these perceptions relate to treatment choices.

Methods: The sample consisted of White (n=224), Hispanic (n=85) and Asian (n=21) mothers of a child with ASD. A mixed methods approach was used in this secondary analysis focusing on parental perceptions about the causes of ASD and the relationship of these to utilization of services and treatment.

Results: Environmental and genetic factors were most often believed to be the cause or one of the causes of ASD by mothers across all ethnic groups studied. Asian mothers were more likely to cite multiple causes. Environmental causes were associated with receiving 20 or more hours of autism related services per week; while belief in environmental exposures and vaccines and medications as causes were associated with complementary-alternative medicine (CAM) use.

Conclusion: Our findings suggest that ethnic differences in autism causal beliefs and treatment choices may exist. Future research should be conducted to specifically confirm the findings, to understand parental motivation behind their service and treatment choices; and to gain more insight into the types, usage and sources of CAM treatments. Clinicians can use parental autism causal beliefs in discussions about treatment recommendations.

Keywords

Autism spectrum disorder; parental beliefs; causes; services and treatment

Introduction

It is estimated that autism spectrum disorder (ASD) affects 1 in 59 US children (Baio, et al. 2018). For researchers and clinicians, understanding family perspectives in ASD care is integral to research in health system design and forming therapeutic clinical relationships (Carbone, et al. 2013). Research on family perspectives in ASD has focused on families' perceptions of the possible causes of ASD. The body of this research reveals that parents' perceptions of causes have evolved (Elder, 1994; Harrington, Patrick, Edwards, & Brand, 2006; Harrington, Rosen, Garnecho, & Patrick, 2006; Russell, Kelly, & Golding, 2009; Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010; Goin-Kochel, Mire, & Dempsey, 2015; Zuckerman, Lindly, & Sinche, 2016; Fischbach, Harris, Ballan, Fischbach, & Link, 2016) as the scientific community's hypotheses about the pathophysiologic mechanisms underpinning ASD have changed in the last fifty years. The growing consensus in both communities is that ASD is a multi-factorial neurodevelopmental disorder involving the interaction of environmental and genetic factors. However, there is less investigation into the other aspect of family perspectives in ASD care, namely, what influences the use of services and treatments by parents of children with ASD.

There are many potential drivers of ASD service use. In investigating ASD service use from a family perspective, it is helpful to consider parents' decision-making and choices around utilization of services and treatment for their child with ASD as a 'health behavior'. There are accepted theories of health behavior and behavior change, such as the Health Belief Model (Janz & Becker MH, 1984) and the Theory of Planned Behavior (Ajzen & Fishbein, 1980), which define and categorize which factors could lead to service use. From that point of departure, previous research in ASD care helps to refine which specific possible factors highlighted in health behavior models are most promising to consider further. Such research suggests that parents' beliefs, attitudes and subjective norms around ASD care can play mediating roles, and health behaviors can be changed by targeting these constructs. In a review, Hebert and Koulouglioti (2010), cited 13 articles published from 1995 through 2009 and concluded that there is limited research directly examining the link between parental beliefs and their decision regarding interventions for their child with ASD. That same year, Al Anbar et al. (2010) studied this link and found causal beliefs to have strong effects on treatment use. Both external and hereditary causal attributions were associated with the use of nutritional treatments, especially special diets and vitamin supplements. In a review, Carlon, Carter, & Stephenson (2013) found that there are a large number of factors likely to be involved in parents' decision-making around utilization of treatments and services. As such, they recommended that future research should focus on understanding parents' relative weighing of these factors when making decisions. Their review focused only on declared decision-making factors, acknowledging that implicit underlying factors such as causal beliefs may also weigh in the decision-making process. Indeed, Zuckerman, Lindly, &

Sinche (2016) called for examining the impact of beliefs about causes of ASD on treatment utilization.

In addition beliefs, norms, and attitudes, previous research also suggests focusing on families' own characteristics, such as primary language, socio-economic status (SES), ethnicity or race (Hebert & Koulouglioti, 2010), as other possible determinants of ASD care. In a review, Mandell and Novak (2005) reported some limited evidence to suggest members of different cultures respond differently to similar impairments of ASD, including interpretation of symptoms, family decisions regarding interventions and interactions between families and the healthcare system. In 2010, Al Anbar et al. found parental age and years of education were not associated with any treatment (Al Anbar 2010). Conversely, a recent study found that some social determinants of health (SDH) were associated with variation in health services utilization (Zuckerman, Lindly, Sinche, & Nicolaidis, 2015). Near-poor families were less likely to believe they had the power to change their child's condition; parents of minority children were more likely to believe their child's condition was temporary than white parents; and less educated parents or those from lower SES were more likely to think their child's ASD was a mystery. Ultimately, the authors noted that it is unclear whether differing beliefs are helpful or harmful or what the variation in parental beliefs even means.

Our overall goal for this current exploratory and descriptive study is to build on these health behavior theories refined by this previous research to inform future research directions and clinician-family communications about ASD treatment choices (Zuckerman et al., 2016). We used a stepwise mixed methods secondary analysis of a large dataset to expand on current literature about parents' perception of ASD causes, how these may influence treatment choices, and how these may be influenced by parental demographic characteristics. We pursued three specific analytic steps. First, we sought to qualitatively analyze mothers' beliefs about ASD causes and reported ASD treatment utilization. Second, we sought to describe the distribution of ASD causal beliefs and treatment utilization overall and by race/ethnicity and primary language. Lastly, we sought to investigate whether ASD causal beliefs were associated with ASD treatment utilization.

Methods

Participants

The (REMOVED FOR BLINDING) study is an ongoing (starting in January 2003) population-based case-control study with subjects sampled from three strata: children with autism spectrum disorder (ASD), children with developmental delay (DD) but not ASD, and children selected from the general population (GP). We limited this secondary analysis to families of children diagnosed with ASD to focus on the parental perceptions about the causes of ASD and the relationship of these to utilization of services and treatment. A total of 330 mothers with children with ASD and who met our criteria for this secondary analysis were enrolled in the primary study between January 2003 and December 2009, the timeframe for our secondary analysis. All participating children met the following eligibility criteria: (a) between the ages of 24 and 60 months, (b) living with at least one biologic parent who speaks English or Spanish, (d) born in California, and (e) residing in one of the

catchment areas of a specified list of Regional Centers (RC) in California. Children with ASD are identified from within the California Department of Developmental Services (DDS), which provides services for individuals who qualify with developmental disabilities, regardless of race, ethnicity, socioeconomics, or immigration status.

The diagnosis of ASD was confirmed with the Autism Diagnostic Interview, Revised (ADI-R) (Le Couteur, Lord, & Rutter, 1993) and Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000) administered by trained, research-reliable clinicians. We focused on the causal beliefs of mothers because they were nearly always the parent who completed the research interview and questionnaires. We included data only from mothers who self-identified as White, Hispanic, and Asian race/ethnic groups because the proportions of mothers from other ethnic groups were too small to be generalizable. Mothers who reported: White race only and no other race or ethnicity were coded as “White” (n=224); Hispanic ethnicity regardless of the race reported were coded as “Hispanic” (n=85); and Asian race only and no other race or ethnicity were coded as “Asian” (n=21). The institutional review boards for the State of California and the BLINDED approved the study. Informed consent was obtained from all participants prior to data collection.

Data Collection

Every child with ASD in the BLINDED study received a set of standardized measures described previously (citation removed for blinding). Measures relevant to this secondary analysis include the Multiple Language Questionnaire (MLQ); the Environmental Exposure Questionnaire (EEQ); and the physician-administered child and family medical history interview, including a Services and Treatment Interview (STI).

The MLQ is a brief questionnaire used to determine languages used at home. Primary language was determined based on the MLQ question “What is the language spoken *most often* to your child?” The EEQ is a structured telephone interview with the mother and includes questions about demographic characteristics, environmental exposures and the open-ended question, “What do you think causes Autism?” The STI provided data on treatments sought in four areas. Area 1 encompassed ASD-related services provided by professionals. These included: behavioral modification therapy through a psychologist or paraprofessional/home trainer; speech therapy; occupational therapy; physical therapy; sensory integration therapy; psychiatry; vision services; nutrition; music therapy; and art therapy. This outcome variable was categorized as yes/no for receiving any “professional” services. Area 2 included the total number of service hours per week the child is currently receiving. This outcome variable was categorized as 20 hours per week or 20 hours per week. While there is a limited but growing evidence-base to support any dose or mode of therapy for ASD in terms of long-term outcomes, some experts recommend 20 hours per week or more of autism specific services in early childhood based on promising results in clinical trials (National Research Council, 2001). Area 3 encompassed all conventional prescription medications used by the child. These included psychotropic medications; anti-convulsants; gastric reflux medications; constipation medication; other miscellaneous medications; and medically prescribed diets. Area 4 related to ASD treatment currently or ever received by the child through complementary and alternative medicine therapies,

special diets, vitamins, food supplements, or alternative treatments including special injections (e.g., immunoglobulins, secretin, chelation agents). These definitions have been fully described previously (Citation removed for blinding).

Qualitative Analysis

Two researchers with different areas of expertise independently coded parent responses to the open-ended question “What do you think causes autism?” Specific coding categories were created using a hybrid deductive and inductive process. First, we predetermined categories based on literature which included: environmental, genetic, vaccines, maternal factors, childhood illnesses, antibiotics, food, mercury, autoimmune/immune-related, pregnancy complications, old age when conceiving, maternal drugs/alcohol use, neonatal/childhood illness and neurological. Then, additional categories were created based on emerging themes from parent responses. In the interim, the two researchers kept notes and had regular discussions and check-ins about how to code parent responses. Causal beliefs were then collapsed into six main themes: Environmental, Genetic, Vaccines/Medications, Biomedical/Maternal, Biomedical/Child, and “Don’t Know.” This last category consisted of only those mothers who stated they did not know what causes autism and did not make any guesses. After independent coding, the percent agreement for responses was quantified and discrepancies >1% were identified, discussed and resolved. For example, if one researcher coded 2.4% of all responses into the ‘immune’ category and the second researcher coded 3.5% of all responses into the ‘immune’ category, then the two researchers discussed the types of responses coded into that category until there was consensus about how to handle such discrepancies. Only two categories (prior to grouping into the six main categories) had discrepancies >1%.

Statistical Analysis

Descriptive Analyses—We examined demographic characteristics across race/ethnic groups using likelihood ratio chi-square tests for categorical variables (or Fisher’s exact test when cell sizes were <5) and one-way analysis of variance (ANOVA) for continuous variables. We calculated proportions to describe the distribution of the categories of causes of ASD overall and by race/ethnicity. In the course of our qualitative analysis, we discovered that mothers could report more than one causal belief. Therefore, we calculated proportions to describe the distribution of the number of ASD causal beliefs held by participants, overall and by race/ethnicity.

Comparative Analyses—We used regression analyses to test for apparent differences while adjusting for maternal demographic characteristics. Because participants often cited more than one cause and beliefs are not strongly correlated with each other (Zuckerman et al., 2016), we examined differences in each categorical theme of perceived ASD cause between race/ethnicity groups (Hispanic and Asian each vs. White respondents). Second, we examined differences in each perceived ASD cause category by language (English-speaking vs. non-English-speaking) irrespective of race/ethnicity (Hispanic or Asian). Third, we investigated the differences in number of causes cited by parents by race/ethnicity (Hispanic and Asian each vs. White respondents). Fourth, we examined differences in services and treatment utilization between race/ethnic groups (Hispanic and Asian each vs. White

respondents). Fifth, we examined the relationship between ASD causal beliefs and service and treatment utilization. For binary outcomes, we estimated prevalence ratios and 95% confidence intervals using Poisson regression with robust error variance. For the outcome number of causes, we used a Poisson regression model to estimate the mean difference in log counts (β coefficient) and 95% confidence intervals. In all models we adjusted for (where appropriate) maternal education, race/ethnicity and/or primary language.

Results

Descriptive Outcomes

In our study sample, over half of Asian and White mothers had completed formal higher education (college degree or higher) compared to one-third of Hispanic mothers, $p < 0.0001$ (Table 1). Approximately two-thirds of this study population was White, one-quarter was Hispanic and less than ten percent was Asian. Approximately a quarter of Asian mothers and one-third of Hispanic mothers reported a language other than English as their primary language. Table 2 provides a list of the specific ASD causes that resulted from our qualitative analysis, organized within the six categorical themes into which they were grouped for quantitative analyses: Environmental, Genetics, Vaccines/Medications, Biomedical/Maternal, Biomedical/Child, and Don't Know. Table 3 provides the distribution of categories of ASD causes in the sample regardless of the number of causes reported by a given participant. That is, respondents can be counted more than once if they gave more than one cause. Overall, Genetic (51.5%) and Environmental (50.9%) factors were the most commonly cited causes of ASD, with Biomedical/Maternal being the least (5.5%). Table 4 presents the distribution of the number of causal belief categories reported by each mother. Overall, mothers were as likely to report singular (1 cause or don't know; 48.5%) than multiple (2 or more causes; 51.5%) causal beliefs. Of mothers who cited causes of ASD, most cited two causes, with few citing 3 or 4 causes and the largest number of causes being 5 (reported by only 1 participant).

Comparative Outcomes

Table 3 summarizes the findings of comparison in causal belief categories with respect to race/ethnicity. There was a difference in percent, with Hispanic mothers being less likely (41.2%) and Asian mothers being more likely (61.9%) to cite genetic causes than White mothers (54.5%), but when adjusted for maternal education and language, there were no statistically significant differences. Similarly, comparison of causal beliefs between mothers whose primary language was English versus non-English yielded no statistically significant differences (data not shown). Table 4 contains results of comparisons in the number of causal belief categories reported by each mother by race/ethnicity. Percents differed by race/ethnicity, with Asian mothers appearing more likely to report more than one cause (the one person reporting 5 causes was an Asian respondent). This was reproduced in crude Poisson models, where Asian mothers cited 1.25 more causes than White mothers (95% CI 1.01, 1.54; $p = 0.036$), but was not statistically significant when adjusted for maternal education and language (1.22; 95% CI 1.0002, 1.50; $p = 0.0498$). The comparison for Hispanic respondents to White respondents was not significant. There was great variability in the specific combinations and types of causes when mothers reported more than one

cause, precluding further analysis of these combinations by race/ethnicity and supporting other evidence that specific causes are not correlated with each other. Ethnic/Race comparisons of services and treatment utilization did not reveal any significant differences between groups when stratified by education level (data not shown).

Several noteworthy relationships emerged between causal beliefs and utilization of services and/or treatments after adjusting for maternal education, maternal race/ethnicity and maternal primary language (Table 5). The children of mothers who reported Environmental factors as a cause of ASD were more likely to receive 20 or more hours of services per week and to use complementary-alternative medicine (CAM) treatments than those who did not cite Environmental causes (adjusted PR [aPR] 1.38, 95% CI 1.09, 1.78 and aPR 1.72, 95% CI 1.16, 2.56, respectively). Similarly, those who cited Vaccines/Medications as a cause were more likely to report use of CAM treatments than those who did not cite Vaccines/Medications as a cause (aPR 1.65, 95% CI 1.13, 2.42). Finally, mothers who reported “Don’t Know” as a cause were more likely to use conventional medications than mothers who cited at least one causal factor (aPR 1.55, 95% CI 1.02, 2.36).

Discussion

Our overall goal was to explore family perceptions of ASD care in an effort to provide new insight on factors that may influence ASD service use. We specifically examined ASD causal beliefs and family demographic factors as potential levers of ASD treatment choice based on health behavior theories; a novel and recommended approach (Carlton, Carter, & Stephenson, 2013) refined by previous research. Beginning with our investigation of causal beliefs, we found that maternal beliefs about the causes of ASD did not differ across ethnic groups nor by language fluency. In general, environmental and genetic factors were most often believed to be the cause or one of the causes of ASD by mothers across all ethnic groups. The least endorsed causes were maternally-related biomedical factors. As multi-factorial causes are being increasingly supported by research, the public acceptance of such findings has grown as well. At least half of our sample believes environmental or genetic factors are implicated in the development of ASD. These findings are consistent with the literature describing trends in public beliefs about ASD causes over time, showing that beliefs in environmental and genetic factors have increased while beliefs that vaccinations cause ASD have decreased (Harrington, et al., 2006; Harrington, et al., 2006; Russell et al., 2009; Al Anbar et al., 2010; Goin-Kochel et al., 2015; Fischbach, et al. 2016; Zuckerman et al. 2016; Mitchell & Locke, 2015).

The decline in vaccines being cited as a cause of ASD coincides with the retraction of the Wakefield study that suggested a possible link between the measles-mumps-rubella (MMR) vaccine and ASD (Wakefield et al., 1998) and with the increase of epidemiological studies that have weighed against this hypothesis, to a point where it can reasonably be considered disproven (Institute of Medicine, 2012; Taylor et al., 1999). It is worth noting that studies continue to indicate prevailing beliefs that vaccinations cause ASD may still exist among various groups, including parents of children with ASD (Bazzano, Zeldin, Schuster, Barrett & Lehrer, 2012; Wolff & Madlon-Kay, 2014; Fischbah et al., 2016; Mitchell et al., 2015). It is unclear why vaccine-associated beliefs persist in studies, although it may depend in part

on the group sampled (scientists, childcare providers, general public, or parents) (Fischbah et al., 2016; Mitchell et al., 2015). One study found that parents tend to incorporate new information within their existing beliefs about the etiology of ASD (Reiff et al., 2017). Perhaps for individuals who have experience with adverse vaccine reactions, the plausibility that vaccines cause ASD would fit into their existing beliefs where vaccinations are associated with adverse effects.

It was not our intent to investigate the number of causal beliefs reported by each mother. However, we did proceed with the analysis, as it became apparent that mothers reported more than one causal belief category as often as reporting a single one. Reporting more than one causal belief is consistent with previous studies (Harrington et al., 2006; Harrington et al., 2006; Al Anbar et al., 2010; Zuckerman, et al., 2016; Reiff et al., 2017). However, previous studies have not described to the extent that we have, the types, number and combination of causes cited by parents. In doing so, we found that parents typically cited between one and five causes of autism, where the greatest number of mutually exclusive combinations involved parents who cited two causes. Overall, there was great variability in the specific combinations and types of causes when more than one cause was cited. The number of mutually exclusive combinations is actually greater than what was depicted in our summary table, since parents actual responses were coded and collapsed into categorical themes. Indeed, in one qualitative study, over 40 different environmental causes were identified regarding the etiology of ASD, illustrating the array of beliefs as well as the potential degree of conviction that some beliefs carry over others (Russell et al., 2009), all of which add complexity to understanding how beliefs might influence health seeking behaviors. Consistent with Zuckerman et al. (2016) there did not appear to be any correlation between the specific types of causal belief categories when multiple were reported, supporting our analytic approach in comparisons by race/ethnicity and language. When looking at race/ethnicity, Asian mothers were more likely to cite more than one cause compared to White mothers. This finding should be interpreted with caution, as it was marginally significant after adjusting for maternal education and language.

We did not find differences in service utilization and treatment across ethnic groups. This may be due to identifying participants from the California Department of Developmental Services (DDS) database, where the local Regional Center determines eligibility and coordinates provision of services for California children with ASD. Perhaps there is little variation in service utilization between ethnic groups because there are specific Regional Center referral guidelines based on the Lanterman Developmental Disabilities Act (www.dds.ca.gov) for determining eligibility and provision of services. Previous studies have shown though, even within this highly coordinated statewide agency responsible for identifying and providing services for children and adults with developmental disabilities, disparities still exist with all racial and minority groups having significantly lower odds of receiving any Regional Center services and of those who received services, lower expenditures spent compared to whites (Harrington & Kang, 2008).

When looking at treatments not dictated by the Regional Center, namely CAM, differences across ethnic groups were not found. CAM use was relatively consistent across all ethnic groups (27.9% White, 20.3% Hispanic, 19.2% Asian; $p=0.35$). This finding differs from

previous findings that Latino children recently diagnosed with ASD were six times more likely than children of other ethnicities to use non-traditional treatment strategies (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003). These differing results may be due in part to variation in national origin among Hispanics and/or education level. Our Hispanic sample in California is largely of Mexican origin with a higher education level than that typically seen in most research studies, such as the Hispanic sample from Philadelphia, Pennsylvania (Levy et al., 2003). Our findings about CAM use overall is consistent with a more recent multi-site, population-based study showing that 28% of the sample reported any CAM use (Perrin et al., 2012). This is in contrast to other studies reporting much higher prevalence of CAM use overall, ranging from 50–95% (Akins, Angkustsiri, & Hansen, 2010; Levy & Hyman, 2008). In summary, our study adds to the variability of findings in ASD-associated CAM.

As in previous research, we found relationships between particular causal beliefs and utilization of services and treatment (Dardennes, Al Anbar, Prado-Netto, Kaye, & Contejean, 2011; Zuckerman et al., 2015). First, mothers who “Don’t Know” what causes ASD were more likely to use conventional medications compared to mothers who cited specific cause(s). One explanation might be that mothers who know what causes their child’s ASD may look for specific types of treatments for the given cause, even if non-conventional, while those who don’t know are likely to take recommended ones. That is, parents who “don’t know” may rely more heavily on their child’s healthcare provider’s guidance, where use of conventional medications is common. Second, belief in Environmental causes was associated with receiving 20 or more hours of educational/behavioral autism-related services per week. Conceivably parents who believe in an environmental cause (e.g., mercury in fish, pesticides, air pollution) may view their child’s ASD as more malleable or likely to improve with interventions. Such parents may be more willing to try a wider range of interventions. Another possibility is that mothers who believe in an environmental cause of ASD may prefer to try “natural” remedies often associated with CAM (Astin, 1998). We did not investigate whether the number of causal beliefs held by each mother predicted service utilization or treatment use. First, this was an unanticipated finding and thus, precluded preplanned analysis. Second, there is no apparent correlation between specific causal beliefs reported among those holding multiple, and to group those holding multiple beliefs together just on the nature of the number of beliefs reported may be a false presumption. The finding does, however, highlight a need for such a preplanned analysis in future studies.

Third, we found that belief in Environmental causes and Vaccines/Medication causes were also associated with CAM use. Those who believe vaccines and conventional medications cause ASD may distrust conventional medicine and utilize CAM exclusively instead. Hanson et al. (2007) found the main reason for choosing CAM over conventional treatments among families with ASD was concern about the safety and side effects of prescribed medications. Another study demonstrated the potential role of anti-vaccine conspiracy beliefs in shaping health-related behaviors (vaccination intention), where mediating variables include perceived dangers of vaccines, feelings of powerlessness and mistrust in authorities (Jolley & Douglas, 2014). Conversely, Wei et al. (2009) found that vaccine refusers do not generally opt out of the healthcare and continue to use services, although

with lower utilization for some services in children age 2 and under. Of greater concern, is literature suggesting that correcting misinformation may actually be problematic. In a randomized trial where parents were assigned to pro-vaccine messaging interventions, none of the interventions increased intent to vaccinate a future child. Moreover, the intervention that corrected false claims about the vaccine/autism link actually decreased intent to vaccinate in parents with the least favorable attitudes (Nyhan, Reffler, Richley, & Freed, 2014). Another study tested a new set of strategies to correct vaccine misinformation, but concluded such strategies are ineffective and often backfire, reinforcing misconceptions about vaccination and reducing intentions to vaccinate (Pluviano, Wat & Sala, 2017). The latter study discussed literature examining the consequences of misinformation and the cognitive processes involved that complicate reversal or undoing misconceptions. This observation leads us back to the “Individual level” as a theoretical and practical focal point for researchers and practitioners to engage. Healthcare providers need to encourage and facilitate open discussions with families about current knowledge regarding etiologies, the relationship (or lack thereof) of etiologies to evidence based treatments, and the importance of ongoing communication regarding decisions about CAM treatment choices that require monitoring for safety and efficacy.

Findings from this case-control study suggest beliefs about the etiology of ASD may influence the types, consistency and intensity of services and treatments sought. Reiff et al. (2017) qualitatively explored parental beliefs and how they affect expectations and pursuit of treatment. Parents who received pathogenic genetic testing results thought of their child’s condition as more permanent and less modifiable, which, for some parents, resulted in decreased expectations and less motivation to pursue treatment. More importantly, the study highlights that healthcare providers should be aware of the ways in which genetic information can influence attitudes and decisions about treatment, and actively discuss attitudes with families. Our findings support the need for clinicians, health professionals and service providers to share current knowledge about the complex etiology of ASD and inquire about parents’ own beliefs that may influence their use of both evidence-based and CAM treatments.

Our results should be taken in the context of some limitations. First, there was a possible confounding effect of the study name (BLIND), which implicates genetics and environment as having potential roles in the development of ASD. Similarly, administration of the Environmental Exposure Questionnaire (EEQ) may have primed participants to consider possible environmental causes for ASD. However, the study was commonly referred to as “the (BLIND) study”, rather than its entire name, which may have negated some of the name’s influence. Second, we had a limited sample of ethnic minority groups to make broader comparisons and as such, the generalizability of our findings to more diverse populations is limited. However, it is generally difficult to obtain data from families with autism spectrum disorder outside of large prospective studies such as this one and this is especially true for diverse populations. In that light, the diversity we have is a strength. Third, our data is older although it takes time for public uptake (Institute of Medicine, 2001), and as our cited literature points out, not much has changed in that time. Finally, more detailed information regarding the intensity and duration of past and present use of services

and treatments, particularly CAM treatments, would have allowed for a more in-depth exploration between parental perceptions of ASD causes and treatments of choice.

As an exploratory and descriptive study guided by previous research and health behavior theory, our findings help inform researchers that there *may* be ethnic differences, which exist and argue for a larger, specific study to quantify them. More importantly, future research should seek to understand parental motivation behind their choices of services and treatments beyond those currently considered evidence based and conventional interventions. Future research should also attempt to gain more insight into the types, usage and sources of CAM treatments. Most families adopt multiple treatment approaches and many discontinue treatment if there is no perceived improvement (Bowker, D'Angelo, Hicks, & Wells, 2011). However, much remains to be determined in terms of understanding why families receive certain treatments, outside of the individual/personal factors we chose to focus on in this study. For example, both age and severity of diagnosis seem to play a role (Mire, Raff, Brewton, & Goin-Kochel et al., 2015; Bowker et al., 2011). Mire, et al. (2015) found the preschool years to be when most treatment types were being used, however psychotropic medication use increased as children increased in age. CAM treatment use remained steady across age groups. Future studies should examine how causal beliefs, among other factors, might influence treatment choices across the lifespan of an individual with ASD. Specifically, families' choices and use of services can be related to healthcare access and quality that may require more comprehensive system-level interventions to address health disparities in ASD (Zuckerman, Lindly, Sinche, & Nicolaidis, 2015). When clinical interventions are informed by an awareness of family beliefs, families are more engaged in the intervention process (King et al., 2006). The findings of this study will help researchers, clinicians and other health professionals utilize information about parents' beliefs regarding causal factors related to their child's autism in discussions about treatment interventions to parents of children with ASD.

Acknowledgments

Dr. Fernandez y Garcia's work on this publication was supported by National Institute of Mental Health of the National Institutes of Health under award number K23MH101157. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Key points

- Few studies have examined the choice of treatments sought by parents of children with ASD and what influences those choices.
- Findings from this study suggest beliefs about etiology of ASD may influence the types, consistency and intensity of services and treatments sought.
- Healthcare providers need to encourage and facilitate open discussions with families about current knowledge regarding etiologies, the relationship (or lack thereof) of etiology to evidence based treatments, and the importance of ongoing communication regarding decisions about complementary or alternative treatment choices that require monitoring for safety and efficacy.

Table 1. BLINDED STUDY demographics for children with autism and autism spectrum disorders by maternal race/ethnicity (n=330)

| | White n=224 | Hispanic n=85 | Asian n=21 | P value |
|---|----------------|------------------|---------------|---------|
| Maternal age (Mean SD) | 31.4 ± 5.2 | 31.2 ± 5.6 | 32.8 ± 5.6 | 0.44 |
| Child's age | | | | 0.35 |
| 2 year olds (24–35 months) | 22.3% | 21.2% | 15.0% | |
| 3 year olds (36–47 months) | 38.8% | 35.3% | 25.0% | |
| 4 year olds (48–59 months) | 35.7% | 36.5% | 60.0% | |
| 5 year olds (60 months+) | 3.1% | 7.1% | 0.0% | |
| Maternal education | | | | <0.0001 |
| Less than high school | 1.3% | 11.8% | 4.8% | |
| High school | 8.0% | 15.3% | 0.0% | |
| Some college | 38.4% | 40.0% | 33.3% | |
| College degree | 36.2% | 28.2% | 14.3% | |
| Graduate / Profession degree | 16.1% | 4.7% | 47.6% | |
| Child's vaccination status | | | | 0.27 |
| Up-to-date | 81.9% | 92.6% | 87.0% | |
| Behind | 16.5% | 5.6% | 13.0% | |
| None | 1.7% | 1.9% | 0.0% | |
| Child's cognitive/adaptive function level | | | | 0.91 |
| Low | 74.9% | 80.5% | 76.2% | |
| Mixed | 9.9% | 7.3% | 9.5% | |
| High | 15.3% | 12.2% | 14.3% | |
| Primary language is English | 97.8% | 67.1% | 76.2% | <0.0001 |
| SD Standard Deviation | | | | |

Table 2.

Categorical themes of maternal beliefs regarding autism cause(s)

| Environmental | Environment |
|-----------------------------|---|
| | Heavy Metals |
| | Food |
| | Chemicals |
| | Pollution |
| | Pesticides |
| | Miscellaneous biological agent (fungus, mold, bacteria, etc.) |
| | Lifestyle |
| | Parenting |
| Genetics | Genetic predisposition |
| | Sporadic (“Born with it”) |
| Vaccines/Medications | Vaccines and mercury in vaccines |
| | Medications |
| | Antibiotics |
| Biomedical/Maternal | Pregnancy complication |
| | Maternal illness / disease / stress |
| | In-utero substance exposure |
| | Advanced maternal age |
| Biomedical/Child | Neurological |
| | Autoimmune / immune-related |
| | Neonatal / childhood illness or injury |
| True “Don’t Know” | |

Comparison of maternal beliefs about six categories of causes of autism (yes/no for each) across race/ethnicities n=330

Table 3.

| | Overall | | White | | Hispanic | | Asian | | Hispanic vs. White | | Asian vs. White | |
|-----------------------------------|---------|-------|-------|-------|-----------------|------------|-----------------|-------------|--------------------|--------|-----------------|--------|
| | n=330 | n=224 | n=85 | n=21 | PR ^e | 95% CI | PR ^e | 95% CI | PR ^e | 95% CI | PR ^e | 95% CI |
| Environmental ^a | 50.9% | 50.9% | 47.1% | 66.7% | 1.02 | 0.77, 1.35 | 1.31 | 0.97, 1.78 | | | | |
| Genetic | 51.5% | 54.5% | 41.2% | 61.9% | 0.92 | 0.69, 1.23 | 1.18 | 0.85, 1.64 | | | | |
| Vaccines/Medications ^b | 22.4% | 22.3% | 21.2% | 28.6% | 0.89 | 0.52, 1.53 | 1.20 | 0.57, 2.53 | | | | |
| Biomedical/Maternal ^c | 5.5% | 4.0% | 7.1% | 14.3% | 2.00 | 0.71, 5.62 | 3.24 | 0.98, 10.67 | | | | |
| Biomedical/Child ^d | 12.1% | 12.1% | 12.9% | 9.5% | 0.97 | 0.47, 1.98 | 0.72 | 0.19, 2.76 | | | | |
| True "Don't know" | 21.8% | 19.6% | 28.2% | 19.1% | 1.11 | 0.67, 1.84 | 0.92 | 0.39, 2.21 | | | | |

^aIncludes heavy metals; food; chemicals; pollution; pesticides; miscellaneous biological agents; lifestyle; parenting

^bIncludes vaccinations, mercury in vaccines, medications, antibiotics

^cIncludes pregnancy complications; maternal illness/disease/stress; in utero poly-substance exposure; advanced maternal age

^dIncludes neurological; autoimmune/immune related; neonatal/childhood illness/injury

^eAdjusted for maternal age, education (Bachelor degree vs no), and primary language spoken (English vs no)

PR prevalence ratio; CI confidence interval

Table 4.

Mutually exclusive combinations of causes cited by race, N=258*

| Causes | Overall (n=258) | | White (n=180) | | Asian (n=17) | | Hispanic (n=61) | |
|--|-----------------|-------------|---------------|-------------|--------------|-------------|-----------------|---|
| | n | % | n | % | n | % | n | % |
| 1 cause | 88 | 34.1 | 35.0 | 17.7 | 17.7 | 36.1 | | |
| Environment | 24 | 9.3 | 7.8 | 5.9 | 5.9 | 14.8 | | |
| Genetic | 34 | 13.2 | 15.0 | 5.9 | 5.9 | 9.8 | | |
| Vaccines/Meds | 12 | 4.7 | 5.6 | 0.0 | 0.0 | 3.3 | | |
| Biomedical/Maternal | 4 | 1.6 | 1.7 | 0.0 | 0.0 | 1.6 | | |
| Biomedical/Child | 14 | 5.4 | 5.0 | 5.9 | 5.9 | 6.6 | | |
| 2 causes | 136 | 52.7 | 52.8 | 52.9 | 23.5 | 52.5 | | |
| Environment, Genetic | 85 | 33.0 | 35.0 | 41.2 | 17.7 | 24.6 | | |
| Environment, Vaccines/Meds | 22 | 8.5 | 8.3 | 0.0 | 0.0 | 11.5 | | |
| Environment, Biomedical/Maternal | 3 | 1.2 | 0.6 | 5.9 | 5.9 | 1.6 | | |
| Environment, Biomedical/Child | 1 | 0.4 | 0.0 | 0.0 | 0.0 | 1.6 | | |
| Genetic, Vaccines/Meds | 7 | 2.7 | 1.7 | 5.9 | 5.9 | 4.9 | | |
| Genetic, Biomedical/Maternal | 2 | 0.8 | 1.1 | 0.0 | 0.0 | 0.0 | | |
| Genetic, Biomedical/Child | 10 | 3.9 | 3.3 | 0.0 | 0.0 | 6.6 | | |
| Vaccines/Meds, Biomedical/Maternal | 1 | 0.4 | 0.6 | 0.0 | 0.0 | 0.0 | | |
| Vaccines/Meds, Biomedical/Child | 3 | 1.2 | 1.7 | 0.0 | 0.0 | 0.0 | | |
| Biomedical/Maternal, Biomedical/Child | 2 | 0.8 | 0.6 | 0.0 | 0.0 | 1.6 | | |
| 3 causes | 27 | 10.5 | 10.6 | 23.5 | 6.6 | 6.6 | | |
| Environment, Genetic, Vaccines/Meds | 19 | 7.4 | 7.2 | 17.7 | 17.7 | 4.9 | | |
| Environment, Genetic, Biomedical/Maternal | 2 | 0.8 | 0.6 | 0.0 | 0.0 | 1.6 | | |
| Environment, Genetic, Biomedical/Child | 3 | 1.2 | 1.7 | 0.0 | 0.0 | 0.0 | | |
| Environment, Vaccines/Meds, Biomedical/Maternal | 1 | 0.4 | 0.0 | 5.9 | 5.9 | 0.0 | | |
| Environment, Vaccines/Meds, Biomedical/Child | 1 | 0.4 | 0.6 | 0.0 | 0.0 | 0.0 | | |
| Genetic, Vaccines/Meds, Biomedical/Child | 1 | 0.4 | 0.6 | 0.0 | 0.0 | 0.0 | | |
| 4 causes | 6 | 2.3 | 1.7 | 0.0 | 4.9 | 4.9 | | |
| Environment, Genetic, Vaccines/Meds, Biomedical/Maternal | 2 | 0.8 | 0.0 | 0.0 | 0.0 | 3.3 | | |
| Environment, Genetic, Vaccines/Meds, Biomedical/Child | 4 | 1.6 | 1.7 | 0.0 | 0.0 | 1.6 | | |

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| | Overall (n=258) | White (n=180) | Asian (n=17) | Hispanic (n=61) |
|--|-----------------|---------------|--------------|-----------------|
| 5 causes | 1 | 0.4 | 5.9 | 0.0 |
| Environment, Genetic, Vaccines/Meds, Biomedical/Maternal, Biomedical/Child | 1 | 0.4 | 5.9 | 0.0 |

* 258 mothers cited 1 or more causes; excluded 72 classified as "true don't know"

Table 5. Comparison of autism service and treatment utilization (yes/no for each) across autism causal beliefs

| Causal belief | Service or treatment | Adjusted PR ^d | 95% CI |
|-----------------------------------|---|--------------------------|-------------------|
| Environmental ^b | Receiving recommended 20 service hrs/wk | 1.38 | 1.07, 1.78 |
| | Receiving any professional services | 1.01 | 0.98, 1.05 |
| | Conventional medications | 1.09 | 0.73, 1.62 |
| | CAM treatment | 1.72 | 1.16, 2.56 |
| Genetic | Receiving recommended 20 service hrs/wk | 1.23 | 0.95, 1.58 |
| | Receiving any professional services | 1.01 | 0.98, 1.04 |
| | Conventional medications | 0.75 | 0.49, 1.13 |
| | CAM treatment | 1.00 | 0.69, 1.47 |
| Vaccines/Medications ^c | Receiving recommended 20 service hrs/wk | 1.01 | 0.76, 1.35 |
| | Receiving any professional services | 1.03 | 1.01, 1.05 |
| | Conventional medications | 1.01 | 0.64, 1.61 |
| | CAM treatment | 1.65 | 1.13, 2.42 |
| Biomedical/Maternal ^d | Receiving recommended 20 service hrs/wk | 0.51 | 0.24, 1.11 |
| | Receiving any professional services | 0.91 | 0.77, 1.07 |
| | Conventional medications | 1.04 | 0.46, 2.35 |
| | CAM treatment | 0.81 | 0.29, 2.29 |
| Biomedical/Child ^e | Receiving recommended 20 service hrs/wk | 1.00 | 0.68, 1.46 |
| | Receiving any professional services | 1.03 | 1.01, 1.05 |
| | Conventional medications | 0.58 | 0.25, 1.36 |
| | CAM treatment | 1.13 | 0.64, 2.01 |
| True "Don't know" | Receiving recommended 20 service hrs/wk | 0.84 | 0.60, 1.17 |

| Causal belief | Service or treatment | Adjusted PR ^d | 95% CI |
|---------------|-------------------------------------|--------------------------|-------------------|
| | Receiving any professional services | 0.98 | 0.93, 1.03 |
| | Conventional medications | 1.59 | 1.05, 2.41 |
| | CAM treatment | 0.59 | 0.34, 1.04 |

^a Adjusted for maternal education (Bachelor degree vs no), maternal race/ethnicity (Asian, Hispanic vs White), and maternal primary language (English vs other)

^b Includes heavy metals; food; chemicals; pollution; pesticides; miscellaneous biological agents; lifestyle; parenting

^c Includes vaccinations, mercury in vaccines, medications, or antibiotics

^d Include pregnancy complications; maternal illness/disease/stress; in utero poly-substance exposure; advanced maternal age

^e Includes neurological; antibiotics/medications; autoimmune/immune related; neonatal/childhood illness/injury

CAM Complementary Alternative Medicine

CI Confidence Interval

PR Prevalence Ratio