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THE ROLE OF CULTURE IN FAMILIES' TREATMENT DECISIONS FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS

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There is little information available about how and why parents of children with autism spectrum disorders (ASD) make decisions regarding which of the many available treatments to implement with their children. Given the lack of available information regarding treatment efficacy, it is likely that parents' beliefs about child development, interpretation of the symptoms of ASD, its etiology and course, and their experiences with the health system influence treatment decisions. This article addresses these issues within the context of cultural influences. We review the small body of existing literature regarding cultural influences on decisions regarding ASD and draw implications for the study and treatment of ASD from the larger body of literature on culture and other health conditions of childhood. In addition to examining the potential for differences in clinical presentation by culture and different experiences with the healthcare system, we use Kleinman's framework of questions for understanding the role of culture in the interpretation and treatment of ASD. These questions address interpretation of symptoms and beliefs about their cause, course, and treatment. Finally, we present specific language for clinicians to use in discussion with families with different cultural beliefs about the use of less traditional treatment strategies.

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Key Words: autism; complementary and alternative medicine; culture; race; ethnicity; treatment

A bewildering array of treatments for autism spectrum disorders (ASD) have been described in the scientific and popular literature, including various behavioral, cognitive, pharmaceutical, vitamin, and diet therapies [Hyman and Levy, 2000; Levy and Hyman, 2002]. Although the effectiveness of most of these treatments has not been tested using traditional scientific methods, many, if not most, families of children with ASD still use at least one of them [Levy et al., 2003; Nickel, 1996], sometimes beginning treatment even before the diagnosis is confirmed [Levy et al., 2003].

There is little information available about how and why parents make decisions regarding which treatments to implement with their children. Ideally, observed effectiveness would be the predominant strategy, but progress is sometimes difficult to determine [Coplan et al., 2003]. Even some of the most

common treatments for ASD lack rigorous testing of their effectiveness [Volkmar et al., 2004], and complete amelioration of symptoms is rare [Howlin, 1997]. Healthcare providers often have poor understanding of the symptoms, prognosis, and treatment of ASD [Mandell et al., 2002; Shah, 2001], and parents receive conflicting information about treatment from multiple sources [Mandell et al., 2004]. Given the inconsistent messages families receive about their children's condition, it is likely that families' recognition and interpretation of the symptoms of ASD, their beliefs about its etiology and course, and their experiences with the health system in which their child may receive care play important roles in treatment decisions.

The meaning parents attach to their children's symptoms and their associated beliefs about the symptoms' causes, prognosis, and most appropriate course of care can be described within the context of culture. Culture is often defined as a group of people's way of life, consisting of predictable patterns of values, beliefs, attitudes, and behaviors. These patterns are learned and passed from generation to generation [Kakai et al., 2003]. Since cultural factors are intertwined with thoughts and behaviors, they may assume a major role in the way families address deviations in their children's development [Pachter and Harwood, 1996] and may influence the extent to which they subscribe to various intervention strategies [Danseco, 1997]. Since many of the treatments families implement with their children may have iatrogenic effects [Levy and Hyman, 2002], and they sometimes may be substituted for treatments with proven efficacy [Levy and Hyman, 2002; Levy et al., 2003], it is

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vitaly important that we have a better understanding of how and why families make these treatment decisions and it is critical that we consider the cultural context of these decisions [Bailey et al., 1999].

Despite the important role that culture may play in influencing the treatment choices families make, a dearth of research has examined this issue in children with autism. In one study, Levy et al. [2003] found that Latino children recently diagnosed with autism were six times more likely than children of other ethnicities to use nontraditional treatment strategies. Their sample of Latino children was very small, however, and the authors were unable to further explore this finding. To our knowledge, this is the only study that has specifically examined the role of culture using any definition of or proxy for culture in treatment decisions for ASD. Studies of cultural contributions to treatment decisions among children with other conditions, however, have found that, among families of the same culture, those who are less acculturated have lower adherence to physician-prescribed treatments [Pachter and Weller, 1993], giving some evidence of the critical relationship between culture and treatment decisions.

The purpose of this review is to examine existing research on how culture and related beliefs may contribute to the use of different treatments for ASD. Kleinman [1980] suggests a framework of questions for understanding the role of culture in the interpretation and treatment of illness. These questions address interpretation of symptoms and beliefs about their cause, course, and treatment. We present what is known in each of these areas with regard to ASD, information regarding cultural factors associated with families' interactions with the healthcare system that may affect treatment decisions, and evidence for the possibility that the presentation of ASD may differ among different cultural groups. Because of the lack of relevant ASD-specific literature, we also cite research from other health conditions of childhood that may inform understanding of treatment decisions among children with ASD. We then present specific language for clinicians to use in discussion with families with potentially different cultural beliefs about the use of complementary and alternative treatment strategies.

MEASURING CULTURE

Measuring culture, cultural identity, and beliefs is challenging [Weller and Baer, 2002; Salant and Lauderdale,

2003]. It is therefore not surprising that there is great variability across studies in how culture is defined. Studies often use participants' race, ethnicity, or country of origin as a proxy for culture [Brown and Rogers, 1997]. In our review, we relied on a broad definition of culture and related proxies. We included studies that operationalized culture using concepts such as nationality, race, or ethnicity.

CULTURAL DIFFERENCES IN THE PRESENTATION OF ASD

It may be that there are cultural differences in the presentation of the symptoms of ASD due to genetic or environmental factors. A number of researchers, citing the multiple ways in which the autism spectrum can manifest, have suggested conceptualizing ASD as a set of behavioral phenotypes (rather than a continuum), both across the spectrum and within specific categories of the spectrum [Volkmar and Pauls, 2003; Volkmar et al., 2004]. If these specific categories exist, families and clinicians may be more sensitive to the presence of some phenotypes than others.

Evidence for underlying phenotypes has been mixed. At least three studies have shown reliable and valid differentiation by clinicians among autistic disorder, PDD-NOS, and Asperger's disorder, suggesting that these may be categorized as distinct phenotypes [Szatmari et al., 1995; Mahoney et al., 1998; Fombonne et al., 2004]. Other research has attempted to identify specific behavioral phenotypes within categories of autistic behavior. In their analysis of restricted and repetitive behaviors among children with ASD, Cuccaro et al. [2003] identified two distinct factors: repetitive sensory motor actions and resistance to change. Likewise, Tadevosyan-Leyfer et al. [2003] identified five clusters of symptoms that may have relevance for genetics research. On the other hand, Constantino et al. [2004] conducted a factor analysis of ASD symptoms and found one, continuously distributed underlying factor, suggesting no subphenotypes. Spiker et al. [2002] found similar results using similar measures in a different population. These contradictory findings may be a result of researchers' focus on different types of behaviors or parts of the autism spectrum, the use of different instruments, and different statistical methods.

To date, no published studies have examined possible ethnic differences in the presentation of particular symptoms or in behavioral phenotype. Written communication with Cuccaro regarding ongoing research suggested differences

between African-American and white children, while similar communication with Lord suggested no such differences. Clearly, research is needed in this area.

INTERPRETATION OF SYMPTOMS

Unlike some other psychiatric and developmental disabilities, there is good agreement on the symptom profile associated with autism and good to excellent reliability in its diagnosis and differentiation of subtypes [Eisenmajer et al., 1996; Mahoney et al., 1998; Hill et al., 2001; Fombonne et al., 2004]. As with other developmental and psychiatric disorders such as attention deficit/hyperactivity disorder (ADHD), however, families may attribute symptoms to something other than a health condition [Bussing et al., 1998]. For example, a child's failure to respond to parental direction may be interpreted as "willfulness" [Mandell et al., 2002] and other unusual behaviors as falling within the bounds of normalcy [Glascoe and Dworkin, 1993; Glascoe, 1997]. Lau et al. [2004] found that Asian/Pacific Islander and African-American parents were less likely than white parents to agree with teachers that their children's behavior was indicative of an underlying disorder. How parents interpret these symptoms may have a critical impact on the type of treatments they use or whether they elect to engage in treatment at all. To date, few studies have examined this issue among families of children with ASD, and fewer have examined these interpretations within the context of culture. Daley [2004] and Daley and Sigman [2002] examined how Indian families responded to their child's autism symptoms and their help-seeking process. Daley [2004] interviewed 95 families of children with autism and found that 45% of Indian parents initially noticed social difficulties in their children, followed by 32% of families who noticed a delay in speech. These findings are in contrast to studies of American families in which parents were more likely to detect general developmental delays or regression in language skills rather than social or communicative deficits [Coonrod and Stone, 2004; Mandell et al., 2004]. Daley postulates that these differences are due to the fact that India's culture is one that highly values social conformity more than the United States. Further evidence of this hypothesis is found in two recent studies. Coonrod and Stone [2004] found that parents of children with autism in the United States did not provide information specific to their child's social interactions unless

probed by their clinician. The authors suggest that parents were less aware or concerned about social milestones than they were about development in other areas such as language; another hypothesis offered by the authors is that parents make special, and sometimes unconscious, accommodations for their children to compensate for these delays. In their interviews with 68 families of children with autism residing in one metropolitan area in the United States, Mandell et al. [2004] found that parents tended to mention factors such as suspected hearing loss, language delay, and language regression. Deficits in social interaction were reported much less or not at all.

It is possible that members of different cultures respond differently to similar delays, placing different emphasis on the importance of language acquisition or social skills, for example. Whether symptom profiles truly vary by culture or whether families of different cultures prioritize different developmental skills, they may choose treatments that focus on improving specific deficits about which they are most concerned.

BELIEFS ABOUT THE CAUSE AND COURSE OF AUTISM SPECTRUM DISORDERS

Perhaps more than their interpretation of symptoms, families' beliefs about the etiology and prognosis of autism may affect their treatment decisions. A number of etiological pathways have been posited for autism, with associated treatments that purport to target different mechanisms. Levy and Hyman [2003] categorize treatments according to their proposed mechanism of action. For example, if families believe that autism is caused by or associated with changes in gastrointestinal function, they may engage in treatments such as secretin, gastrointestinal medications, or antifungal agents. Families that believe that autism is caused by heavy metal toxicity may use treatments such as chelation, DMPA, or other detoxification agents.

While the relationship between beliefs about etiology and treatment decisions has not been examined among families of children with autism, researchers have examined cross-cultural differences in families' interpretations of the causes of their child's health conditions in general. Both Yeh et al. [2004] and Bussing et al. [1998] surveyed parents of children with mental disorders to identify racial or ethnic differences in their beliefs about their child's condition. Yeh et al. [2004] found that African-American; Asian/Pacific Islander, and

Latino parents were all less likely than white parents to endorse personality, relational, or familial issues, or trauma as causes of children's problems. Asian/Pacific Islander and Latino families were less likely than white and African American families to endorse physical causes. Bussing et al. [1998] found that white families were more likely than African-American families to use medical language to describe their children's problems. They also found that, even among families endorsing biological explanations, African-American parents were more likely to ascribe their children's problems to less traditional etiological models, such as diet. The authors suggested that ethnic minorities may be less likely to view symptoms as related to a health condition and therefore may be less likely to seek care through traditional medical systems.

Beliefs about the course of autism may also affect treatment decisions. For example, families that believe that autism is a curable condition may follow a treatment regimen designed to cure the disorder. If symptoms are not ameliorated, they may become frustrated and switch or add treatments. Levy et al. [2003] found that, on average, families engaged in three treatments concurrently. Families that believe that autism in a chronic condition whose symptoms and related disability may be alleviated but not cured may make different, perhaps more stable treatment decisions. At the other end of the spectrum, families that believe that autism cannot be cured or improved with treatment may do little to try to change the trajectory of the disorder.

Research on other health conditions sheds light on how culture may influence beliefs about the course of ASD. Flores et al. [1999] point to the compelling example of "fatalismo," which refers to the belief in some Latino cultures that individuals can do little to alter their fate. Families with this belief system may be less likely to seek medical care. Folk illness beliefs may potentially lead to delay in seeking care or use of harmful treatments [Pachter; 1994; Flores et al., 1999].

CULTURE AND INTERACTIONS WITH THE HEALTHCARE SYSTEM

Of all the hypothesized associations between culture and treatment decisions, cultural differences in interactions with the healthcare system are probably the best studied. A large body of research has documented differences in the healthcare experiences of ethnic minorities relative to white children, especially regarding

the use of health services and the assignment of diagnoses. Some of this work has been specific to autism. For example, Cuccaro et al. [1996] found that the race of a child described in a vignette did not affect clinicians' diagnosis of autistic disorder; however, vignette studies may not provide an accurate picture of what occurs in practice. In a study of Medicaid-eligible children, Mandell et al. [2002] found that African-American children were diagnosed on average a year and a half later than white children. While white children entered the specialty service system at an earlier age, this difference did not fully explain the difference in the age of diagnosis. Once in treatment, African-American children required three times the number of visits over a period three times as long as European-American children before receiving an autism diagnosis.

Mandell et al. [2002] speculated that the delay in diagnosis might be associated with clinician factors, family factors, or the interaction of the two. They point out that African-American children are less likely than whites to use specialty care [Hoberman, 1992; Cooper-Patrick et al., 1999b; Diala et al., 2000], to have a usual point of primary care, or to have regular primary care visits [Kass et al., 1999]. This lack of or decrease in regular care may reduce the probability that developmental problems will be noticed. The authors also suggest that clinicians may have different expectations about treatment and service needs by ethnicity and may therefore not screen for ASD in African-American families as quickly as they would among white families. Research has found considerable differences by ethnicity in how clinicians assign diagnoses of other psychiatric and developmental disorders [Kilgus et al., 1995; Strakowski et al., 1995]. Physicians may also more quickly discount the concerns of African-American parents than they do the concerns of white parents related to their children's developmental delays, or not elicit those concerns in the first place, a hypothesis that has found evidence in research with adults [Cooper-Patrick et al., 1999a].

The disparities described above may be what lead African-American families to report more negative experiences with specialty care than European-Americans [Diala et al., 2000] and to have shorter courses of treatment [Bui and Takeuchi, 1992; Cuffe et al., 1996]. While African-American families' relatively low participation in specialty care for their children is well documented, it is unknown whether these differences re-

Table 1. Questions for Understanding Parents' Beliefs about Autism (Levy et al., 2003)

1. What did you call your child's problem before it was diagnosed?
2. What do you think caused it?
3. Why do you think it started when it did?
4. What do you think autism does? How does it work?
5. How severe is it? Will it have a short or long course?
6. What are the chief problems your child's autism has caused?
7. What do you fear most about it?
8. What kind of treatment do you think your child should receive? What do you expect from this treatment?

sult in a greater use of less traditional treatments. Chan et al. [2003] report no differences by ethnicity in the use of CAM for the treatment of ADHD, but this issue has not been specifically addressed for autism, for which the range of etiological models and potential treatments is much greater [Levy and Hyman, 2003].

Culture may also affect treatment decisions inasmuch as it is often associated with certain socioeconomic or geographical constraints related to accessing care. For example, Daley [2004] pointed out that, in order to obtain help, some families of children with autism had to travel upwards of 200 kilometers to seek out an appropriate physician. Studies have found that geography plays a greater role than other sociodemographic characteristics in determining the proportion of children diagnosed with ASD [Mandell and Palmer, 2005; Palmer et al., 2005] and access to specialty care for children with other psychiatric disorders [Sturm et al., 2003].

RECOMMENDATIONS FOR CLINICIANS

Despite the paucity of research in this area, clinicians can still engage families in constructive discussions around the use of nontraditional treatments (American Academy of Pediatrics, 2001). Pachter et al. [1995] suggest two sets of questions to guide clinicians' interactions with families. The first set is derived from Kleinman's [1980] explanatory model of illness, which has been used to study families' perceptions of autism and appropriate treatment [Gray, 1993; 1995]. Table 1 provides a list of eight questions adapted from

Kleinman [1980]. Responses to these questions will assist clinicians in understanding parents' beliefs both about their child's disorder, their reasons for using certain treatments, and their expectations of those treatments.

The second set of questions, presented by Pachter et al. [1995], are designed to help clinicians negotiate treatment decisions with families. The questions are adapted here with the permission of the authors, who suggest initiating the following dialogue:

"Some of my patients have told me that there are ways of treating autism that are known in the community that physicians don't know about or use. Have you heard of any of these treatments?"

If a parent responds in the affirmative, the clinician should then ask, "Are you using or have you ever used this treatment with your child?"

If the answer is yes, and the clinician determines that the treatment is not toxic, the clinician might respond with, "I am not sure if this treatment is effective for treating autism, but I know that if used/taken as directed, it will not be harmful. If you believe it is effective, you can continue to use it. But I think that your child will show greater improvement if you use the treatments I have prescribed in addition to this other treatment."

Pachter et al. [1995] also present methods for discussing potentially harmful treatments with parents. They point out that any harmful practice must be discouraged but can be replaced with acceptable substitutes. For example, clinicians can negotiate lower concentrations of substances like some vitamins that may be toxic at high doses. Other potentially harmful practices, such as withholding vaccines, can be switched with more acceptable replacements, such as changing the timing and spacing of vaccines.

It is important to remember that the goal of many of these treatments is most likely not to treat autism *per se*, but rather to address some of the associated problems faced by children with autism. For example, melatonin is given to treat the sleep disturbances that affect many children with autism. Likewise, gastrointestinal medicines are given to many children with autism who experience gastrointestinal distress, although many parents use these drugs because they believe them to affect autism-specific symptoms. It is important to remember that parents have different beliefs regarding the effectiveness of treatment and have different tolerance for treatment risk. If parents feel that clinicians do not respect their

beliefs and decisions or are unwilling to negotiate around the use of addition treatment strategies, these strategies may become alternative rather than complementary.

CONCLUSION

The communities in which children with ASD are identified in increasing numbers are often unprepared to meet their needs [Jacobson and Mulick, 2000; Newschaffer and Curran, 2003]. Despite the benefits of early diagnosis, children are routinely diagnosed late [Howlin and Moore, 1997; Mandell et al., 2002]. After diagnosis, children with autism have more difficulty than other children with special healthcare needs in obtaining appropriate care [Smith et al., 1994; Knafl et al., 1995; Krauss et al., 2003], primarily because services for children with ASD are not available in many communities [Jacobson and Mulick, 2000; Jarbrink and Knapp, 2001].

Given the lack of consensus regarding appropriate care models for children with ASD and the dearth of resources in many communities, it is not surprising that a growing body of research has documented ethnic disparities in the care [Mandell et al., 2002; Mandell and Palmer, 2005; Palmer et al., 2005]. It is likely that variations in the use of nontraditional treatment strategies are at least in part the result of the interplay of culture and communities' ASD-related resources. Because some of these nontraditional treatments are iatrogenic or may replace proven effective treatments, and because use of these treatments may also result from disparities in access to appropriate care, understanding the relationship of culture and treatment decisions takes on a particular urgency.

To build upon existing research, we must take a more nuanced approach to disentangling the relationship between culture and treatment decisions. We have attempted to structure this review in such a way as to suggest a direction for future research that focuses on specific areas in which differences may lie, such as cultural differences in the behavioral phenotype of ASD, recognition of symptoms, interpretation of symptoms, families' decisions regarding medical and educational interventions, and interactions between families and the healthcare system. Hopefully, the results of such research will lead to culturally sensitive clinical practice that decreases the age at which all children with autism are

diagnosed and improves the quality of their care. ■

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