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John W. Harrington, Patricia A. Patrick, Karen S. Edwards and Donald A. Brand

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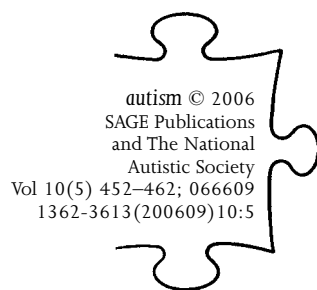
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Parental beliefs about autism

Implications for the treating physician



JOHN W. HARRINGTON *New York Medical College,
Valhalla, USA*

PATRICIA A. PATRICK *New York Medical College, Valhalla,
USA*

KAREN S. EDWARDS *New York Medical College, Valhalla, USA*

DONALD A. BRAND *New York Medical College, Valhalla, USA*

ABSTRACT This study investigated parental beliefs about the etiology, diagnosis, and treatment of autism spectrum disorders. Sixty-two families of affected children completed a questionnaire asking when the parent first noticed developmental or behavioral problems, when they were told the diagnosis, how confident they were about the ability of their child's physician to recognize autism, whether they believed anything specific might have caused their child's autism, and what medications and complementary or alternative therapies they had tried. Two-thirds of parents suspected a specific cause, and three-quarters questioned their physician's ability. Parents who perceived a greater delay in diagnosis or who had tried more different therapies both tended to have less confidence in their physician ($p = 0.20$ and $p = 0.07$, respectively). Physicians should inquire about parental beliefs concerning etiology, learn what treatments the children are receiving, perform screening at the 18 month visit, and make referrals for further evaluation as soon as a child begins to exhibit signs suggestive of autism.

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ADDRESS Correspondence should be addressed to: JOHN W. HARRINGTON, Department of Pediatrics, New York Medical College, 312 Munger Pavilion, Valhalla, NY 10595, USA. e-mail: John_Harrington@nymc.edu

As many as 1 in 150 children in the USA will be diagnosed with an autism spectrum disorder before reaching age 4 (Bertrand et al., 2001; Yeargin-Allsopp et al., 2003). An average pediatric practice, with up to 5000 patients, will therefore include about 30 such children. To serve the needs of these patients and their families, primary care physicians must understand parents' beliefs about this disorder.

While parents of children with autism spectrum disorder generally recognize that this is a complex and sometimes misunderstood condition,

physicians may not realize how desperate some parents feel when they discover that conventional medicine has few effective treatments to offer. These parents may fill this void by adopting unproven theories of causation, turning to complementary and alternative medicine (CAM), and using drug therapies of questionable value in an attempt to treat the core symptoms of the disorder (Hyman and Levy, 2000; Nickle, 1996). If a physician fails to ask about use of CAM and drug therapies for autism at primary care visits (Levy et al., 2003; Nickle, 1996) or glosses over a parent's response to such an inquiry, parents may feel that their concerns are not taken seriously and lose confidence in their physician's ability to treat their child's autism. (The term 'autism' will be used in the remainder of this report as shorthand for the entire autism spectrum disorder.) These feelings may be intensified if the doctor had been slow to acknowledge that there was something wrong with their child, possibly causing a delay in the patient's referral and subsequent diagnosis (Sices et al., 2004). Parents who lose confidence may begin to distrust their physician's recommendations about routine preventive care and treatment of acute illnesses.

To counteract such tendencies, primary care physicians need to understand parental beliefs about autism and use that understanding to foster a mutually trusting, collaborative approach to the child's medical care. The purpose of the present study was to examine parental beliefs about the etiology, diagnosis, and treatment of autism by surveying parents of children with autism. The study also investigated relationships between these beliefs and a parent's confidence in their physician's ability to recognize autism.

Methods

Study design

This was a cross-sectional survey of parents of children with autism. Participants attended an annual conference on autism that is jointly sponsored by the Foundation for Educating Children with Autism, The National Alliance of Autism Research, and the Westchester Institute for Human Development. The conference, which encompasses behavioral teaching strategies and current research for children with autism, is intended for parents, educators, and health professionals.

Recruitment

During registration for the 2002 conference held in the city of White Plains, New York, one of the investigators (JWH) asked registrants whether they were parents of a child with an autistic spectrum disorder. If so, they were invited to complete a questionnaire and return it to a drop box. Parents were informed that this was an anonymous survey to gather

information concerning their perceptions about their child's diagnosis and that the findings might eventually be published. Parents who wished to receive a summary of the survey results wrote their address on a tear-off sheet and returned it to the investigator. Participation was voluntary, and no inducements were offered. This study was approved by the Institutional Review Board at New York Medical College.

Survey instrument

The self-administered questionnaire asked parents to record their child's sex and date of birth and to indicate when they first noticed developmental or behavioral problems in their child, when they recalled having been told the diagnosis of autism by a health professional, how confident they were about their primary care physician's ability to recognize autism ('not at all', 'somewhat', 'very', or 'extremely'), and whether they believed anything specific might have caused or contributed to their child's autism ('yes', 'no', or 'maybe', with blank space to write in details and indicate how their belief had changed their attitudes toward providing routine healthcare for their child). The questionnaire also presented a checklist of treatments, asking the parent to indicate which treatments they had used for their child's autism. The checklist included dietary restrictions (e.g. gluten free), dietary supplements (e.g. calcium, folic acid), other CAM treatments (e.g. antifungal agent, hyperbaric oxygen), and medications (e.g. tranquilizer). Extra space was provided for the parent to write in any additional treatments not explicitly listed. The questionnaire may be obtained from the first author upon request.

Questionnaire items were intended to assess parental beliefs about the etiology of autism, to obtain their views about the timeliness of the diagnosis and possible role their primary care physician played in facilitating or perhaps delaying the diagnosis, and to ascertain the frequency of use of different CAM and drug treatments.

Analysis

We calculated response frequencies for all closed-ended questions, and we analyzed open-ended questions by categorizing parents' written responses into themes identified from those responses. We also examined the data for a possible association between parents' confidence in their physician's ability to diagnose autism and their belief in a specific cause of the autism, between parents' confidence and their perceived delay in the diagnosis, and between their confidence and the number of different treatments they had used for their child's autism.

The Kruskal–Wallis (non-parametric ANOVA) test was used to measure the association between parents' confidence and their belief in a specific

cause. The Spearman rank-order correlation coefficient was used to measure the association between parents' confidence and their perceived delay in diagnosis, and between their confidence and the total number of treatments they had used for their child's autism.

Results

Seventy-five parents representing 71 families attended the conference. (In four families, both parents attended and completed a single questionnaire.) Families came from New York, New Jersey, Pennsylvania, and Connecticut, nearly all of them representing middle or upper income households, based on census tract (FFIEC Geocoding System, 2003). Parents from 62 of the 71 families (87%) completed all items and returned the questionnaire. Forty-eight of the 62 children (77%) were male and 14 (23%) were female (a male-to-female ratio of 4:1). The median age of the children studied was 8 years (range 2 to 28 years).

Beliefs about etiology

A total of 26 percent of parents answered 'yes' to the question concerning a belief that something specific had caused or contributed to their child's autism, and another 45 percent answered 'maybe'. Parents cited eight categories of causes, most commonly immunizations, genetic predisposition, and environmental exposure of the mother or child (Table 1). Parents who answered 'yes' or 'maybe' to the question about causation were asked to explain how their belief in a specific cause had changed their attitudes toward providing routine healthcare for their child. Table 1 summarizes parents' open-ended written responses by categorizing them into seven thematic topics parents wrote about. The most frequent responses involved delaying or withholding immunizations.

Timeliness of diagnosis

The time interval between a parent's first observation of developmental or behavioral problems and the diagnosis of an autistic spectrum disorder by a health professional will be referred to as the *perceived delay* in diagnosis. The median perceived delay was 9 months (range: 0 months to 13 years). The median age at diagnosis was 2 years and 3 months (range: 14 months to 14 years).

Treatments used

Most parents (87%) reported having used at least one CAM or drug treatment for their child's autism. The median number of different treatments tried was six (range 0 to 27). Sixty-nine percent of parents had tried at

Table 1 Parental beliefs about the causes of autism and changes in attitudes about providing routine healthcare among parents who suspected a specific cause (N = 62)

| | No. | (%) |
|--|-----|------|
| <i>Causes cited</i> | | |
| Immunizations | 18 | (29) |
| Genetic predisposition | 16 | (26) |
| Environmental exposure (mother or child) | 11 | (18) |
| Early childhood illness or injury | 8 | (13) |
| Pregnancy complication | 6 | (10) |
| Antibiotic taken by child | 4 | (6) |
| Other medication taken by child | 1 | (2) |
| Premature birth | 1 | (2) |
| <i>Changes in attitudes about providing routine healthcare</i> | | |
| Would delay or wait longer between immunizations | 8 | (13) |
| Would refuse some or all vaccinations | 8 | (13) |
| Would increase use of complementary and alternative medicine | 6 | (10) |
| Would use pediatrician for routine care but seek specialist for other care | 5 | (8) |
| Has decreased trust in traditional medicine or pediatricians | 4 | (6) |
| Would do more research before making healthcare decisions | 3 | (5) |
| Would give antibiotics only as a last resort | 3 | (5) |

Note: parents' written responses were grouped into thematic categories, as shown.

least one dietary restriction, 60 percent at least one dietary supplement, 63 percent at least one other CAM therapy, and 53 percent at least one medication (Table 2). Within each of these categories the median numbers of treatments were: two dietary restrictions (range 0 to 4), one dietary supplement (range 0 to 14), one other CAM treatment (range 0 to 7), and one medication (range 0 to 7). Fifteen percent of parents had used treatments from one of the four categories, 15 percent from two categories, 31 percent from three categories, and 27 percent from all four categories.

Confidence in physician

Most parents indicated that they were either 'not at all' (40%) or 'somewhat' (32%) confident in their primary care physician's ability to recognize autism. Only about one parent in four chose 'very' (19%) or 'extremely' (8%) confident.

Confidence in physician versus beliefs about etiology, timeliness of diagnosis, and treatments used

Parents who believed something specific might have caused their child's autism did not differ from other parents with respect to confidence in their

Table 2 Number of parents who reported having used specific treatments for their child's autism (N = 62)

| | No. | (%) |
|---|-----|------|
| <i>Complementary and alternative therapies</i> | | |
| <i>Dietary restriction:</i> | | |
| None | 19 | (31) |
| Gluten-free diet | 41 | (66) |
| Casein-free diet | 37 | (60) |
| Sugar-restricted diet | 15 | (24) |
| Yeast-free diet | 2 | (3) |
| Other ^a | 7 | (11) |
| <i>Dietary supplement:</i> | | |
| None | 25 | (40) |
| Megadose vitamin (A, B ₆ , B ₁₂ , C, or E) | 29 | (47) |
| Dimethyl glycine | 23 | (37) |
| Omega-3 fatty acid | 22 | (35) |
| Probiotic | 17 | (27) |
| Magnesium | 14 | (23) |
| Folic acid | 13 | (21) |
| Zinc | 13 | (21) |
| L-carnosine powder | 8 | (13) |
| Garlic | 2 | (3) |
| Alpha lipoic acid | 2 | (3) |
| Other ^b | 8 | (13) |
| <i>Other therapy:</i> | | |
| None | 23 | (37) |
| Antifungal agent | 22 | (35) |
| Secretin | 21 | (34) |
| Auditory Integrative Therapy | 14 | (23) |
| Chelation for lead or mercury | 8 | (13) |
| Glutathione peroxidase | 3 | (5) |
| Dolphin swim therapy | 3 | (5) |
| Music and dance therapy | 3 | (5) |
| Sensory integration | 2 | (3) |
| Chiropractic | 2 | (3) |
| Homeopathy | 2 | (3) |
| Other ^c | 8 | (13) |
| <i>Medications</i> | | |
| None | 29 | (47) |
| Antidepressant (e.g. Prozac TM , Zoloft TM) | 23 | (37) |
| Atypical neuroleptic (e.g. Risperdal TM , Seroquel TM) | 20 | (32) |
| Stimulant (e.g. Ritalin TM , Adderall TM) | 13 | (21) |
| Anticonvulsant (e.g. Neurontin TM , Tegretol TM) | 13 | (21) |
| Typical neuroleptic (e.g. Haldol TM , Navane TM) | 7 | (11) |
| Other ^d | 5 | (8) |

^a One each of the following dietary restrictions: phenol, corn, peanut, salicylate, allergin, ketogenic, carbohydrate.

^b One each of the following dietary supplements: milk thistle, artichoke, taurine, *Saccromyces bonlardii*, Super Nu-Thera[®], digestive enzymes, manganese, biotin.

^c One each of the following other therapies: behavioral optometrist, energy healer, facilitated communication, horseback riding, manual integrative therapy, pet therapy, Reike, visual training.

^d One each of the following medications: benedryl, Chinese medicine, gamma-globulin infusion, thymus extract, tryptophan (for sleep).

physician's ability to recognize the disorder ($p = 0.47$). Parents who perceived a greater delay in the diagnosis of autism did tend to have less confidence in their physician, although this tendency was not statistically significant ($p = 0.20$). Parents who had tried a greater number of different therapies to treat their child's autism also tended to have less confidence ($p = 0.07$) (Figure 1).

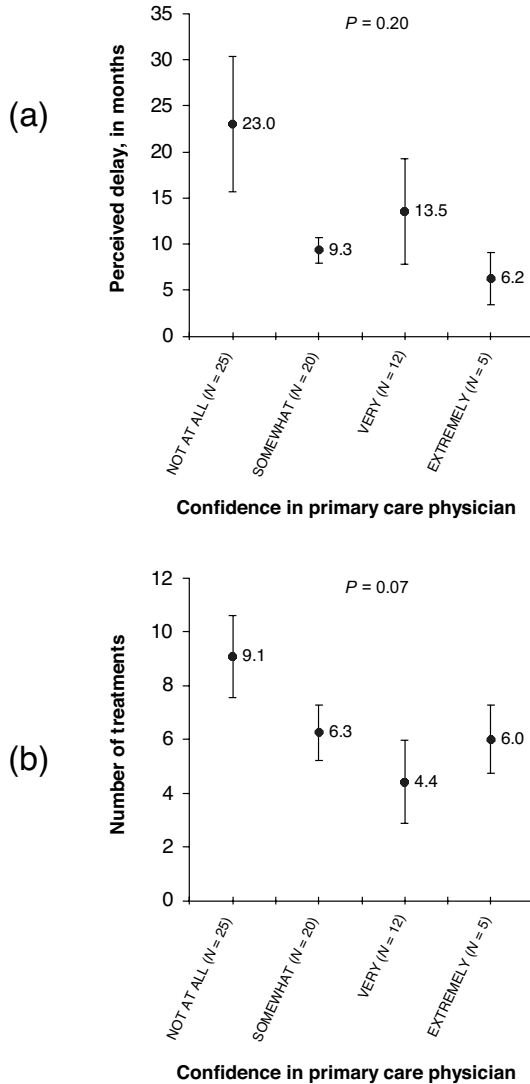


Figure 1 (a) Mean perceived delay in the diagnosis of autism and (b) mean number of treatments tried versus parental confidence in primary care physicians' ability to recognize autism (N = 62)

Discussion

Many parents in our survey expressed a belief in one or more specific causes of their child's autism, and most of them had tried numerous treatments. Study parents reported a much greater use of CAM treatments than has been previously reported for children with autism and other developmental and physical disabilities (Levy et al., 2003; Nickle, 1996), possibly because of differences in survey techniques or demographics of study subjects. Three-quarters of parents expressed little or no confidence in their primary care physician's ability to recognize autism, and our data suggest that a greater perceived delay in diagnosis may lead to a decrease in this confidence and an increase in the use of CAM therapies. The following comment conveys one parent's perception:

I believe it was a lack of knowledge on the physician's part that delayed a diagnosis for my child. Even after I expressed my concerns, I had to fight for referrals to specialists and still did not receive them. I had to go it on my own and essentially look past my regular physician toward other alternatives.

Confirming the diagnosis of autism may require a protracted evaluation period, involving specialized screening tests and the help of numerous professionals (Seltzer et al., 2000). Study parents reported a median delay in diagnosis of about 9 months. While this finding suggests an improvement over previously reported delays of 1 to 5 years (Howlin and Moore, 1997; Yeargin-Allsopp et al., 2003), any diagnostic delay due to watchful waiting and failure to refer for more specific testing may jeopardize a parent's confidence in the physician. Delays can also deprive the child and family of benefits such as parent support groups, genetic counseling, and intensive behavioral training (McEachin et al., 1993).

Recommendations

Given that there are few convincing demonstrations of treatment efficacy for autism other than early intensive behavioral therapy, many parents are understandably frustrated with conventional medicine. There are, however, three positive steps physicians can take. They can (1) help expedite the diagnosis by conducting a preliminary evaluation as soon as a parent expresses concern, (2) make timely referrals to a specialist to confirm or rule out the diagnosis, and (3) provide information about autism and refer parents to additional resources if the diagnosis is established.

To minimize unnecessary delays, physicians should consider recent guidelines urging recognition of early signs of autism (Committee on Children with Disabilities, 2001). In addition, they might adopt a policy of administering an autism screening test when a parent first expresses concern about their child's development (Baird et al., 2000; Robins et al.,

2001). While such tests have not been sufficiently audited for universal screening, they appear to be adequate for helping to detect autism in the subset of children whose parents report developmental or behavioral problems (Scambler et al., 2001).

To sustain an open, trusting relationship with parents of children with autism, physicians should inquire about parental beliefs concerning etiology and learn what treatments the children are receiving. Using a non-judgmental tone will maximize a physician's chances of uncovering critical information needed to avert potentially harmful practices, such as withholding immunizations, delaying the use of antibiotics, or using unconventional therapies that could impair or injure the child (e.g. dietary restrictions that may cause nutrient deficiencies or megavitamin regimens that can produce toxic levels: Mcguire et al., 2000). Investigators have offered helpful techniques to aid physicians in eliciting CAM usage (Levy and Hyman, 2003).

Limitations

We surveyed parents from predominantly middle and upper income households who chose to attend an educational conference. Our findings therefore reflect the views and behaviors of a resourceful, actively engaged group. Since beliefs about autism may differ in other socioeconomic groups, future studies should target other populations.

Since there were limited existing instruments that measure or address parental beliefs about autism, we had to develop a survey instrument specifically for the present study. As a result, we are not able to report previously published validity and reliability statistics.

Conclusions

The prevalence of autistic spectrum disorder in childhood now exceeds that of Down's syndrome, diabetes, or cancer (Filipek et al., 1999). Since autism is no longer a rare disorder, physicians should be screening at the 18 month visit. Making the appropriate referral for further evaluation as soon as possible after a child begins to exhibit signs suggestive of autism should increase parental confidence in the child's physician while assuring timely access to intensive behavioral therapy, genetic counseling, and support groups.

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