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Information Avoidance and Information Seeking Among Parents of Children with ASD

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Abstract

We estimated the effects of information avoidance and information seeking among parents of children diagnosed with ASD on age of diagnosis. An online survey was completed by 1,815 parents of children with ASD. Children of parents who self-reported that they had preferred “not to know,” reported diagnoses around 3 months later than other children. Children of parents who raised concerns that they perceived as having been dealt with adequately reported diagnoses about 4 months earlier, but the children of parents who reported raising concerns repeatedly and felt that those concerns were dealt with inadequately were diagnosed over a year later.

These findings suggest that failure of educational and healthcare professionals, in either substituting for parents who avoid information, or supporting those who seek information, can significantly delay the age of diagnosis.

Keywords: Autism Spectrum Disorder; Autism; age of diagnosis; Information avoidance.

Introduction

Multiple lines of evidence indicate that earlier diagnosis of children with autism syndrome disorder (ASD), enabling earlier intervention, can lead to better outcomes (Anderson, Liang, & Lord, 2014; Bradshaw, Steiner, Gengoux, & Koegel, 2014; Dawson, 2008; Filipek et al., 1999; McPheeters et al., 2016; Siu et al., 2016; Warren et al., 2011). Therefore, identifying and addressing factors that delay diagnosis is important for improving treatment outcomes for ASD.

Prior research examining age of diagnosis has largely focused on parents' characteristics and family structure. This research finds that children in households with higher educational attainments tend to be diagnosed earlier (Fountain, King, & Bearman, 2011; Hrdlicka et al., 2016). The evidence concerning other socio-economic characteristics, such as income and ethnicity is more mixed (after controlling for parents' level of education). Other research focusing on family structure finds that the constellation of

experienced adults that are in close contact with a child, most notably the presence of a maternal grandmother, affects the age of diagnosis (Sicherman, Loewenstein, Tavassoli, & Buxbaum, 2018). The same research also finds that the presence of siblings and birth order affect the age of diagnosis.

The conventional logic of rational decision making assumes that more information can only improve outcomes and, therefore, accounting for the cost of acquiring the information, decision makers should always opt for more information (Stigler, 1961). In recent years, however, numerous studies have shown that, for psychological reasons, individuals often avoid information despite potential benefits. Such information-avoidant behavior has been documented in various domains, ranging from finance to healthcare. For example, reducing transmission of HIV has been stymied by limited testing on the part of at-risk individuals (Sullivan, Lansky, Drake, & HITS-2000 Investigators, 2004), and testing for Huntington's Disease is rare among those who are at known risk (Oster, Shoulson, & Dorsey, 2013). We are not aware, however, of any empirical studies that address the impact of information avoidance or information seeking on age of diagnosis of ASD.

Here, we present research addresses the degree to which parents' tendency to avoid or to seek out information plays a role in delayed diagnosis of ASD. Both of these phenomena – information avoidance and seeking -- have been identified in anecdotal reports as potential determinants of age of diagnosis, but have not been examined in quantitative empirical research. For example, considering first information avoidance, there has been discussion in the ASD literature that parents of children diagnosed with ASD sometime exhibit denial with regard to their child's condition.(Hastings et al., 2005; Mansell & Morris, 2004) On the information-seeking side, researchers have noted that paying vigilant attention to any sign of a potential problem, and proactively seeking information, can accelerate diagnosis, and treatment (Mackintosh, J. Myers, & Goin-Kochel, 2005; Tzoy, Connolly, & Novak, 2007). While focusing mainly on the role of information avoidance in contributing to later ASD diagnosis, in this study we also identify the subset of parents who actively seek out information and estimate the effect of such behavior on the age of diagnosis.

Methods

Sample

An online survey (reproduced in Online Appendix A, and available at http://tiny.cc/AJIDD_SLLLMB_Appendices), approved by the Institutional Review Board, was completed by 1,815 parents of children who were previously diagnosed with ASD (see (Daniels et al., 2012) for reliability of diagnosis). Potential participants, who were contacted by email, were selected from the Interactive Research Network (IAN) Research Database at the Kennedy Krieger Institute, Baltimore, MD. It is difficult to estimate response rate. We estimate that the email went to approximately 11,300 e-mail addresses (excluding emails of participants reported as deceased, bounced emails, and emails excluded per participant request). However, we cannot tell how many email accounts were monitored. Thus, the response rate would be at least 16%.

Demographic and socio-economic information on parents collected in the study included ethnicity, education, household income, and urban/rural residence. Our data was matched and confirmed with information previously collected by IAN on each of the children in our sample.

In cases where more than one child in the family was diagnosed, parents were asked to answer the survey with regard to their first diagnosed child. After deleting cases where crucial variables were missing (e.g., age of diagnosis), the sample size was reduced to 1,743. Descriptive statistics of the sample are reported in Table 1.

Table 1. Sample Socio-Economic Characteristics
Compared with the US Population

A. Race and ethnicity

	Freq.	Percent	US Ages 0-25	US Total
White only	1273	77.7%	55.6%	64.3%
Hispanic	180	11.0%	20.8%	15.6%
Other/Mixed	299	18.2%	4.4%	2.9%
Asian only	27	1.7%	4.3%	4.5%
Black only	36	2.2%	14.9%	12.7%

B. Parents' education

	Father	Mother	U.S. (25+) Adults	
			Men	Women
Less than HS	4.5%	0.9%	12.7%	12.0%
HS Grad	16.5%	6.5%	30.8%	30.0%
Some college	27.3%	27.8%	25.1%	27.5%
College grad	25.2%	33.5%	19.8%	19.9%
More than college	26.2%	31.2%	11.6%	10.7%

C. Household income

	Freq.	Percent	US Total
Below \$25,000	162	10.5%	25.1%
\$25,000-\$49,999	393	25.4%	24.9%
\$50,000-\$99,999	585	37.1%	29.1%
\$100,000-\$199,999	312	20.2%	16.8%
\$200,000 or higher	76	4.9%	4.2%

D. Level of Urbanization

	Freq.	Percent	US (2010)
Urban	1392	87.6%	80.70%
Rural, Large	115	7.2%	19.30%
Rural, Small	47	3.0%	
Rural, Isolated	36	2.3%	

Measuring Information Avoidance and Information Seeking

Information avoidance in certain health related domains is relatively easy to observe and measure. For example, individuals who turn down the opportunity to have a specific test conducted for free from blood samples they already provided can be said to be avoiding information. In the case of children with ASD, where the key potential information-avoiders are the parents, however, identifying information avoidance is more challenging. One approach might be to view late diagnosis as an indicator of information avoidance, but this would be clearly problematic in a study in which a central goal is to determine whether information avoidance is predictive of late diagnosis.

In this study our approach to detecting information avoidance was to ask the parents of children diagnosed with ASD a direct question: “Thinking back to before X (child first name) was diagnosed: Do you think that at some level you suspected that X had a serious condition, but you preferred not to know?”

In addition to the above question, we used a second question that could, indirectly, reflect information avoidance: “Thinking back, do you believe that anybody else had a concern that your child might have a problem before you did?” A positive response to this question might reflect an acknowledgment that the parents, at some level, ignored, avoided, or did not notice, cues that other individuals picked up on.

Indeed, an affirmative response to the question could be interpreted as an indication that the parents did not immediately pick up on concerns expressed directly or indirectly by other individuals.

Although both questions were crafted specifically for this study, they benefited from our own prior research that touched on these issues (Sicherman et al., 2018) as well as our prior experience with measuring information preferences (Ho, Hagmann, & Loewenstein, 2020).

While some parents might avoid information, others might behave in the opposite way, paying attention to any alarming sign of behavior and actively seeking information concerning their child’s condition and diagnosis. We attempted to identify such a pattern of information seeking with a sequence of three questions. First, we asked: “Did you raise concerns with a healthcare or educational professional before x (child first name) was diagnosed?”

A positive answer to the above question does not, however, necessarily reflect information-seeking by parents; it is also possible that an affirmative response could reflect deficiencies in the guidance received from professionals, including, potentially, a reluctance to give parents bad news they would have been ready to hear. In other words, since nobody else raised concerns, the parents eventually did.

Also, even if parents were seeking information by raising concerns early, diagnosis could be delayed if their concerns were not treated adequately. Therefore, parents who responded positively to the above question were asked two additional questions: “As far as you can recall, how often did you raise such concerns?” followed by asking “would you say your concerns were...” (with the following answers: a. brushed aside/ignored; b. attended to, but inadequately; c. attended to, somewhat adequately; d. dealt with very adequately).

Estimation Method

Since there are various factors that could affect the age of diagnosis beside information avoidance and seeking, we used regression analysis to account for such effects. In particular we accounted for the presence of various clinical signs and symptoms, and their severity around the time of diagnosis, as reported by the parents. In the survey, we provided the parents with a list of 25 signs, and for each sign the parents indicated its presence and severity. Most signs were taken from the diagnostic criteria for autism from the Diagnostic and Statistical Manual for Mental Disorders (DSM). Some modifications to the list were made following a pilot study in which parents also listed signs that are not unique to individuals with autism (Sicherman et al., 2018). This prior study found that there were some signs that, while not unique to ASD, were frequently cited by parents, and may have led them to seek professional help and to obtain a diagnosis.

We conducted factor analysis to cluster the 25 signs and symptoms into 5 factors (See Online Appendix B for details). Three of those factors mapped well onto a triad of ASD diagnostic impairments (social interaction, communication, and restrictive/repetitive behaviors). Two additional factors represented items relevant to developmental regression and aggressive behaviors, respectively. The scores for each of the five factors are included in each regression.

RESULTS

Information Avoidance

The first survey question used to identify parents who exhibit information avoidance was: "Thinking back to before X (child first name) was diagnosed: Do you think that at some level you suspected that X had a serious condition, but you preferred not to know?". Using such an approach could result in underestimation for two reasons. First, information avoidance could be subconscious, and, second, parents may find it difficult to acknowledge such behavior. Nevertheless, 19.7% (n=328) of the parents replied to the question with "yes, definitely", and 30.6% (n=509) replied with "Possibly" (the third possible answer was "no"). If we count "possibly" as a positive answer, then approximately half of the sample acknowledged that they "preferred not to know," implying a delay in accessing available information.

We examined whether the likelihood of responding positively to this question is correlated with any socio-economic or other characteristic of the parents, and found that wealthier (and to some extent, more educated) parents were less likely to report themselves as avoiding information. No other parents' characteristics were correlated with the answer to this question.

Asking parents if they believed that anybody else had a concern that their child might had a problem before they did, 48% (n=796) responded with a positive answer. Thirty-four percent (n=563) replied with "possibly yes", 8.5% (n=141) replied with "very likely", and 5.5% (n=92) replied with "certainly". A positive reply to such a question does not necessarily imply a tendency for information avoidance, but could reflect, at least in part, that the parents were fortunate to be close to individuals (e.g., friends and family, teachers, healthcare professionals) who had expertise or close daily exposure to the child that parents lacked.

The correlation between the above two measures of information avoidance is positive (.15) and statistically different from zero ($p < .001$). A closer look at the correlation between the two measures is provided in Table 2.

Table 2
Two Measures of Information Avoidance

suspected but preferred not to know	Believe that Other Suspected Before Parents		Total
	No	Yes	
No	487	335	822
Yes	364	460	824
Total	851	795	1,646

As can be seen in the table, the number of respondents who provided a consistent response to the two questions (n=947) is higher than those who did not (n=699). Two-sample test of proportions shows this difference to be highly significant (p=0.000). Approximately 70% of the respondents provided a positive answer to at least one of the questions.

Information Seeking

The first question we use to identify information seeking is “Did you raise concerns with a healthcare or educational professional before x (child first name) was diagnosed?” Eighty-seven percent (n=1441) of the parents surveyed responded with a positive answer. As mentioned earlier, the answer to such a question could reflect either parents’ characteristics or the conditions of the environment. We use two additional questions to separate information seeking as a parent’s characteristic from that of a non-supportive environment.

Parents who responded positively to the above question were asked two additional questions. The first was: “As far as you can recall, how often did you raise such concerns?”. As can be seen in Table 3, 14% (n=204) of the respondents reported raised concerns only once, and 43% (n=612) reported that they had raised concerns a “few times,” indicating a responsive environment (number of observations followed by standard deviation are in parentheses). However, 43% (n=616) reported raising concerns “repeatedly,” indicating frustration about a non-responsive environment. Next, the parents were asked how their concerns were addressed. Thirty-seven percent (n=527) of the respondents’ replied with “Brushed aside/ ignored” and 25% (n=364) answered “attended to, but inadequately.” Both answers again seem to reflect frustration on the part of parents regarding a non-responsive environment. Nineteen percent (n=279)

answered “attended to, somewhat adequately,” and 18% (n=262) answered “dealt with very adequately,” reflecting greater satisfaction with a more responsive environment.

Table 3 also reports the mean age of diagnosis depending on the answers to the two questions. As the Table clearly shows, when parents’ concerns were addressed adequately, the age of diagnosis was lower. For example, with a likelihood of 95% the gap between “very adequate” and “ignored” is at least 5.4 months. Similarly, the more frequently parents raised concerns, indicating less responsive healthcare professionals, the later their child was diagnosed. At the extreme, the difference in age of diagnosis between cases in which parents raise concerns repeatedly and were ignored (mean=51.47), and cases in which parents raise concerns only once and their concerns were addressed very adequately (mean=33.28) is quite dramatic: 18 months. With a likelihood of 95% the difference is at least 14.3 months.

These findings strongly suggest that information seeking can lead to earlier diagnosis only if parents’ concerns are addressed adequately. In the next section we subject these observations to a more rigorous statistical scrutiny.

Table 3
Mean Age of Diagnosis by Frequency of Concerns Raised & How Concerns
Were Addressed (# of observations & STD in parentheses)

How often raised concerns	How were concerns addressed				
	Ignored	Indequate	Somewhat adequate	Very adequate	Total
Once	37.31 (14, 18.94)	34.81 (26, 9.81)	34.74 (43, 20.2)	33.28 (121, 17.53)	34.05 (204, 17.37)
A few times	41.71 (211, 24.2)	48.4 (170, 26.81)	42.4 (149, 23.69)	38.89 (82, 24.88)	43.36 (612, 25.08)
Repeatedly	51.47 (302, 29.75)	59.45 (168, 34.77)	56.44 (87, 3.45)	49.56 (59, 29.1)	54.13 (616, 31.36)
Total	47.21 (527, 27.84)	52.41 (364, 30.74)	45.56 (279, 26.58)	38.66 (262, 23.68)	46.63 (1432, 28)

The Effects of Information Avoidance and Information Seeking on Age of Diagnosis using Regression Analyses.

We used regression analyses to estimate the effects of information avoidance and information seeking on the age of diagnosis reported by the parent. In each regression the dependent variable was the parent-reported age of diagnosis (in months). The independent variables that we focused on were various measures of information avoidance and information seeking, as well as indicators of how responsive various professionals were to information seeking on behalf of the parents.

To account for other factors that are likely to affect the age of diagnosis, we included in all regressions the following variables: First, we accounted for the presence of clinical signs around the time of diagnosis by including the scores for the five factors estimated using factor analysis (see Online Appendix B for details). In addition, since children with Asperger are diagnosed significantly later than other children with ASD, we included a dummy variable indicating an Asperger diagnosis. Since over time there has been a decrease in the age of diagnosis, we included in all regressions the child's year of birth to account for this cohort effect. Prior research has shown that the accessibility and proximity to various healthcare professionals and facilities have a strong effect on reducing the age of diagnosis. To capture such an effect, we included a dummy variable indicating residence in an urban area.

In Table 4 we report the estimation results of the various regressions. Below we discuss the results. Each column (model) reports the estimation results of a single multi-variable regression. In all models the dependent variable is the age of diagnosis (in months). All regressions include, as independent variables, the variables listed above and a dummy variable indicating if both parents graduated from college.

In the first column (Model 0) we report the estimation results of our "base" regression, excluding all variables of interest. For each of the other models we report the incremental R^2 relative to the base model. The results reported in models 1-3 show that, using different definitions, information avoidance increases the age of diagnosis, on average, by around three months. These, and all subsequent estimated coefficients measuring information avoidance and seeking discussed below, were statistically significant by conventional standards (significance levels are indicated by asterisks, and standard errors are reported in parentheses).

Information seeking among parents is likely to reduce the age of diagnosis only if parents' concerns are properly addressed by professionals. The results in model 4 might appear counter-intuitive; they show that children of parents who raised concerns with a professional were diagnosed approximately 7 months later. This effect almost certainly reflects the fact that parents were only likely to have raised concerns if others did not come forward first to identify and diagnose the problem, in which case diagnosis was delayed. The results reported in models 5-6 show, however, that if parents' concerns were addressed adequately, the child was diagnosed about 4 months earlier.

Parents' education: In all the estimated models reported in Table 4 children in households where both parents had at least a college degree were diagnosed 4-5 months earlier than other children, holding all other variables (included in each model) constant. If more educated parents are more likely, on average, to be more informed and are more capable to seek, process, and understand information, then this finding provides further, indirect, support for the hypothesis that information seeking reduces the age of diagnosis. The consistently significant effect of parental education could, alternatively or additionally, reflect discrimination; educational and healthcare professional might pay more attention and treat more seriously questions and concerns raised by more educated parents.

Table 4
Information Avoidance, Information Seeking, and the Age of Diagnosis

	model 0	model 1	model 2	model 3	model 4	model 5	model 6
		Information Avoidance			Information Seeking		
If definitely or possibly suspected but preferred not to know		2.62* (1.203)					
If definitely suspected but preferred not to know			3.57* (1.517)				
believe that other suspected before parents did				3.30** (1.212)			
Raised concerns with a professional?					7.19*** (1.855)	8.79*** (1.921)	
Concerns addressed adequately						-4.13** (1.340)	-3.94** (1.362)
Factor 1: Regressive Autism	-1.96** (0.643)	-1.91** (0.646)	-1.97** (0.647)	-1.75** (0.648)	-1.85** (0.646)	-1.91** (0.644)	-1.83** (0.701)
Factor 2: Social Awkwardness	-0.82 (0.712)	-0.67 (0.712)	-0.72 (0.712)	-0.71 (0.715)	-0.71 (0.713)	-0.83 (0.712)	-0.80 (0.773)
Factor 3: Communication Difficulties	-13.34*** (0.736)	-13.28*** (0.736)	-13.31*** (0.736)	-13.28*** (0.739)	-13.38*** (0.739)	-13.26*** (0.738)	-13.89*** (0.804)
Factor 4: Sensory Reactivity & Need for Sameness	-2.39** (0.731)	-2.46*** (0.733)	-2.47*** (0.732)	-2.33** (0.738)	-2.51*** (0.735)	-2.73*** (0.737)	-2.47** (0.804)
Factor 5: Aggressive Behavior	6.24*** (0.716)	6.35*** (0.716)	6.28*** (0.716)	6.35*** (0.720)	6.24*** (0.721)	6.06*** (0.721)	6.18*** (0.777)
Diagnosed with aspergers (1=Y,0=N)	10.70*** (1.832)	10.89*** (1.832)	10.93*** (1.832)	11.14*** (1.843)	10.71*** (1.833)	10.82*** (1.828)	11.91*** (1.968)
urban	-2.83 (1.779)	-2.94 (1.780)	-3.02 (1.781)	-2.47 (1.788)	-2.91 (1.792)	-2.80 (1.787)	-2.94 (1.918)
Both parents have College or more	-4.33*** (1.245)	-4.16*** (1.246)	-4.33*** (1.245)	-4.17*** (1.253)	-4.35*** (1.253)	-4.51*** (1.250)	-4.55*** (1.351)
Year of Birth	-0.76*** (0.100)	-0.75*** (0.100)	-0.75*** (0.100)	-0.73*** (0.100)	-0.74*** (0.100)	-0.73*** (0.100)	-0.76*** (0.107)
Constant	1561.27*** (200.015)	1552.46*** (199.830)	1549.84*** (199.772)	1517.31*** (200.696)	1532.08*** (200.404)	1505.43*** (199.937)	1567.85*** (214.199)
R ²	0.38	0.39	0.39	0.39	0.39	0.40	0.41
Incremental R ² compared to Model 0		0.01	0.01	0.01	0.01	0.02	0.03
N	1331	1323	1323	1308	1309	1309	1151 [¶]

* p<0.05, ** p<0.01, *** p<0.001

¶ Model 6 includes only individuals who raised concerns

Discussion & Implications

Previous research has shown that family structure and the presence of other individuals besides the parents can reduce the age of diagnosis (Sicherman et al., 2018). In this study we show that parents' attitude towards information avoidance and information seeking affect the age of diagnosis. Children of parents who reported that, at some level, they preferred "not to know," were diagnosed around 3 months later than other children. We have a similar finding when using an alternative indicator of information avoidance: parents' report that they believed others suspected that their child had a serious condition before they did.

Information seeking, on the other hand, is not likely to reduce the age of diagnosis unless parents have access to a network of professionals and their concerns are treated adequately. Our findings support this assessment. Children of parents who raised concerns that were dealt with adequately were diagnosed about 4 months earlier. The finding that children of more educated parents were diagnosed about 4 months earlier is likely to reflect the fact that such parents raised concerns relatively earlier and that their concerns were addressed more adequately than concerns raised by less educated parents.

Our central hypothesis was that information avoidance will increase the age of diagnosis, while information seeking will reduce the age of diagnosis. We predicted, however, that these effects would be mitigated by the way professionals respond to parents' concerns or behave in the absence of such concerns. In the case of information seeking we provide evidence that a responsive environment accelerates the age of diagnosis, while an unresponsive one causes a delay in diagnosis, despite parents' vigilance.

When it comes to efforts to advance age of diagnosis, modifying parents' information avoidant tendencies does not seem feasible, both because such preferences tend to be relatively fixed (Ho et al., 2020) and because parents of children with ASD cannot be identified prior to the child's diagnosis. Our findings suggest, therefore, that the potential for progress in ASD diagnosis rests with professionals. On the one hand, when dealing with parents who avoid information, professionals need to substitute for the parents' lack of vigilance by raising alarms when their suspicions are triggered. When dealing with parents who seek information, by the same token, professionals need to pay attention to their concerns.

Our findings suggest that failure of educational and healthcare professional in either substituting for the parents when they avoid information, or supplementing them when they seek information, can significantly delay the age of diagnosis.

Limitations

The main limitation of our study is that the data are observational as opposed to experimental. This is inevitable, since information avoidance is not something that can be manipulated experimentally, but it nonetheless limits our ability to draw causal conclusions. It is possible that some third variable we have not measured or, hence, controlled for, such as psychiatric conditions of the parents, may influence both information avoidance and age of diagnosis.

A second limitation is that the study is based on parents' self-reports, which are not perfectly reliable, and could potentially be subject to bias. For example, parents' answers to the information seeking and avoidance questions could be influenced by their awareness of whether their child received an early or late diagnosis. Nevertheless, we should note that we went in to the research with very specific hypotheses that we tested, which strongly and consistently supported by the data. Also, measured information avoidance in a wide range of other situations consistently predicts information-related behaviors (Ho et al., 2020).

In addition, given the retrospective nature of our study, the accuracy and quality of responses could diminish with the time elapsed from when the child was diagnosed until the survey was completed. The mean time elapsed between when the child was diagnosed and when the survey was completed is 122 months. Although the length of this period does raise issues of memory bias as well as the possibility that ASD definitions may have changed over time, in Online Appendix C we report the results of several tests suggesting that our data is most likely not subject to recall bias.

Since parents self-selected to respond to the survey, our study does not report on a representative sample of parents of children with ASD. One manifestation of this issue is that minority children are under-represented in our sample (see Table 1). However, our findings are unlikely to be affected by this under-representation, since we did not find any statistical differences in responses to the key questions in our survey by race, parents' education, or parents' wealth.

Another limitation of the research is that it includes only parents of children diagnosed with ASD.

Suspicion that a child has ASD that is not subsequently supported by such a diagnosis (a kind of false-alarm that could be associated with hyper-vigilant information seeking) could cause stress to the child and the family, not to mention unnecessary burdens and costs on the healthcare system. Likewise, children who have ASD that does not get diagnosed will not appear in the sample.

Information avoidance might have the benefit of reducing false alarms, but given the benefits of early treatment, the costs seem greater than any such benefits. The bottom line, however, is that both potential negative effects can be mitigated by accommodating environments in which experienced individuals, such as teachers and healthcare professional, can substitute for parents by noticing and addressing any alarming signs early enough, either by rejecting the possibility of an ASD diagnosis, or by putting the child on the path to diagnosis.

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