CAREGIVER PERCEPTIONS AND THE AGE OF AUTISM SPECTRUM DISORDER DIAGNOSIS

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ABSTRACT

In an effort to understand what may lead to differences in age of diagnosis for children with Autism Spectrum Disorder (ASD), this study investigated correlates of the timing of diagnosis. These correlates include individual differences in magnitude of concerns about early "red flag" behaviors and attributions of initial symptoms. The findings indicate that caregivers' level of worry about initial ASD symptoms and caregivers' attributions of the symptoms to behavioral challenges were related to age of ASD diagnosis. These findings are consistent with the hypothesis that individual differences in caregivers' knowledge and interpretation of symptoms related to ASD may have an impact on age of ASD identification, and may have implications for promoting public awareness of symptoms related to ASD.

KEYWORDS: autism, diagnosis, parents, attributions, perceptions

Research has shown that there is a positive relationship between younger entry age into intensive intervention and eventual placement into less restrictive educational settings for children with Autism Spectrum Disorders (ASD; Harris & Handleman, 2000; Dawson et al., 2010). In fact, Koegel, Koegel, Ashbaugh, and Bradshaw (2014) recently published a commentary on compiled data that suggests that, in general, children who receive early intervention services are more likely to be included in regular education classrooms and see a significant reduction of their symptoms. ASD is a complex developmental and neurologically based disorder that affects reasoning, feelings, communication, and social interactions across contexts (American Psychiatric Association, 2013). The Centers for Disease Control and Prevention ([CDC], 2018) estimates that it impacts 1 in 68 children and is reported in all racial, ethnic, and socioeconomic groups. Early diagnosis is not only the gateway to EI services but it also can improve parents' understanding of their children's developmental challenges and lessen parental stress (Koegel et al., 2014). Studies of parental attitudes toward ASD diagnosis have documented feelings of relief and increased family support due to having an explanation for unexplained behaviors (Mansell & Morris, 2004; Osborne & Reed, 2008). Given the importance and benefits of early diagnosis, it is critical to examine and document factors that may delay or hinder early diagnosis.

The referral and diagnostic process for children with developmental disorders, such as ASD, often begins with parental recognition, initiation, and presentation of relevant concerns to medical providers. Previous research on parental reporting behavior has focused on whether or not parents recognized/reported the presence of atypical development (De Giacomo & Fombonne, 1998) and what types of symptoms were associated with age of recognition by parents (Chawarska et al., 2007). However, very few researchers have examined why parents might not report atypical development. One class of potential causes of not reporting atypical development is parental causal attributions about the symptoms (i.e., beliefs about the origins), which thus may be associated with and contribute to the timing of ASD diagnosis. To further understand the potential impact of variation in beliefs on caregivers' bringing their concerns to the attention of physicians, it is useful to consult the Health Belief Model (Rosenstock, 1974). The major premise of the Health Belief Model is that individuals will take action

to ward off or screen for health conditions if they see themselves (or their children) as vulnerable to the have a sense of serious associated condition, consequences, feel that the course of action available to them would be beneficial, and perceive that the anticipated barriers of taking the action are outweighed by its benefits (Strecher, Champion, & Rosenstock, 1997). Extending this model to parents seeking help for suspected developmental difficulties for a young child, a parent would have to see their child as vulnerable to or demonstrating signs of developmental disabilities, believe that the absence of intervention for concerning behaviors could lead to less favorable outcomes, and believe that seeking professional help is worth potential difficulties faced from various sources of resistance (e.g., discord among other family members, financial concerns, navigating complex health systems, fear of labels, etc.).

When determining whether a child is demonstrating or susceptible to developmental difficulties, parents will have to depend on their personal knowledge and expectations regarding infant behaviors, which are influenced by culture, family values, education, and past experiences (Bornstein, 2012). Past research has indicated that some parents may view infants as having the capacity to be purposively difficult or willful (i.e. negative intentionality; Reznick, 1999; Burchinal, Skinner, & Reznick, 2010). A study examining the beliefs systems of mothers with young child between the ages of 2 and 18 months of age found two sets of beliefs among the participants. The first set of beliefs held that infants were too young to understand right from wrong, while the second set of beliefs credited infants with the capacity to misbehave intentionally and supported the need for discipline to respect the mother's authority (Burchinal, Skinner, & Reznick, 2010). Thus, if parents attribute initial symptoms of autism to willfully difficult behavior, then they may choose to deal with early behaviors related to ASD independently and forgo professional support. Dealing with behaviors solely within the family context may continue until behaviors reach a personally defined threshold of unacceptable and concerning (Rao, 2000). Additionally, labels such as developmental disorder or delay may be in direct conflict with how parents interpret or perceive their children's behavior (Bussing, Schoenberg, Rogers, Zima, & Angus, 1998). As such, some families may genuinely disagree with the notion of "disability" because they hold different views of typical development and expectations regarding

development than do professionals (Rao, 2000). This reaction may be particularly present in cases where the child's developmental disability is accompanied by little to no physical impairment, as is often the case with ASD. Essentially, differential interpretation of and reaction to behaviors associated with developmental disabilities, including ASD, may determine whether caregivers raise concerns and seek professional guidance, more specifically a diagnosis.

Findings from studies examining diagnosis or recognition of ASD indicate that several dynamics may influence age of diagnosis, including: (a) physician knowledge and practices (Sices, Feudtner, McLaughlin, Drotar, & Williams, 2004); (b) severity of ASD symptoms (Giacomo & Fombonne, 1998; Mandell, Novak, Zubritsky, 2005); (c) access to healthcare (Mandell et al., 2005); (d) race/ethnicity (Mandell, Listerud, Levy, & Pinto-Martin, 2002); (d) IQ level (Mandell et al., 2009; Shattuck et al., 2009) and (e) developmental history, including a regressive versus non-regressive pattern (Shattuck et al., 2009). Although these factors may explain a portion of the variance in the age of diagnosis of ASD, the impact of caregiver perceptions and beliefs has yet to be examined in the literature.

In the current study, we used retrospective methods to measure parental perceptions. These retrospective methods were chosen as an initial step toward designing instruments and generating hypotheses for future prospective studies. Many discoveries and important advances in early identification of children with ASD began with retrospective studies. For example, retrospective video studies and parental interviews have provided researchers with a framework for classifying early emergent behaviors in children who have later been diagnosed with ASD (Baranek ,1999; Osterling & Dawson, 1994; Watson, Baranek, Crais, Reznick, Dykstra, & Perryman, 2007). Such studies have been instrumental in helping identify behaviors that have been informally observed by clinicians and families, yet had not been measured in early identification efforts prior to such studies. For instance, studies by Osterling and Dawson (1994) and Baranek (1999) highlighted hyporesponsiveness to social stimuli by infants later diagnosed with ASD as demonstrated by a failure to orient readily to name calls. Subsequently, this characteristic has become a standard question in present-day assessments, screening tools, and questionnaires used to detect social

communication difficulties. Such hypothesis-generating studies provided important information to researchers regarding which behaviors should be studied prospectively in large investigations of infants in the general population, and eventually informed clinical practice.

Similarly, we wanted to begin to expand our understanding of what may help distinguish between children who get diagnosed at younger ages versus those who get diagnosed at older ages. Because of caregivers' essential roles in the referral process, we decided to begin there. However, a significant challenge was that no one had examined parents' pre-diagnostic causal attributions of their children's behavior related to ASD and the potential association of such attributions with age of ASD diagnosis. This necessitated the development of new instruments as part of the current project in order to look at these types of questions.

The aim of this study was to examine expected associations among parental causal attributions about behaviors associated with ASD and the child age of ASD diagnoses, above and beyond demographic correlates of age of diagnosis previously suggested in the literature: race/ethnicity, severity, and SES. This study reports on additional analyses of data derived from participants included in a previous study (Perryman, Watson, & Chumney, 2018). The current study expands on the previous literature by examining factors related to early perceptions of ASD symptoms and their relationship to age of diagnosis. The hypothesized correlates of age of diagnosis outside of these demographic factors are: (a) levels of concern about initial ASD symptoms and (b) attributions about initial ASD symptoms.

Method

Participants

A total of 192 North Carolina caregivers (59 Black; 131 White; 2 other racial identities) of children with a current diagnosis of ASD were recruited for this study. With one exception (a caregiver recruited via a private practice agency) caregivers were recruited through the University of North Carolina Neurodevelopmental Disorders Research Center (NDRC) Autism Registry (N=191). The families in the NDRC registry had previously agreed to be contacted for research participation. Inclusion criteria

for the participants were that they be primary caregivers of a child with ASD. In addition, participants were only included if they had a child who: (a) was from 3 to 11 years old; (b) was diagnosed with ASD at 12 months or older by a qualified medical professional, service provider, or agency; (c) was ambulatory, with no severe motor impairments, other genetic disorders, evidence of other neurological impairments, or significant co-existing medical conditions; and (d) had a Social Responsiveness Scale ([SRS] Constantino, 2005) total scale score consistent with a diagnosis of ASD. Initially, the registry mailed 650 informational flyers to caregivers whose children fit the inclusion criteria to inform them about the study. Next, we mailed packages, which included the SRS, to 210 caregivers who agreed to participate in the study (see section below for description of SRS). Of the 210 questionnaire packages mailed, 192 were returned. We applied the inclusion criteria (e.g., meeting ASD threshold on SRS) for the participants who returned the questionnaires. After applying the inclusion criteria, a total of 168 caregivers remained eligible for the study. Thus, a total of 24 participants were excluded from the study because they did not meet the inclusion criteria. and 2 summarize the demographic characteristics for the participants.

Table 1. Demographic Characteristics (Categorical Variables).

Participant Characteristics	N	%	
Gender (Female; Respondent)	157	92	
Condor (Molo: Child)	113	66	
Gender (Male; Child) Race	113	00	
Black	50	30	
White	118	70	
Educational Status (Maternal)	110	70	
No High School Diploma or	4	2	
GED			
Completed High School or	20	12	
GED			
Some college or technical	39	24	
school			
Associate Degree	25	15	

Bachelors Degree	51	31
Graduate or Professional	27	16
Degree		
Place of Residency		
Large City	18	11
Suburb	42	25
Small town or city	82	48
Rural	25	15

Table 2. Demographic Characteristics (Continuous Variables).

Participant Characteristics	M	SD	Range
Age (Respondent) ^a	37.92	6.15	22 - 65
Current Age (Child) ^a	7.02	2.08	3 - 11
Age of Diagnosis b	45.55	22.10	12 -
			104
SRS Total Scale	81.52	8.89	61 - 90
Score			

Note. ^a measured in years ^b measured in months

Data collection procedures

After the initial mailing of the informational packets to targeted families, NDRC Autism Registry staff followed up with letters to nonresponders to ascertain interest/disinterest in the study. Once caregivers expressed interest in participation, the NDRC Autism Registry staff immediately sent a questionnaire package containing the Social Responsiveness Scale (SRS), the investigator-developed measures and the demographic survey (combined into an 8 x 11 survey booklet), and a small cash incentive. Returned questionnaires were tracked via participant-numbers (assigned by the researcher) that linked the questionnaires with the caregiver's response cards.

Predictor variables and measures

Two instruments were developed to measure level of worry/concern about symptoms related to ASD and attributions of initial ASD symptoms. In addition to these two instruments, caregivers completed a demographic questionnaire and the Social Responsiveness Scale (SRS). The measures included in the questionnaire package are described in more detail below.

Level of worry about autism symptoms measure (LOW: Perryman 2009). The LOW was developed to measure parents' perceptions of their initial concerns about early flags of ASD. The content of the measure was based upon previous studies of early symptoms and behaviors associated with ASD (Baranek, 1999; Osterling & Dawson, 1994; Reznick, Baranek, Reavis, Watson, & Crais., 2007; Wetherby et al., 2004; Zwaigenbaum et al., 2005). The measure consists of eight items that ask parents to gauge, retrospectively, their levels of worry about early ASD red flags in their children's behavior prior to diagnosis. The items inquire about both the absence of typical behaviors and the presence of atypical behaviors related to: (a) object play, (b) response to social interaction and social stimuli, (c) play and engagement, (d) motor movements, (e) joint attention (pointing) behaviors, (f) eye contact and looking behaviors, (g) speech development, and (h) imitation skills. response format for the measure of initial level of concern is a Likert scale in which 1 = not worried, 2 = somewhatworried, and 3 = very worried.

Attributions of autism symptoms measure (AOAS; Perryman, 2009). The AOAS was developed to measure parents' initial thoughts about the causes of behaviors related to ASD. Parents are asked to respond retrospectively to items concerning early red flag behaviors thought to be associated with a later diagnosis The content of the scale was based upon of ASD. previous research documenting differences explanations of behaviors (Bussing et al., 1998; Cohen et al., 1998). The items on the instrument ask if parents think behaviors were caused by conditions/reasons such as: (a) another medical condition (hearing loss or brain injury), (b) intentional disobedience or stubbornness, (c) slower but typical development, (d) shyness, (e) uniqueness or personality differences, or (f) spiritual influences. The response categories for initial attributions of behaviors uses a binary-scale format of yes, "I thought my child's behavior may have been caused by this condition/trait" and no, "I did not think that my child's behavior could have been caused by this condition/trait."

Demographic information. Parents were asked to complete a survey requesting information on family demographics and their diagnostic experiences. The survey includes questions that focused on: (a) caregiver and child racial or ethnic group affiliation; (b) educational level attainment and income (as a measure of SES); and

(c) agency or location where diagnosis of ASD took place (e.g., hospital, Children's Developmental Service Agency, TEACCH clinic).

Social Responsiveness Scale ([SRS]; Constantino, 2005). The SRS is a 65-item rating scale that measures the severity of ASD symptoms as they occur in natural settings (Constantino, 2005). The SRS was normed on a sample of more than 1,600 children and is appropriate for use with children from 4 to 18 years of age. Although the current study included a few 3-year-olds, the majority of the study sample (n = 158) was 4 years or older. Pine, Luby, Abbacchi, and Constantino (2006) validated the SRS via its correlations with teacher reports, the Vineland Adaptive Behavior Scale (VABS; Sparrow, Balla, & Cicchetti, 1984) composite score, and the social impairment/adaptive scores on the Autism Diagnostic Interview - Revised (ADI-R; Lord et al., 1994), considered one of the gold standards in establishing a clinical diagnosis of autism. They found the following correlations between the SRS and the above measures: (a) teacher report (r = 0.785); VABS (r = -0.862); and ADI-R (r = 0.634). The current study used the cut-off score of 59 for total scaled score as an inclusion criterion; scores at or above this value indicated deficits in social and communication skills consistent with those associated with ASD according to Constantino et al. (2003).

Analyses

A preliminary step in examining the data for the research aims involved conducting separate factor analyses for the researcher-created AOAS (attributes) measure to establish which subscale/s would be used in group comparisons and the regression analysis. Based upon the factor analysis, the items were grouped into 5 potential subscales. The criteria for retention of a subscale were three or more items with a single factor loading above .40 and a subscale with an alpha above .60. Factor analysis of the AOAS validated one subscale that met all the criteria for retention and thus could be used in further analyses to address the study aims. A total of four items loaded on this "Behavioral Challenges subscale ($\alpha = .72$)," wherein caregivers attributed early symptoms to the possibility that the child: (a) needed more discipline, (b) was being stubborn or disobedient, (c) might be spoiled, and (d) had a difficult personality.

The LOW measure, conceptualized and designed as a unidimensional measure, also met the criterion for internal consistency (α =.87), and was included in subsequent analyses.

Prior to conducting the regression analysis, bivariate Pearson product-moment correlations were conducted to examine the relationships between the predictor variables (AOAS-BC and LOW) and the outcome variable. LOW scores were negatively correlated with age of diagnosis, r(168) = -.22, p = .004 (i.e., small to moderate relationship) and AOAS-BC scores were positively correlated with age of diagnosis, r(168) = .31, p = .000 (i.e., moderate relationship).

A hierarchical regression model was selected to test the theory that caregiver beliefs and perceptions about initial ASD symptoms may explain a significant amount of variance in age of diagnosis above and beyond variables associated with age of diagnosis of ASD in previous research. Sequential entry of predictor variables into the hierarchical regression model was based upon prior research showing that a child's level of functioning or severity of symptoms (Goin-Kochel et al., 2006; Mandell, et al., 2005), SES (Mandell et al., 2005), and race/ethnicity (Mandell, Listerud, Levy, & Pinto-Martin, 2002) each has a relation with age at diagnosis. Therefore, race/ethnicity, severity, maternal educational levels, and income were entered into the model first because they were identified as covariates related to recognition of symptoms from the previous literature. The predictors of primary interest were: (a) LOW scores and (b) AOAS-BC scores. These variables were entered last because they have never been studied before in relation to age of ASD diagnosis and because the current study was interested in examining their influence above and beyond the covariate variables.

Results

Due to missing information (e.g., pertinent demographic information or scores on instruments, n = 6), a total of 162 caregivers' responses were included in the regression analysis. The first block (race/ethnicity) resulted in an $R^2 = .02$, F change (1, 160) = 3.01, p = .09, indicating that race/ethnicity alone did not explain a significant amount of variance in the age of diagnosis. The second block (SRS; Severity) did not result in a significant change in the model, $R^2 = .03$, F change (1, 159) = 1.48, p = .23; thus,

this demographic variable only explained an additional 1% of the variance in age of diagnosis. The third block (maternal education), also was not significant, $R^2 = .03$, F change (1, 158) = .02, p = .90. The addition of income (fourth block), did not explain additional variance in the dependent variable, $R^2 = .03$, F change (1, 157) = 0, p =1.00. The final block and model with the LOW total score and AOAS-BC subscale score was significant, with R^2 = .16, F change (2, 155) = 12.21, p < .001 and adjusted R^2 = .13. The results suggest that for this sample, magnitude of concerns and attributions contribute to the variance seen in the age of diagnosis above and beyond race, severity, SES, or geographical location. The R^2 change for the final block is .13, suggesting a moderate effect size. A summary of the final hierarchical regression results is provided in Table 3.

Table 3. Hierarchical Regression Model Predicting Age of Diagnosis of ASD.

Variables	В	SE B	β
T. 116 116			
Final Model Summary			
Constant	30.946	19.46	
Race/Ethnicity	-4.27	3.97	09
SRS total scaled	.25	.19	.1
score			
Maternal education	-1.01	1.64	05
level			
Income level	06	1.18	004
Level of Worry	-1.14	.38	23*
About ASD symptoms			
Attributions of ASD	4.13	1.15	.27**
symptoms: Behavioral			
Challenges			
Chancinges			

To further investigate the unique contributions that level of worry and attributions of ASD symptoms to behavior challenges make to age of diagnosis, a simultaneous regression analysis was used. A summary is provided in Table 4. The squared part correlation (partialing out the effect of AOAS-BP) for the LOW measure was .04, which translates to a small effect (Cohen, 1992). The squared part correlation (partialing out the effect of LOW) for the AOAS-BP was .08, which translates to a small to medium effect (Cohen, 1992).

Table 4. Parsimonious Multiple Regression Predicting Age of Diagnosis of ASD.

Variables	В	SE B	Partial r	R ² Change
Constant	36.46	9.26		
Level of	-1.03	.35	22*	.04
Worry About				
ASD symptoms				
Attributions	4.46	1.10	.29**	.08
of ASD				
symptoms:				
Behavioral				
Challenges				

^{*} *p* < .05; ** *p* < .001

Discussion

The purpose of this study was to explore associations between age of diagnosis and caregiver factors above and beyond factors previously explored in the literature (e.g. race, SES, symptom severity). As stated earlier, previous literature has shown associations between race (Mandell. Listerud, Levy, & Pinto-Martin, 2002), SES (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell et al., 2005), and the age of diagnosis of ASD. However, these findings have not been consistent in all cohort studies, including the current study's population, potentially due to variations in data collection and population characteristics (Perryman et al., 2018; Mandell et al., 2005). While it is important to continue to examine the role of demographics in early diagnosis, there may be further insight gained by investigating constructs influenced by differences in demographics, such as attributions, values, and beliefs. The latter are influenced by a variety of factors, including culture.

For this sample, race did not predict the age of diagnosis, nor did a number of other demographic variables (Perryman et al., 2018). However, age of diagnosis had a small relation with the magnitude of caregiver concerns and a small to moderate association with caregiver attributions of early symptoms to behavioral challenges. The regression results showed that the relationship between the above factors and diagnosis of developmental disorders is important to consider, beyond commonly cited barriers to early diagnosis.

Because this study widens our understanding about the preliminary conditions leading up to help-seeking, it has potential value for understanding the conditions influencing early identification of ASD. The current study provides a unique contribution by examining associations between parental concerns or beliefs about initial ASD-related symptoms and age of diagnosis. Although prospective research is needed to confirm that initial perceptions and beliefs about ASD-related behaviors are predictive of the presentation of concerns to health care providers, the current study identifies two candidate variables that may influence the overall referral process.

For instance, previous research has shown that physicians are less likely to refer children for ASD assessment if behaviors are disruptive or appear to be related to behavior challenges (Sices, Feudtner, McLaughlin, Drotar, & Williams, 2004). Parents' interpretations of their children's ASD-related behavior as a "behavior problem" may influence physicians' interpretation of the same behaviors. That is, parents may present concerns in a way that minimizes their complexity (e.g., behaviors are due to personality differences or willfulness). Indeed, Clayman and Wissow (2004) found that a minority of the doctors in their study actively sought to understand the parents by requesting elaboration of the words they used to describe their children's behavior, words that may potentially be "red flags" for developmental difficulties.

In another scenario, attributions of ASD-related behaviors to behavioral challenges may deter parents from expressing concerns to their children's physicians, and result in parents attempting to deal with the behaviors on their own. In such cases, the underlying reasoning and logic can be tied back to the Health Belief Model. If parents attribute behaviors to "controllable origins", they may not view their child as being vulnerable to a developmental disorder or have a sense of associated consequences (i.e., more social interaction difficulties as the child ages). On the other hand, if parents perceive that there is a medical origin for exhibited behaviors and have subsequent higher levels of concern, they may deem that professional help-seeking is beneficial and outweighs any potential barriers to getting answers. In the current study, there was an observed positive relationship between the magnitude of caregiver concern and age of diagnosis. Perhaps higher levels of concern were partly responsible

for earlier efforts to seek medical advice or services for atypical behaviors.

One limitation of the current study was the use of researcher-created instruments. This was necessary due to the lack of existing tools to examine the constructs of interest in the study. All of these instruments will require further examination and refinement for use in additional studies. The latter would include a study that uses the instruments in a prospective study to examine prediagnostic concerns and eventual age of diagnosis in young children showing developmental delays. The second limitation was that the sample was recruited from a research registry of families who had expressed an interest in being involved in research, and thus may not have been fully representative of the general population of parents of children with ASD. Third, although the retrospective methodology provided a feasible inroad to the initial examination of the influences of caregiver interpretation of early ASD symptoms on age of diagnosis, retrospective research has some inherent limitations. For example, without further research, one cannot rule out the alternative explanation that age of diagnosis influenced parent's retrospective views (i.e. recall bias) about their attributions or levels of concern. In addition, determining the exact nature and severity of early autism symptoms for individual children was not possible with a retrospective methodology. We did examine the possibility of parental recall of level of concern was biased by the child's current level of symptom severity, and found that the correlation between the LOW and the SRS scaled score was small (r=.10) and nonsignificant (p=.20). Given this finding, the severity of current ASD-related symptoms was not a contributor to parents' reported pre-diagnostic levels of concern.

Despite the limitations of this retrospective study, there were several advantages to using a retrospective approach as first step in this line of research. First, prospective studies are expensive, and the present retrospective research provides preliminary evidence supporting the value of investing resources in future research on caregiver factors that predict age of diagnosis of ASD. Second, the retrospective approach provided a means to develop and evaluate new instruments to measure key variables, also essential groundwork for future prospective investigations. In summary, this study, similar to retrospective studies on the earliest symptoms of ASD in infants and toddlers, provides a foundation for

further, hypothesis-driven research in a heretofore underexamined area.

Conclusion

The present study provides new information about the importance of parental concerns and attributions in the quest to identify children at risk for ASD at younger ages. If future studies support a prospective association between the parental attributions and concerns about ASD-related behaviors and age of diagnosis, the findings suggest the need to educate physicians and develop strategies to help families understand developmental milestones so that they can distinguish between intentional versus unintentional difficult behaviors in their children, and be more aware of which behaviors may be indicative of risk for developmental disorders.

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