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The relationship of parental first concerns and autism spectrum disorder in an early intervention sample

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ABSTRACT

Experts in the treatment of children with developmental disabilities emphasize the need to identify at-risk children at an early age. The ability to distinguish children at risk for particular developmental disabilities, such as autism (ASD), can help to target treatment to mitigate core symptoms and the deleterious effects of early delay on developmental trajectory. The present study investigates the relationship between parental first concerns (FC) (communication, social/emotional, cognitive/adaptive/global, behavior problems, motor, hyperactivity, and medical/other concerns) on ASD diagnosis in a sample of 2905 toddlers who presented for early intervention assessment in the state of Louisiana. We also examine whether developmental quotient (DQ) contributes to a diagnosis of ASD. Individuals deemed at-risk for a developmental disability represent a heterogeneous population, and this investigation aims to provide direction for identifying children likely to be diagnosed with an ASD according to parental perceptions of disability. Findings illustrating the differences in ASD diagnosis within each FC category are discussed.

1. Introduction

Autism spectrum disorders (ASDs) are neurodevelopmental disorders characterized by core features including impairment in social interactions, impairment in communication, and a restricted or stereotyped pattern of activities, interests and behaviors (Clarke et al., 2011; Duffy & Healy, 2011; Gillberg, 2010; Kaland, 2011; Worley & Matson, 2011). Researchers have promoted early identification and interventions for ASD, to reduce the impact of delays on later functioning (American Academy of Pediatrics Committee on Children with Disabilities, 2001; Committee on Educational Interventions for Children with Autism, 2001). Identification of deficits by parents is a key factor in initiating the process of assessment, diagnosis, and intervention.

Symptoms of ASDs generally become apparent early in development; one recent study reported 76.2% of parents had concerns about their child's development before three years of age (Jónsdóttir, Saemundsen, Antonsdóttir, Sigurdardóttir, & Ólason, 2011). Kishore and Basu (2011) found many parents reported concerns before one year of age. Guinchat et al. (2012) reported a mean age of 19 months when parents first noted concern and 27 months when parents first sought professional advice for children later diagnosed with ASD. For children with Asperger's syndrome, parents report their first concern (FC) around 26 months, with diagnosis at a mean age of 110 months (Noterdaeme & Hutzelmeyer-Nickels, 2010). In one study of 424 young children with ASD, the majority of parents (64.7%) first noted problems related to their child's

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socio-emotional development including social withdrawal, abnormal gaze or eye contact, and poor social interaction (Guinchat et al., 2012).

Although parents frequently report communication problems as the first or primary concern (Howlin & Moore, 1999; Kozlowski, Matson, Horovitz, Worley, & Neal, 2011; Meek, Robinson, & Jahromi, 2012), a variety of other problems are also reported. DeGiacomo and Fombonne (1998) found that while parents most often reported delayed language development as the FC about their child's development, social problems, challenging behaviors and regression of skills were also reported as behaviors of FC. Coonrod and Stone (2004) found that retrospective parent reports indicate that young children later diagnosed with ASD may demonstrate more motor impairment, unusual sensory or repetitive behaviors, atypical play patterns and behavioral problems than children with other developmental disabilities. Guinchat and colleagues (2012) found challenging behaviors not specific to ASD caused concern in 53.3% of their sample, including tantrum behavior, anxiety, passivity, and lack of attention.

Most previous studies have examined FCs in samples which do not differentiate by ASD subtype, though there is evidence that types of behaviors causing initial concern may vary by subtype of ASD. Noterdaeme and Hutzelmeyer-Nickles (2010) found that social problems (41.2%) and general behavioral problems (32.5%) were most likely to be first noted for children later diagnosed with Asperger's syndrome, whereas parents of children with ASD were first concerned about language problems (48.5%) in addition to social problems (25.7%). Those with atypical ASD, which would fall under the pervasive developmental disorder not otherwise specified (PDD-NOS) category in the DSM-IV-TR, were also likely to have parents first concerned with language problems (51.4%) and social problems (22.9%), but these parents also reported more concern with general behavior problems than those with classic ASD (11.4% and 5.6%, respectively) (Noterdaeme & Hutzelmeyer-Nickles, 2010). A more recent study found that caregivers of atypically developing children without an ASD were more likely to report impaired motor skills and somewhat more likely to report communication as a FC, though communication was the most frequently cited FC for all groups (Kozlowski et al., 2011). This study also found challenging behaviors and attention problems to be more frequently noted in children with ASD compared to atypically developing children. This is consistent with previous research finding that problem behaviors, such as self-injurious behavior, tantrums/aggression, stereotypy, were reported to a more frequently occurring and severe problem when compared to atypically developing peers as early as at one year of life (Fodstad, Rojahn, & Matson, 2012).

ASDs often go undiagnosed for three or more years following their first visit to a health care professional, despite reported parental concerns (Lin, Chen, & Chou, 2012; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Siklos & Kerns, 2007). Delays in diagnosis can be impacted by many factors. Parental denial or lack of knowledge regarding the normal course of child development may contribute to delays in diagnosis; additionally, symptoms often overlap with other disorders or may be attributed to transient problems or other developmental delays (Gardiner & Iarocci, 2012). Delay in the diagnosis and treatment of developmental problems increases parental stress (Dyches, Smith, Karth, Roper, & Mandieco, 2012). It is important to note that parents' FCs are not necessarily the first symptoms that emerge. Although social-communicative deficits are commonly reported in young children with ASD, parents may develop compensatory strategies of communication and methods of engaging their child as the child develops, and thus may not be aware of these deficits (Adrien et al., 1993; Baranek, 1999). Many parents first report their concerns to a pediatrician or other general practitioner; therefore awareness of commonly reported FCs of these parents can assist in identifying children in need of additional screening or assessment.

Although the criteria for ASDs dictate an onset of symptoms before three years of age, many of the behaviors which would contribute to clinical diagnosis are difficult to assess under the age of two years (e.g. stereotypies, or abnormal language/communication patterns) (Guinchat et al., 2012). Nonetheless, it seems the majority of parents have some concern about their child's development at an early age. Of note, many of these concerns are not areas routinely assessed in typical health care visits, during which a clinician is more likely to assess for gaze abnormalities, delayed language development, and whether a child answers to his or her name (Oosterling et al., 2009). Noterdaeme and Hutzelmeyer-Nickles (2010) noted that particularly in children diagnosed with Asperger's syndrome, professionals may dismiss parents' concerns regarding peculiarities, as these traits may be more apparent in unstructured settings and may not be readily apparent in a clinical setting. However, parents' early concerns should not be dismissed since they have been positively correlated with later scores on the M-CHAT ASD screener and with subsequent ASD diagnosis even if FCs are not ASD-specific (Ozonoff et al., 2009). Therefore whether a parent's FCs are specific to ASD or not, these worries can aid in early diagnosis by alerting the health care professional to children who may need more careful monitoring throughout development.

Previous studies have examined the relationship between reported FCs and degree of impairment in toddlers with and without an ASD diagnosis, whether communication as a FC predicted receiving an ASD diagnosis (Kozlowski et al., 2011). Later investigators examined the relationship between socialization and communication deficits in the same sample of toddlers (Hattier & Matson, 2012). Turygin, Matson, Konst, and Williams (2013) investigated the relationship of communication FCs on a child's developmental quotient(DQ) and symptoms of ASD. In the previous study, communication concerns were associated with more symptoms of ASD compared to those in a non-communication concern group. The present study investigates the relationship between the reported first concern, and the effect each of the other concern categories on the likelihood of receiving the diagnosis. This study builds on findings investigating the variety of concerns first noted in parents of atypically developing children or children with ASDs, and the relationship between these FCs and subsequent development and diagnosis.