Title: Family Impact After a Positive Autism Screen

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Introduction: Raising a child with autism spectrum disorder (ASD) can impact many aspects of the family (Estes et al, 2013; Hartley, DaWalt, & Schultz, 2017; Hayes & Watson, 2013; Lavelle et al., 2014; Pisula & Porębowicz-Dörsmann, 2017; Shivers, McGregor, & Hough, 2017; Valicenti-McDermott et al., 2015), yet no studies have assessed these factors when a child may be displaying ASD symptoms but does not have a formal diagnosis. Further, parents often experience stress when children are referred for diagnostic assessment (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Siklos & Kerns, 2007) regardless of the outcome of the assessment. There is a paucity of research that examines the experiences of families whose child was found to have risk for ASD during universal screening but subsequently completed a comprehensive developmental assessment and received some other, non-ASD diagnosis. Our research questions were: 1. Are there differences in negative family impact between these two groups (eventual ASD vs. non-ASD diagnosis)? 2. Is eventual child diagnosis associated with level of negative impact on the family and, 3. Does child functioning and/or child behavior moderate the relation between diagnostic status and negative impact on the family?

Method: We explored associations between child functioning (Adaptive Behavior Assessment System, 2nd Edition; Rust & Wallace, 2004) and difficult child behavior (Parenting Stress Index - Short Form, Difficult Child subscale; Abidin, 1995) and negative family impact (Family Impact Questionnaire; Donenberg & Baker, 1993) in a sample of 276 families of children, aged 15-28 months, with a positive screen for ASD who were referred for diagnostic assessment for ASD, identified through the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (Robins et al., 2014) or parental concern. The sample included families who were participants in a NIMH-funded randomized controlled trial of Family Navigation. Analyses for the current study focused on baseline measures. Within the sample, 169 children received an ASD diagnosis, and 107 received another developmental, language, or behavioral disorder diagnosis at the completion of the study.

Results: One-way ANOVA analyses revealed that families of children who eventually received a developmental, language, or behavioral disorder diagnosis other than ASD reported a significantly higher level of negative family impact (F=6.29, p=.013). Results from the initial multiple linear regression model showed that child behavior (β = .61, S.E. = .05, p < .001) and eventual diagnosis (β = -.25, S.E. = .10, p = .01) were associated with level of negative impact on the family. More difficult child behavior and receiving a diagnosis a non-ASD diagnosis were each related to a higher level of negative impact on the family, controlling for child functioning, and relevant sociodemographic characteristics. However, when including an interaction term (child behavior x final diagnosis) the relation between eventual diagnosis and negative family impact disappeared and the interaction was significant (β = -.02, S.E. = .01, p = .05), indicating that child behavior moderated the relation between eventual child diagnosis and negative family impact.

Discussion: Understanding parent and family experiences during the time when children are referred for diagnostic assessment but have not reached diagnostic ascertainment is important for efforts to improve access to and engagement in care. The current study included a sample of racially and ethnically diverse, low-income, families whose children screened positive for ASD in primary care in order to better understand family impacts during the diagnostic process in these unique groups. Study findings suggest that having a child who has been identified as having risk for ASD has an impact on the family, regardless of the child’s eventual diagnosis and even prior to receiving a definitive diagnosis and engagement in ASD-specific or other treatment services. These findings have important implications for clinicians and providers and highlight a need to better support families during the period of diagnostic ascertainment.

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References:


