Characterizing the Maternal Psychosocial Experience When Raising a Child with Autism

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Objective

Severity of autism spectrum disorder (ASD) is variable, but symptomatology is distinct and characterized by difficulties with social interaction and prediction, repetitive, stereotyped, and sometimes challenging behaviors, and restricted interests. One in 54 children in the United States receive an ASD diagnosis[1], and the individual lifetime cost for ASD management approaches 2.5 million dollars.[2] It is well-documented that there are inherent challenges to parenting a child with disabilities.[3-4] Families raising a child with ASD report difficulty facing stigma in their communities,[5] engaging their child in mutually meaningful interactions,[6] affording and accessing services,[7] implementing therapies and family routines,[7-8] and identifying supports.[7] Families must often make difficult decisions about employment and their use of time and resources while caring for their child. Abiding societal norms often designate the mother as the primary caregiver for the child, and thus the mother typically incurs the most psychological impact when child-rearing[7,9] Both families and providers would benefit from a greater understanding of the interplay between maternal and child symptoms when raising a child with special healthcare needs, and factors that may impact or moderate maternal anxiety and stress.

Methodology

Data was collected as part of a larger, cross-sectional study, titled *Epigenetics, polygenic risk and the social environment in autism*, and was designed by Principal Investigator Dr. Lane Strathearn MBBS, FRACP, PhD. This study was approved by the University Institutional Review Board and is internally funded by the Attachment and Neurodevelopment Lab at the University of Iowa Hospitals and Clinics (UIHC) Center for Disabilities and Development (CDD). The research team is in the process of securing a P50 grant, aiming to continue data collection for five years.

From this pilot data, this project collated information obtained from mothers about the early childhood environment in families with and without a child with autism. Biologic mother-child dyads were recruited through appointment schedules for the CDD and the UIHC pediatric clinics. All involved families were English-speaking, and children were born in Iowa at full-term and were presently between the ages of 14 months to 35 months. Families first received a letter about the study, and subsequently were contacted via phone and screened for interest and eligibility. Families did not meet inclusion criteria if their child was a twin or if the child had a known genetic disorder or other neurologic disorder. Unless the dyad was being recruited for

the ASD group, they could not have a close family member with a known ASD diagnosis. Mothers meeting study criteria were then instructed to download *BabySteps*, a novel, smartphone application (app) created for this study. On the app, families were guided through the consent process. Once consented, they could begin a series of tasks designed to characterize their child's development and abilities. These tasks included the demographic questionnaire and the Modified Checklist for Autism in Toddlers—Revised MCHAT-R). The MCHAT-R score, coupled with the results of the child's clinical evaluation differentiated dyads into one of three groups: Typically Developing (TD), Autism (ASD), and Development Delay Distinct from Autism (DD).

Mothers were also emailed several surveys to complete via a secure online platform. The ones included in this project were: Maryland Trait Depression Scale (MTSD), State-Trait Anxiety Inventory (STAI), Chronic Stress Survey (CSS), the Adaptive Behavior Assessment System 3 (ABAS-3), the Social Support Questionnaire-6 (SSQ-6), and the Perceived Stress Scale (PSS). Families were reminded of outstanding questionnaires via automated email recontact every few days.

This pilot project aimed to characterize maternal stress, anxiety, and depression, understand the impact of the child's adaptive functioning on the maternal psychosocial state and identify factors that may impact stress or anxiety in mother and child.

Results

This study analyzed data from 9 ASD families, 8 DD families, and 17 TD families. Using the Wilcoxon rank-sum test with continuity correction and the Benjamini-Hochberg Procedure to control false discovery rate, there were no significant differences between groups in regard to reported perceived stress, chronic stress, trait depression, or satisfaction with social supports. There was a statistically significant difference ($P<.05$) between the reported state anxiety score for DD mothers when compared to ASD and TD mothers. There was nearly a statistically-significant difference between all groups in trait anxiety ($P<0.071$) and number of social supports. ($P<0.066$). Increased number of social supports had a more positive effect on ASD and DD mothers than TD mothers. Additionally, increases in maternal anxiety were associated with a slight reduction in child adaptive behaviors in ASD and DD children, but not TD children. Conversely, higher ABAS scores were associated with lower maternal state anxiety scores in ASD and DD mothers, but no such trend existed amongst TD dyads. ASD mothers also appeared particularly resilient to the impact of anxiety across demographic variables, including income and maternal education level, as evidenced by lower mean state anxiety scores.

Conclusion

The most major limitation of this study was a small sample size, which precluded the ability to match families across demographic variables. However, findings from this study suggest that in ASD and DD dyads, there may be a bidirectional impact of maternal psychopathy on the dyad. Findings also suggest that despite the inherent challenges to raising a child with a disability, ASD mothers may be especially resilient to anxiety. This difference between ASD and DD groups could be due to demographic or interpersonal factors such as differences in maternal

education, occupation, or income, or a difference in availability of supports. It is possible that having a confirmed diagnosis may help ASD families identify specific interventions and programs for their family. This research project closely aligns with the Doctor of Nursing Practice Essential VII: *Clinical Prevention and Population Health for Improving the Nation's Health*.[7] Taking an "upstream" approach on the discussion of ASD, this project identifies potential factors which may be putting both mother and child at risk for poorer developmental or psychiatric outcomes—and proposes factors that may moderate these risk factors. Armed with this knowledge, this research will aid nurses and other providers in more appropriately identifying at-risk families so they can provide crucial early intervention services and referrals, with the overall goal of tempering the severity of child or maternal effects. Information collated through this project will contribute to a 5-year longitudinal study, for which researchers will seek publication.

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