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Maternal Mental Health After a Child's Diagnosis of Autism Spectrum Disorder

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JAMA PEDIATRICS

Improving Maternal Mental Health After a Child's Diagnosis of Autism Spectrum Disorder: Results From a Randomized Clinical Trial

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IMPORTANCE The prevalence of psychological distress among mothers of children with autism spectrum disorder (ASD) suggests a need for interventions that address parental mental health during the critical period after the child's autism diagnosis when parents are learning to navigate the complex system of autism services.

OBJECTIVE To investigate whether a brief cognitive behavioral intervention, problem-solving education (PSE), decreases parenting stress and maternal depressive symptoms during the period immediately following a child's diagnosis of ASD.

DESIGN, SETTING, AND PARTICIPANTS A randomized clinical trial compared 6 sessions of PSE with usual care. Settings included an autism clinic and 6 community-based early intervention programs that primarily serve low-income families. Participants were mothers of 122 young children (mean age, 34 months) who recently received a diagnosis of ASD. Among mothers assessed for eligibility, 17.0% declined participation. We report outcomes after 3 months of follow-up (immediate postdiagnosis period).

INTERVENTIONS Problem-solving education is a brief, cognitive intervention delivered in six 30-minute individualized sessions by existing staff (early intervention programs) or research staff without formal mental health training (autism clinic).

MAIN OUTCOMES AND MEASURES Primary outcomes were parental stress and maternal depressive symptoms.

RESULTS Fifty-nine mothers were randomized to receive PSE and 63 to receive usual care. The follow-up rate was 91.0%. Most intervention mothers (78.0%) received the full PSE course. At the 3-month follow-up assessment, PSE mothers were significantly less likely than those serving as controls to have clinically significant parental stress (3.8% vs 29.3%; adjusted relative risk [aRR], 0.17; 95% CI, 0.04 to 0.65). For depressive symptoms, the risk reduction in clinically significant symptoms did not reach statistical significance (5.7% vs 22.4%; aRR, 0.33; 95% CI, 0.10 to 1.08); however, the reduction in mean depressive symptoms was statistically significant (Quick Inventory of Depressive Symptomatology score, 4.6 with PSE vs 6.9 with usual care; adjusted mean difference, -1.67; 95% CI, -3.17 to -0.18).

CONCLUSIONS AND RELEVANCE The positive effects of PSE in reducing parenting stress and depressive symptoms during the critical postdiagnosis period, when parents are asked to navigate a complex service delivery system, suggest that it may have a place in clinical practice. Further work will monitor these families for a total of 9 months to determine the trajectory of outcomes.

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From the moment a developmental concern is suspected, either by a child's parent or a clinician, a family embarks on a lifelong journey of diagnosis and treatment. Receiving a formal diagnosis of autism spectrum disorder (ASD) initiates the journey into the world of ASD. Establishment of an ASD diagnosis determines eligibility for services, including but not limited to behavioral, speech, and occupational therapies. Most parents develop a sense of urgency that early intervention services should be implemented immediately once their child is suspected of having ASD, potentially resulting in parental stress as the diagnostic process unfolds. Parents may feel they have not adequately supported their child if they cannot acquire intervention services in a timely fashion. While an ASD

diagnosis is established and treatment is initiated, parents may experience their own sense of grief as they cope with having a child with a potential ASD.

After the diagnosis is established and treatment initiated, parents are often educated about becoming active participants in delivering therapy to their child. They must learn a new vocabulary and parenting approach that are often very different from their original view of parenting. Being engaged in delivering therapy changes the nature of the parents' relationship with their child. Many early intervention strategies rely on mothers (or other primary caregivers) to continue to use the behavioral, social, and cognitive intervention strategies in the home, in part because it is cost-effective to have

parents in this therapeutic role.¹ Parents learn skills to improve core deficits commonly seen in ASD, including communication and joint attention (the shared focus of 2 individuals on an object) so that these skills continue to be taught and reinforced to the child outside of the therapeutic setting and in the home.^{1,2} Having a child with ASD often changes the dynamics of the family unit and can lead to a more stressful life for the child's caregivers.³ Parents may feel as though their child's outcomes depend on their ability to deliver the intervention activities in the home, leading many parents to quit jobs so they can stay home full-time with their child with ASD.

The complexities involved in raising a child with ASD result in high rates of maternal stress and depression, with rates even higher than those observed in mothers of children with Down syndrome.⁴ These heightened levels of stress and depression can result in an altered relationship between the mother and child and an increase in internalizing and externalizing behaviors in young children, as supported by a long-standing literature examining the reciprocal relationship between maternal depressive symptoms and children's internalizing and externalizing behaviors.^{5,6} Maternal mental health can adversely affect gains children make from interventions delivered by their caregivers. Because of this, it is important that intervention programs consider how maternal mental health may affect treatment outcomes.

In the January 2014 issue of *JAMA Pediatrics*, Feinberg et al⁷ describe an intervention addressing the mental health of mothers of children with ASD. In a randomized trial involving 59 mothers who received problem-solving education compared with 63 who did not, Feinberg et al found that this intervention attenuated certain aspects of maternal mental health at a 3-month follow-up. Clinically significant parental stress was reduced in the intervention group (3.8% vs 29.3%; adjusted relative risk [aRR], 0.17; 95% CI,

0.04-0.65). The relative effectiveness of this short-term intervention demonstrates the feasibility and potential benefits for a maternal mental health component to be added to early intervention programs for children with ASD. Future studies should explore additional evidence-based approaches for improving maternal mental health for caregivers of children with ASD. It is possible that some parental interventions may be more effective when paired with certain child-focused early intervention programs. Even though a variety of programs exist (eg, applied behavioral analysis, pivotal response treatment, reciprocal imitation training), it will be important for future research to address potential common factors of parental mental health interventions that could be successfully implemented across interventions.

The study by Feinberg et al⁷ is an important first step in what will be an ongoing process of assessing and treating parental mental health as a component of early intervention programs for ASD treatment. Larger, more diverse patient samples will provide insight into the generalizability of the current results. Moving forward, it is important to consider that the current study implemented the maternal intervention soon after families received a diagnosis of ASD for their young child. Supporting the needs of parents of children with ASD through the diagnostic process is necessary, but parents will also need support at all of the major turning points in the child's life course: age 0 to 3 years with early intervention, age 5 to 18 or 21 years with advocacy in school systems, and in adulthood with employment support. Some parents have even started their own businesses to ensure employment for their adult with ASD. More research is needed regarding how to better support parents of children with ASD. As parental mental health interventions improve, it is likely that the outcomes for children with ASD will also improve.

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