Maternal mental health after a child's diagnosis of autism spectrum disorder

Permalink
https://escholarship.org/uc/item/5hj9175q

Journal
JAMA - Journal of the American Medical Association, 313(1)

ISSN
0098-7484

Authors
Karp, EA
Kuo, AA

Publication Date
2015-01-01

DOI
10.1001/jamapediatrics.2013.3445

Peer reviewed
Maternal Mental Health After a Child’s Diagnosis of Autism Spectrum Disorder

Elizabeth A. Karp, BA; Alice A. Kuo, MD, PhD

**JAMA Pediatrics**

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

Emily Feinberg, CPNP, ScD; Marilyn Augustyn, MD; Elaine Fitzgerald, DrPH; Jenna Sandler, MPH; Zhandra Ferreira-Cesar Suarez, MPH; Ning Chen, MSc; Howard Cabral, PhD; William Beardslee, MD; Michael Silverstein, MD, MPH

**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).

**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 parent 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). Most intervention mothers (78.0%) received the full PSE and 63 to receive usual care. The follow-up rate was 91.0%. Among mothers assessed for eligibility, 17.0% declined participation.

**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.


**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.\textsuperscript{3} 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.\textsuperscript{1,2} Having a child with ASD of-
ten changes the dynamics of the family unit and can lead to a more
stressful life for the child’s caregivers.\textsuperscript{3} Parents may feel as though
their child’s outcomes depend on their ability to deliver the inter-
vention 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.\textsuperscript{4}
These heightened levels of stress and depression can result in an al-
terred relationship between the mother and child and an increase in
internalizing and externalizing behaviors in young children, as sup-
ported by a long-standing literature examining the reciprocal rela-
tion between maternal depressive symptoms and children’s internal-
izing and externalizing behaviors.\textsuperscript{5,6} Maternal mental health can
adversely affect gains children make from interventions delivered
by their caregivers. Because of this, it is important that interven-
tion programs consider how maternal mental health may affect treat-
ment outcomes.

In the January 2014 issue of JAMA Pediatrics, Feinberg et al\textsuperscript{7}
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 cer-
tain 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 interven-
tion demonstrates the feasibility and potential benefits for a mater-
nal 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 al\textsuperscript{7} is an important first step in what
will be an ongoing process of assessing and treating parental men-
tal health as a component of early intervention programs for ASD
treatment. Larger, more diverse patient samples will provide in-
sight into the generalizability of the current results. Moving for-
ward, it is important to consider that the current study imple-
mented the maternal intervention soon after families received a
diagnosis of ASD for their young child. Supporting the needs of par-
ents of children with ASD through the diagnostic process is neces-
sary, 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 interven-
tion, age 3 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 sup-
port parents of children with ASD. As parental mental health inter-
ventions improve, it is likely that the outcomes for children with ASD
will also improve.

**ARTICLE INFORMATION**

**Author Affiliations:** Department of Psychology, University of Washington, Seattle (Karp); Department of Pediatrics, University of California, Los Angeles (Kuo); Department of Internal Medicine, University of California, Los Angeles (Kuo).

**Corresponding Author:** Elizabeth A. Karp, BA, Department of Psychology, University of Washington, PO Box 351525, Seattle, WA 98195 (ekarp@uw.edu).

**Conflict of Interest Disclosures:** Both authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest and none were reported.

**Additional Contributions:** We thank Sarah Edmunds, BA, and Colleen Harker, MS, Department of Psychology, University of Washington, for their assistance in the preparation of the manuscript. Neither received compensation for her contribution.

**REFERENCES**


