Shared Decision Making and Treatment Decisions for Young Children With Autism Spectrum Disorder

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OBJECTIVE: To describe influences on shared decision making between primary care pediatricians and parents of young children with autism spectrum disorder (ASD).

METHODS: We conducted a qualitative study using key informant interviews with 20 pediatricians of varying experience from 10 primary care practices and 20 English-speaking parents of young children (aged 2–5 years) with a parent-reported diagnosis of ASD. Subjects were recruited through purposive sampling. Interviews were audiotaped, transcribed verbatim, and analyzed using an integrated approach to data analysis. Differences in coding were resolved by consensus. We achieved thematic saturation and ceased recruitment after 20 interviews were completed within each group.

RESULTS: Three primary themes emerged: 1) pediatricians and parents reported knowledge gaps by pediatricians about ASD treatments and community resources as well as ambiguity regarding the pediatrician's role in ASD care; 2) there was little communication between parents and pediatricians about treatment choices; 3) use of complementary and alternative medical treatments created conflict between pediatricians and parents, and as a result, parents may independently pursue treatments, without the benefit of discussing safety and efficacy with pediatricians. Despite these barriers, parents desired increased support and guidance from their pediatricians, including for complementary and alternative medicine.

CONCLUSIONS: Much work is needed to effectively foster shared decision making in the context of ASD treatment decisions in primary care, including pediatrician training in ASD to enhance knowledge about evidence-based and novel treatments, clinical practice guidelines, and community resources.

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Authors: Levy SE, Frasso R, Colantonio S, Reed H, Stein G, Barg FK, Mandell DS, Fiks AG

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