

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



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ABSTRACT

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.

KEYWORDS: autism; autism spectrum disorder; shared decision making; treatment decisions

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WHAT'S NEW

This qualitative study describes substantial barriers to shared decision making (SDM) between parents of young children with autism spectrum disorder (ASD) and pediatricians. Substantial work is needed to promote SDM for ASD in primary care. New guidelines for ASD should address SDM.

SHARED DECISION MAKING (SDM) is a process of reciprocal communication and knowledge transfer, where providers and families share information about treatment options and come to a mutual agreement about treatment choices, taking into account evidence as well as family values, preferences, and goals.¹ Because autism spectrum disorder (ASD) is common, with an estimated prevalence of 14.7 per 1000 (1 in 68) children aged 8 years,² primary care pediatricians will care for many children with ASD in

their practice. Prior research has documented that families need guidance and support from their pediatrician to access, evaluate, and choose treatments and services.^{3,4}

Published practice parameters and toolkits have increased pediatricians' comfort managing children with developmental disorders such as attention-deficit/hyperactivity disorder (ADHD).^{5,6} That is not the case for children with ASD,³ despite clinical reports and toolkits published by the American Academy of Pediatrics.⁷ Many treatments are available for children with ASD⁸ with varying evidence for effectiveness. Treatment selection varies by the child's age, developmental skills, severity of core symptoms (social communication and repetitive behavior), and common comorbid medical, developmental, and behavioral problems.⁹ Research in treatment of preschool children (under age 6 years) has supported evidence for treatment programs including intensive behavioral intervention (such as applied behavior analysis), educational

curricula, speech/language therapy, and occupational therapy.^{8,10,11} A recent Agency for Healthcare Research Quality review of effectiveness of therapies for young children with ASD highlighted 2 child-focused early intensive treatment models, the Early Intensive Behavioral Intervention and the Early Start Denver Model.¹² Both programs use intensive behavioral intervention and parent training and have demonstrated improvement in language and social skills.^{13,14} It is not clear why pediatricians are not comfortable discussing or making treatment recommendations given the clinical reports and reviews promoting screening, early identification, and referral for treatment.

The process of SDM involves engaging families by sharing information and knowledge about treatment options, bidirectionally expressing treatment preferences and goals, and coming to agreement about treatment decisions.^{15,16} SDM is helpful when multiple treatments are available, and when families value evidence for treatments differently and have different perceptions than medical professionals of the associated risks and benefits.¹ As such, ASD is a natural fit for SDM. However, because many treatments for ASD lack data about effectiveness, families of children with ASD may make treatment decisions without consideration of evidence or the potential for harm. Overall, the use of SDM and improved provider–patient communication and partnership has been linked to improved satisfaction, adherence, and health outcomes.^{17,18} These benefits are particularly salient to families of children with ASD who may be overwhelmed with challenges of caring for their children. A recent systematic review of family-centered care including partnering in decision making for children with special health care needs showed a positive association of family-centered care with efficient use of services, access to care, health status, and family functioning.¹⁹ Data from the National Survey of Children With Special Health Care Needs supported benefits of SDM for children with ASD, including less out-of-pocket expenditures, family time coordinating care, and financial stress.²⁰ However, prior research has provided little information about facilitators and barriers to the process of SDM for young children with ASD.

To explore whether such a knowledge gap exists, we surveyed primary care pediatricians and parents of young children with ASD about their experience with SDM and the barriers and potential facilitators they identified.

METHODS

SETTING

We conducted this study in collaboration with the Children's Hospital of Philadelphia's (CHOP) Pediatric Research Consortium (PeRC) and families of children with ASD living in the greater Philadelphia area. The University of Pennsylvania and CHOP institutional review boards approved the study. All participants provided written (for in-person interviews) or verbal (for telephone inter-

views) informed consent. Although loopholes exist, the Omnibus Amendment to the insurance law (PL 885) in Pennsylvania requires that individuals <21 years with ASD receive diagnostic assessment and treatment of ASD (<http://www.legis.state.pa.us/WU01/LI/LI/US/HTM/2008/0/0062.HTM>).

STUDY DESIGN AND PARTICIPANT POPULATION

We chose individual key informant interviews to allow us to compare provider and parent perspectives because they have unique points of view on this shared experience, and we did not want privacy concerns to influence conversations. From May 2011 through March 2012, we conducted semistructured interviews with 20 pediatricians in the CHOP primary care network and 20 parents of children with ASD aged 2 to 5 years. Online [Appendix A](#) provides the wording of e-mails, letters, and brochures introducing the study. The research team invited all primary care doctors (n = 178) from the 31 CHOP Network primary care practices to participate in the study to examine decision making practices for young children with ASD. Forty clinicians responded to the call, and the research team purposefully selected the first 10 respondents who practiced in an urban setting and the first 10 who practiced in a suburban setting to participate (n = 20). All primary care practices in the CHOP network were certified as medical homes, though this did not require implementing SDM for ASD. We recruited English-speaking parents of children aged 2 to 5 with ASD (because that is typically when ASD diagnoses are made and children begin treatment²) in the greater Philadelphia region from several sources: participants in previous PeRC research studies, enrollees in AutismMatch (an electronic mailing list sponsored by CHOP's Center for Autism Research for families who are interested in learning about autism research), and a local Autism Speaks chapter. We deliberately recruited families of different races and ethnicities to best represent the target population. We enrolled and scheduled family interviews sequentially, according to family availability. All recruitment materials can be found in Online [Appendix A](#).

We achieved thematic saturation within both study groups, parents, and pediatricians when additional interviews ceased to provide new perspectives from either group. As such, recruitment ended after 20 interviews with parents and 20 with pediatricians.

DATA COLLECTION

This study was planned and implemented with the explicit goal of understanding parent and pediatrician views of SDM. To do so, we explored how pediatricians and families did or did not jointly identify decisions to be made, exchange perspectives on these decisions, and reach or defer decisions. However, in our questioning, we asked open-ended questions about decision making in order to avoid biases that might arise if the entire study were framed for participants narrowly around SDM. Using this approach, separate interview guides for parents and

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