



Reducing Barriers to Care in the Office-Based Health Care Setting for Children With Autism

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ABSTRACT

The purpose of this survey-design research study was to evaluate the usefulness of a researcher-developed tool designed to improve office-based health care services and to assess the barriers and resources affecting office-based health care services for children with autism spectrum disorder. Fifty-four health care providers (HCPs) and 59 parents participated in the study. HCPs reported child behaviors, communication, and fears as barriers to providing care, whereas parents reported child behavior, sensory issues, and feelings of a disconnect with the HCP as barriers. HCPs identified the parent as a key resource. Parent-identified resources included provider adaptations to the patient, including slowing down the delivery of care and environmental adaptations to the office. In addition, both

HCPs and parents indicated that the researcher-developed tool would be useful in reducing barriers during the HCE. Reducing barriers and improving health care interactions during delivery of care for children with autism spectrum disorder has the potential to improve health outcomes. *J Pediatr Health Care.* (2016) 30, 5-14.

KEY WORDS

Autism spectrum disorder, barriers, resources, primary care, health care delivery

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by marked impairments in reciprocal social communication, as well as restricted interests and repetitive behaviors ([American Psychiatric Association, 2013](#)). Recent data from the Centers for Disease Control and Prevention indicate that 1 in 68 children in the United States have an ASD ([Wingate et al., 2014](#)). Data show that such children have more health care encounters (HCEs) that are longer in duration than their neurotypical peers ([Liptak, Stuart, & Auinger, 2006](#)). It is not uncommon for children with ASD to present to their health care provider (HCP) with complex developmental and behavioral symptom profiles requiring the use of an individualized and innovative approach to managing the child's behaviors within the office setting ([Lombroso, Ogren, Jones, & Klin, 2009](#)).

Given the complex behavioral profile that children with ASD present with, HCPs have reported a lack of confidence and training in appropriate communication skills and strategies needed to interact effectively with families of children with ASD ([Minnes & Steiner, 2009](#); [Weil & Inglehart, 2010](#)). Additionally, parents of children with ASD have reported dissatisfaction with

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Supported by funds from the Delta Lambda Chapter of Sigma Theta Tau.

Conflicts of interest: None to report.

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0891-5245/\$36.00

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Published online October 9, 2015.

<http://dx.doi.org/10.1016/j.pedhc.2015.08.007>

their child's HCEs, citing the HCP's lack of confidence, knowledge, and skills in handling the challenging child behavior that often presents with ASD (Minnes & Steiner, 2009; Rhoades, Scarpa, & Salley, 2007). To date, few empirical data are available regarding the types of office-based supports that HCPs and parents need to enhance the delivery of health care services for children with ASD who present with challenging behaviors. Office-based care presents different challenges than acute care settings for many reasons, including a limited amount of time for appointments, tight appointment schedules, limited office personnel, and limited resources. The purpose of this study was twofold: (a) to evaluate the acceptability and usefulness, from the perspectives of both parents and HCPs, of a researcher-developed tool designed to facilitate communication and improve health care delivery outcomes during HCEs, and (b) to conduct a needs assessment of the barriers and resources that parents of children with ASD encounter during office-based health care delivery.

LITERATURE REVIEW

Research has shown that children with ASD experience a greater number of HCEs per year than do their neurotypical peers (Gurney, McPheeters, & Davis, 2006; Liptak et al., 2006). Furthermore, it has been shown that the length of time the HCP spends during an HCE with a child with ASD is almost two times longer than for other children, including those with chronic illness (Liptak et al., 2006). This increase in visit length is, in part, related to the frequency and duration of challenging behaviors displayed by the child during the encounter. Unfortunately, this increased number of HCEs and increased length of time of the visits do not necessarily translate into a higher quality of health care for this population of children with ASD. Zuckerman, Lindly, Bethell, & Kuhlthau (2014) found that children with autism experience a poorer quality of health care than do children with special health care needs who do not have autism.

CHALLENGING BEHAVIORS EXHIBITED DURING HCES

Researchers have shown that typical behaviors of autism—including screaming or verbalizations, tantrums, aggression toward self or others, inappropriate activities, anxiety, fears, and irritability—complicate the delivery of health care for children with autism because these behaviors are often exacerbated in the health care environment (Bultas, 2012; Hellings et al., 2005; Matson, 2009). Increased anxiety, although not always externalized, may be exhibited by children with ASD when they visit the HCP because of their unfamiliarity with the office routine and their inability to fully communicate their fears and frustrations (Johnson, Bekhet, Robinson, & Rodriguez, 2014). The

social and communication impairments that are central to autism often cause these difficulties for the child. Environmental triggers such as bright lights, noises, and the fast-paced health care setting have also been linked to increased anxiety and fear for children with ASD in the acute care setting, which can then lead to poor compliance with the HCE (Johnson et al., 2014; Scarpinato et al., 2010). Children with autism also have difficulty with emotional regulation, which may also cause anxiety and externalizing behaviors such as aggression and acting out in the HCE (Davignon, Friedlaender, Cronholm, Paciotti, & Levy, 2014).

Another factor complicating behavior for the child with ASD are psychiatric comorbidities (Hofvander et al., 2009; Pondé, Novaes, & Losapio, 2010). These comorbidities include attention deficit hyperactivity disorder, as well as externalizing behaviors that often hinder and interfere with a child's ability to have appropriate interactions (Mayes et al., 2012), especially in the health care setting. Complicating matters, HCPs may have limited experience managing the challenging behaviors children that with ASD often display in the novel health care environment (Johnson, Lashley, Stonek, & Bonjour, 2012). The fast pace of the office-based setting further complicates the situation because of limited appointment lengths, appointment schedules, and lack of resources, including additional staff (Bultas, 2012).

PARENT PERCEPTIONS OF THE HCE

Parents have also expressed dissatisfaction with the HCE, citing the HCP's lack of confidence, knowledge, and skills needed to effectively manage, communicate, and tailor the HCE in order to maximize outcomes (Minnes & Steiner, 2009; Rhoades et al., 2007; Weil & Inglehart, 2010). A disconnect between the HCP and the parent's interpretations of the child's behaviors may confound the delivery and outcomes of the HCE in this population (Davignon et al., 2014). Johnson et al. (2014) found that mothers of children with ASD viewed challenging child behavior occurring in the health care setting as being indicative of their child's frustration and hyperactivity, whereas HCPs interpreted these behaviors as aggression and self-stimulation. Additionally, HCPs and mothers used different strategies to reduce these behaviors. Mothers tended to focus on preparing the child for the encounter, as well as helping the HCP develop strategies to address the child's behavioral needs, whereas HCPs tend to use less child-focused strategies to reduce behaviors (Johnson et al., 2014). Understanding more about the barriers that exist during the HCE for children with ASD, as well as improving collaboration between the HCP and parents, have the potential to reduce and promote effective management of challenging behaviors in the health care setting (Bultas, 2012; Johnson et al., 2014).

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