



Parent Perceptions of Care Received by Children With an Autism Spectrum Disorder^{1,2,3}

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Research in the post-genomic era has provided substantial contributions toward identification of medical, genetic and environmental heritability factors associated with autism spectrum disorder (ASD). A specific etiology related to the diagnosis remains unclear, although prevalence statistics continue to rise with profound impact on families and their primary care providers (PCPs). Support professionals encounter significant challenges delivering comprehensive management for this complex neurobehavioral and developmental disorder. Children with ASD experience significantly higher risk for unmet healthcare needs, and parents report less satisfaction with their care although current literature does not fully explain why this issue persists. This study sought parent insight for the missing answers needed to inform practice. Eleven parents of children with an ASD participated in the study. Parent perceptions of care were examined utilizing Interpretive Phenomenological Analysis (IPA) and the Measure of Process of Care (MPOC-20) to illuminate and describe their lived experiences raising children with ASD, and interactions with their PCPs. Most parents utilized their child's PCP for general health maintenance, and many felt their PCP was unable to manage issues specifically related to their child's ASD. Most did not have an expectation for support with behavioral management in the home and school setting or identification of community and mental health resources, although many struggled with unaddressed needs in both of these realms. Utilizing parent perceptions to highlight practice deficiencies can build a foundation for care models that are more comprehensive and family centered.

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Background

AUTISM SPECTRUM DISORDER (ASD) is a neurodevelopmental and behavioral disorder expressed through

impaired social communication, interactions, and restricted, repetitive, patterns of behavior, activities and interests (American Psychiatric Association, 2013). ASD is a perplexing disorder,

¹ Purpose: The purpose of this study was to examine parent perceptions of care received by children with autism spectrum disorder through their primary care provider, illuminate their lived experiences, identify deficiencies and recognize strengths in care, highlight family centered goals and what they find most meaningful in the care provided for their children, to inform practice, and promote implementation of current guidelines for children with ASD in primary care.

² Design and Methods: This mixed method study included 11 parents who self reported they were primary caregivers for a child (or children) with ASD. Interpretive Phenomenological Analysis (IPA) was utilized for qualitative analysis to understand parents lived experiences raising a child with ASD. The Measure of Processes of Care (MPOC-20) was employed to further describe and underscore parents' spoken words. The MPOC-20 is a parent self-report tool that measures parent perceptions of the family centeredness of their child's care.

³ Practice Implications: Children with ASD often experience many unmet health care needs, potentially affecting their developmental progress, ultimate functionality and the well-being of their family. Understanding parent perceptions and examining their lived experiences provides great insight into the unique challenges they encounter. Lessons learned from this study include promotion of more family centered care models that are individualized, comprehensive and utilize current practice recommendations. Care coordination is foundational to the profession of nursing. Advanced practice registered nurses (APRNs) are well suited to provide holistic management of the complex social, behavioral and medical needs this rapidly increasing population of children and their families require.

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which can exert wide ranging neurological and systemic functions with rather similar behavioral and biological manifestations (Hu, 2013). The term “spectrum” describes how symptoms can range from mild to severe with broad variations in individual presentation and level of functioning. Medical (Chen et al., 2013; Matson & Goldin, 2013), neurological, and psychiatric morbidity commonly co-occur in this population of children, potentially exacerbating primary ASD features (Bauman, 2010) and adding to their need for health care service utilization (Tregango & Cheak-Zamorah, 2012). Treatment goals focus on diminishing core features and related deficits, maximizing independence, and enhancing quality of life for the child and their family (AAP, 2007).

The post genomic era has contributed significant research through exploration of genetic heritability and complex environmental factors believed to influence its development (Veenstra-VanderWeele & Blakely, 2012). Despite this important work a single causative element has yet to be conclusively identified. As surveillance and diagnostic processes have developed in sophistication, greater numbers of children are being identified. ASD is now estimated to affect 1 in 68 children living in the United States, representative of a 123% increase from prevalence statistics first reported in 2002 (CDC, 2014). Presently with no known cause or cure, this complex and enigmatic developmental disorder poses significant challenges surrounding care and management for families and their primary care providers (PCPs).

The Maternal and Child Health Bureau (MCHB), and the American Academy of Pediatrics (AAP) similarly define children with special health care needs (CSHCN) as “those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally”.

Children with ASD are a growing number of CSHCN as nearly all experience ongoing medical and behavioral conditions significantly adding to their need for health and related services. Children with ASD “generally experience a greater burden of illness” and “number of functional difficulties and comorbid conditions” than other CSHCN, and those without (U.S. Department of Health and Human Services Health Resources and Services Administration & Maternal and Child Health Bureau, 2013).

A joint policy statement released by the American Academy of Pediatrics, the Council on Children with Disabilities and the Medical Home Implementation Project Advisory Committee endorses patient and family centered care through a child’s medical home to increase efficiency, lower cost and provide more comprehensive care management (AAP, 2014). Children with ASD who receive care through this model experience fewer health related deficiencies and better access to specialty services (Farmer et al., 2014). It has also been demonstrated that individualized medical home management of children with ASD increased parent satisfaction with care, promoted family involvement, well-being and decreased unmet needs (Golnik, Scal, Wey, & Gaillard, 2012).

Despite endorsement as “ideal” the patient and family centered medical home concept has been difficult to implement for children with ASD whose therapies span multiple providers, agencies and disciplines (Williams et al., 2012). CDC statistics report less than half of children with ASD receive care through a medical home, and are less likely to receive comprehensive management through this model than children with other special health care needs and those without (Child and Adolescent Health Measurement Initiative, 2012). It has been well documented that this population of children faces a significantly higher risk for unmet specialty care needs as PCPs are challenged with attending to treatment options, providing parents support with challenging behaviors, and locating appropriate community resources (Chiri & Warfield, 2012). PCPs cite a lack of time, reimbursement, knowledge and expertise in behavioral management as barriers to medical home provision for their patients with ASD (Carbone, Behl, Azor, & Murphey, 2010).

Parents raising children with ASD report feeling “isolated, frustrated and fatigued” (Carbone et al., 2010) with the burden of coordinating their child’s complex needs by themselves. These parents report less satisfaction with their child’s school, community, and health services (Montes, Halterman, & Magyar, 2009), and are less likely to describe care they receive from their PCP as family centered (Guillermo & Halterman, 2011). Difficulties managing challenging behaviors, impaired social communications, and comorbid physical symptoms can place significant burdens on the family (Silva & Schalock, 2012). Considerable worry, financial hardship, difficulty locating specialty programs, and dissatisfaction with service provision are described as well (Hall & Graff, 2010). Parents raising children with ASD report significantly more stress, and lower levels of personal and marital well-being than parents raising children with other developmental disorders, and those without (Harper, Dyches, Harper, Roper, & South, 2013).

Despite an abundance of studies identifying the unmet health care needs of children with ASD, there is a paucity of literature exploring why these deficiencies persist (Chiri & Warfield, 2012). This evidence gap must be further explored to propose solutions for these unaddressed health disparities impacting functioning and well-being of this high-risk population and their caregivers. Providing comprehensive management to children with ASD requires greater understanding for the lived experience of the parents who are raising them, and the challenges they encounter first hand. This study seeks their valuable insight to identify the missing answers needed to inform practice and address care deficiencies.

Sample

Prior to commencement of the research, details of the proposed study were submitted and approved by the Institutional Review Board (IRB) at St. John Fisher College. A purposeful and snowball sampling technique was utilized for recruitment of parent participants interested in discussing their personal feelings and experiences raising a child with an

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