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The Health Care Experiences of the Preschool Child With Autism

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It is known that children with autism spectrum disorder (ASD) visit health care providers (HCPs) more frequently than typically developing peers, and mothers experience barriers in this process. The purpose of this interpretive phenomenological study was to gain a better understanding of a mother's experiences of taking her child with ASD to the HCP. Two themes related to the health care experience of the child surfaced from the study. These themes included feelings that HCPs do not "get" the complexity of caring for the child and marginalization of mothers by the HCP. The need for creation of child-specific profiles emerged from this study.

Background

THE PREVALENCE OF autism spectrum disorder (ASD) in the population has increased significantly since it was first described in the 1940s. The complex health care needs of children with ASD, along with their unique developmental characteristics, require an innovative approach to health care. Because of this, it is important to study and understand more about the health care experiences of children with ASD, as it can reveal concerns, feelings, resources, and barriers in the delivery of their health care.

There is little nursing literature that identifies specifics regarding the needs of mothers during health care visits for their child with ASD. Certainly, the literature indicates that mothers are dissatisfied with the lack of information received and their difficulty in accessing health care for their child (Minnes & Steiner, 2008; Ruble, Heflinger, Renfrew, & Saunders, 2005). However, there is a lack of information regarding these mothers' specific needs and concerns related to their children's health care experiences.

What does exist in the literature is evidence that mothers of children with autism have a keen sense and understanding of their child (Caronna, Augustyn, & Zuckerman, 2007; Inglese, 2009; Nadel & Poss, 2007). Researchers also know that empowering the mother of a child with ASD leads to an overall better outcome for the child (Kuhn & Carter, 2006). Mothers are most frequently the caregiver that interacts with their child's health care provider (HCP). This is especially true in the early ages of a child's life. Therefore, mothers are uniquely situated to provide important information regarding their child with ASD's health care experiences.

Review of Literature

Increasing Prevalence of Autism

Autism was first described in the 1940s by Dr. Leo Kanner, a psychiatrist. Dr. Kanner presented several case studies of children who demonstrated "fascinating peculiarities" and a condition that differed "markedly and uniquely from anything reported so far" (Kanner, 1943, p. 217). The children showed little affection toward their parents, preferred to be alone, and were able to master skills such as patterning and counting at a very early age (Kanner, 1943). Since then, the definition and diagnostic criteria for ASD has been refined.

The prevalence of ASD in 2002 was estimated to be approximately 1 per 150 children in North America as noted

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by the Centers for Disease Control and Prevention and The Council on Children with Disabilities (Centers for Disease Control and Prevention, 2007; Johnson, Myers, & The Council on Children with Disabilities, 2007). Most recent epidemiological studies now estimate this prevalence to be 1 in 110 children, an increase in prevalence of approximately 57% (Centers for Disease Control and Prevention, 2009). Data show that since 1980, these rates have continued to climb at alarming rates (Blaxill, 2004; Fombonne, 2003; Newschaffer, Falb, & Gurney, 2005).

As these numbers have continued to rise over the last four decades, HCPs continue to try to understand more about the cause of this disorder. What is known is that evidence shows that males are four times more likely than females to be diagnosed with an ASD (Centers for Disease Control and Prevention, 2009). In addition, there is sufficient evidence suggesting an underlying genetic cause of autism (Pickler & Elias, 2009). A sibling predisposition to developing ASD provides more supporting evidence of this genetic link (Nadel & Poss, 2007). Biological and environmental triggers, although what these triggers may be is not known, are also reported to play a role in the increased prevalence of this disorder (Waldman, Nicholson, Adilov, & Williams, 2008). Reasons for the increased prevalence in ASD rates still has not been agreed upon by researchers. Changes in diagnostic criteria, variations in methods of assessing population characteristics, greater awareness among HCPs and parents, or even a true increase in the incidence of ASD are among the possible explanations of the causes of this increase in prevalence (Coo et al., 2008; Waldman et al., 2008).

The statistics for ASDs is frightening to all parents, affected or not by this disorder. Of an even bigger concern is that there continues to be no validated medical treatment for ASDs. Without a determined cause of ASD and no preventative strategies or cures, the increase in children diagnosed with ASD is not expected to diminish.

Health Care for a Child With ASD

A diagnosis of ASD frequently starts with the child's primary HCP. The HCP administers screening tools and developmental questionnaires along with addressing concerns from parents. Neurologists and psychiatrists are just some of the specialists that, along with the child's primary provider, become regular HCPs for a child with ASD. It comes as no surprise that the child with ASD interfaces with the health care field many times in the early years (Myers, 2009).

The Complex Health Care Needs of a Child With Autism

Children with ASD often have coexisting health care needs (Department of Health and Human Services [DHHS], 2008; Liptak, Stuart, & Auigner, 2006). These conditions include seizures, environmental allergies, gastrointestinal complaints, psychiatric diagnoses, behavioral difficulties, and sometimes intellectual disabilities. These conditions lead to a greater number of HCP interactions and complicate the child's treatment. Evidence reveals that children with ASD see their HCPs with more frequency than typically developing children (Liptak, Stuart, et al., 2006); they present with ongoing needs and require ongoing medical management (Myers, 2009).

One of the difficulties in treating comorbidities, in children with autism, is that the child's biological response to usual medical treatments and therapies for these conditions is frequently unpredictable (Volkmar, Wiesner, & Westphal, 2006). The primary reason for these atypical responses may be due to the wide range of behaviors displayed by children with ASD, further evidence that they have increasingly complex medical needs (Volkmar et al., 2006). Children with ASD have reactions in the environment that are not typical and neither are their reactions to medical treatments.

Several studies document the health care expenditures of children with disabilities and specifically children with ASD. Estimates of health care expenditures for this population have been between 3 and 10 times greater for children with autism than that of typically developing children (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006). These increased health care expenditures are another indication that children with ASD are frequent consumers of health care services. Several studies also support the claim that a diagnosis of autism places a significant financial health care burden on the family (Croen et al., 2006; Liptak, Stuart, et al., 2006; Shimabukuro, Grosse, & Rice, 2008).

Meeting the Unique Health Care Needs of the Child and Family

The HCP of children with ASD and their families admit that they have concerns when caring for this population. These concerns include feelings of inadequacy and a lack of confidence in treating and providing service for the child with an ASD (Minnes & Steiner, 2008; Rhoades, Scarpa, & Salley, 2007). Certainly, the increasing prevalence of ASDs has led to increased awareness of the need to screen for the disorder. However, HCPs have difficulty understanding how to manage the health and comorbidities and providing the resources necessary for families with a child with autism (Johnson et al., 2007).

The family of a child who has a disability has significant needs. Those needs include increased amounts of health information, increased amounts of health education related to their child's specific disabilities, and increased time from the HCP to provide this information (Guralnick, 2004). It has been shown that when mothers of children with autism have increased amounts of information and resources available,