Fathers' Experience With Autism Spectrum Disorder: Nursing Implications

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ABSTRACT

Introduction: Autism spectrum disorder (ASD) is a lifelong condition characterized by very mild symptoms to severe impairments in communication skills, social interactions, and unusual behaviors that interfere with independent functioning and interactions with others. ASD may cause financial, social, and emotional difficulties that negatively affect the entire family. The main focus of current research in caregivers of children with ASD focuses on the mothers rather than fathers or both parents, and no studies have used the fathers' words to describe their experience with ASD. Fathers have an important role to improve outcomes for their children receiving therapy. With more fathers taking on the primary caregiver role, it is important to understand their experience with ASD and their needs to help them actively engage in their role as fathers. The purpose of this study was to describe fathers' experience with ASD using their own words and identify any resources needed to help them actively engage in their role as a father of a child with ASD.

Methods: A single-case, multiple-participant, phenomenological approach case study was conducted to describe the experience of fathers of children with ASD. The case was defined as White non-Hispanic (the population identified as having the highest incidence of ASD) fathers who are living in the same home with their child(ren) who has/have a formal diagnosis of ASD. Fathers answered open-ended questions about their experience with ASD, including the challenges they face, their advice for other fathers of children with ASD, and what they need to overcome the challenges of ASD. The theoretical model for the study was the Resiliency Model of Family Stress, Adjustment, and Adaptation. The model was designed to help health care professionals identify a family's strengths and weaknesses as they face existing and new stressors related to a long-term medical condition and then provide interventions to help the family become resilient so they can meet the challenges.

Results: Fathers in this study had experiences similar to those described in previous studies with regard to mothers of children with ASD. The similarity of the findings in the small sample size of fathers and those in studies with larger sample sizes of mothers supports development of clinical interventions that will benefit both mothers and fathers of children with ASD. Fathers described the adjustments made by each member of the family to face the challenges of ASD. Fathers also explained their needs, including money, teamwork, honesty, information, and time. The fathers experienced stages of grief and loss that are similar to those that occur when experiencing a death.

Discussion: Nurses are the eyes and ears of the health care team and the voice for the parents, thus creating a critical connection between the parents and health care team. Fathers in the current study and mothers in previous studies described their need for someone to listen to them, educate them and others about ASD, acknowledge their experience and emotions, and direct them to appropriate resources. Nursing implications include taking action to lead the parents through the challenges and helping them develop resiliency and facilitating improved outcomes for the children and the entire family. A resource book or computer file including information about available resources and information about ASD and treatment can be a valuable tool to help overcome challenges related to ASD. J Pediatr Health Care. (2016) *30*, 453-463.

KEY WORDS

Autism spectrum disorder, fathers' experience, making adjustments, needs, grief and loss, nurse's role, nursing implications, resource book

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Conflicts of interest: None to report.

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Autism spectrum disorder (ASD) is a lifelong neurologic condition characterized by unusual behaviors and impairments in communication skills and social interactions (American Psychiatric Association [APA], 2013). The impairments range from very mild symptoms to severe impairments that interfere with the ability to function independently and interact appropriately with other people (APA, 2013). Children with ASD often appear normal (i.e., without physical deformities), but social interaction, communication, and behavioral abnormalities set them apart from other children and pose challenges for parents (Hock, Timm, & Ramisch, 2012; Karst & Vaughn Van Hecke, 2012; Neely-Barnes, Hall, Roberts, & Graff, 2011).

Approximately 50% of children with ASD show signs of impairments during their first year of life and 80% do so during the second year of life, yet almost half of all children with ASD reach school age before receiving the diagnosis (Centers for Disease Control and Prevention [CDC], 2015). The first 3 years of life are a time of intense cognitive and physical development including communication skills, socialization, and connection with others and their surroundings (Behrman, Kliegman, & Jenson, 2004). Delaying the diagnosis and valuable interventions for children with ASD until school age can be extremely detrimental to the children and their parents. Searching for answers to their questions, ascertaining the diagnosis, and obtaining appropriate treatment are daunting challenges for most parents and can cause financial, social, and emotional difficulties that negatively affect the entire family (Hock et al., 2012; Karst & Vaughn Van Hecke, 2012; Neely-Barnes et al., 2011).

In previous studies, researchers reported that mothers of children with ASD experienced financial burden, decreased family cohesion, increased divorce rates, depression, anxiety, and leaving the workforce to become the primary caregiver for the children with ASD (Barker et al., 2011; Beer, Ward, & Moar, 2013; Davis & Carter, 2008; Hartley et al., 2010; Hock et al., 2012; Jones, Totsika, Hastings, & Petalas, 2013; Karst & Vaughn Van Hecke, 2012; Kelly, Garnett, Attwood, & Peterson, 2008; Lavelle et al., 2014; Lee, 2009; Lutz, Patterson, & Klein, 2012; Phetrasuwan & Miles, 2009). Mothers of children with ASD usually assume the caregiver role and are the focus of research about the experience of ASD for the parents; few studies have included fathers. It is important to understand the experience of fathers of children with ASD to determine if they have similar experiences and needs and to help them actively engage in their role as fathers. Fathers have an important role improving outcomes for their children who receive therapy and in improving the well-being of the entire family (Bagner, 2013; Livingston, 2013).

SIGNIFICANCE OF FATHERS

Children with developmental delays, an early warning sign for ASD, demonstrated initial and sustained improvements in behavior and development of cognitive and language skills when their fathers were actively engaged with the children and their therapies (Bagner, 2013). The families also reported improved family cohesion, stability, and well-being when the fathers were actively engaged (Bagner, 2013). No studies were found examining children with ASD and actively engaged fathers, but because developmental delays are an early sign of ASD, it can be assumed that similar results may occur in children with ASD who have actively engaged fathers.

More fathers are taking on the role of primary caregiver for their children. Single-parent homes are more common now than during any time in history. Among the 11.2 million children in the United States living in single-parent homes, approximately 24% live with single fathers, a 60% increase from the previous decade (Flippin & Crais, 2011; Livingston, 2013). Approximately 24% of preschool age children in single-parent and two-parent families have fathers as the primary caregiver (Flippin & Crais, 2011). Census numbers are not available for the number of children with ASD living in single-parent homes with a father or who have fathers as their primary caregiver. It can be predicted that some children with ASD are being raised in single-parent homes with a father and have fathers as their primary caregiver. It is important to understand fathers' experiences with regard to ASD, their needs, and methods to help them actively engage in their role as fathers to improve the outcome and well-being of their children and families.

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METHOD

A single-case, multiple-participant, phenomenological approach case study was conducted to describe the experience of fathers of children with ASD. A phenomenological approach is used when the aim of the study is hearing, understanding, and accurately telling the story of the research participants to gain a better understanding of the phenomenon (Munhall, 2012). Case