"A hard, tiring, counterintuitive privilege": A Descriptive Study Investigating Parenting a Child with Autism Spectrum Disorder

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INTRODUCTION

- Autism spectrum disorder (ASD) is a neurodevelopmental disorder that presents in young children and is characterized by deficits in verbal communication, social interaction, and restricted or repetitive behaviors (American Psychiatric Association, 2013).
- Children with ASD often exhibit co-occurring behavioral problems such as depression, anxiety, aggression, and self-injurious behaviors (e.g., Ming, Brimacombe, Chaaban, Zimmerman-Bier, & Wagner, 2008).
- Research has demonstrated that caregivers of children with ASD have more permissive parenting styles when compared to parents of typically developing children (Hutchison, Feder, Abar, & Winsler, 2016). Importantly, more permissive parenting styles have been related to higher levels of parenting stress (Hutchison et al., 2016).
- Research has also demonstrated that caregivers of children with ASD tend to have more compassionate parenting goals when compared to parents of typically developing children (Conti, 2015). When caregivers have more compassionate parenting goals, they also tend to have more positive feelings about parenting (Conti, 2015).
- Previous studies have demonstrated that caregivers of children with ASD typically report high levels of stress (e.g., Bitsika & Sharpley, 2004; Montes & Halteman, 2007), even when compared to caregivers of children with other developmental and medical disorders (Estes et al., 2013; Hayes & Watson, 2013). However, caregivers of a child with ASD that have more positive feelings about parenting tend to report lower stress levels (Kayfritz, Gragg, & Orr, 2010).
- The purpose of this study was to qualitatively examine how having a child with ASD has influenced caregivers’ parenting.

METHOD

Participants
- Participants were 115 caregivers (15 males) and their 115 children (95 males). Caregivers were ages 24 to 53 years (M = 35.28, SD = 5.58), and the majority identified as biological parents (95.7%) and adoptive parents (2.6%).
- Children were ages 4 to 11 years (M = 6.98; SD = 1.94), and the majority were identified as White (79.1%), Bi/multiracial (9.6), and Black (6.1%).
- Caregivers self-reported that their children were diagnosed with ASD (88.7%), Asperger’s (7.8%), and PDD-NOS (3.5%).

Measures
- Participants completed a battery of assessments including the open ended question: “How has having a child with autism affected your parenting practices?”
- Measures
  - Procedures
- Caregivers recruited through online resources, flyers, and snowball sampling. After completing the survey, caregivers received a $10.00 gift card from their choice of Walmart, Target, or Amazon.
- A thematic analysis was conducted on the written responses to the open ended question. First, responses were independently coded by three coders. Then, coders met together to discuss and finalize the themes.

RESULTS
- From the 115 responses 13 themes were determined from the thematic analysis (Figure). These included the following (with number of responses indicated in parentheses):
  - Patience (30); Compassion/Understanding Others (24); Flexibility (24); Changes in Discipline (22); Parenting Different than TD Children (20); Draining (16); Parenting the Same as TD Children (15); Personal Growth (14); Seeking Support (12); Extra Effort (9); Unsure/Difficulty Disciplining (9); Appreciation (8); Planning (6); and Planning (3).
- Caregivers reported a wide variety of expressions about how being a parent of a child with ASD has affected their parenting styles. An increase in patience, flexibility, and understanding were a few of the more common themes stated by caregivers.
- The findings of this study give insight into the experiences of caregivers who are raising a child with ASD. The themes found help demonstrate some of the common changes in parenting practices for caregivers of children with ASD.
- This study was limited by the brevity of the question and its reliance on online data collection. Future studies may consider conducting a longer, in-person interview with parents to fully develop a theory about changes in parenting related to having a child with ASD.
- The amount of participants in this study was not large enough to give a general statement on the experience of caregivers of children with ASD.
- Future research should also explore factors that decrease negative feelings about parenting in caregivers of children with ASD.

DISCUSSION
- Draining
- Compassion/ Understanding Others
- Parenting Different than TD Children
- Personal Growth
- Planning

Figure 1. Themes Derived from the Descriptive Analysis of Caregiver’s Responses (with Examples)

- Extra Effort
- Changes in Discipline
- Parenting Same as TD Children
- Appreciation
- Flexibility

- Parenting a child with a special need requires you to accept less-than-perfect.
- In other ways I’ve become more relaxed. I have to go with the flow and not get too upset if everything doesn’t go perfectly all the time.
- I’ve learned to let go. Things get destroyed and expectations have to be reevaluated.
- We have to stay flexible and change what we are doing when it’s not working.

- Parenting a child with autism requires you to accept less-than-perfect.
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