Title: Differences in How Mothers Conceptualize ASD Generally and in Their Children: When Increased Knowledge Does Not Lead to Acceptance

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Introduction: Caregivers’ conceptualization of their child’s autism spectrum disorder (ASD) and ASD severity has significant long term implications, particularly in the amount and type of treatments parents choose (Dardennes et al., 2011). For Latino caregivers, lack of knowledge about ASD is a common barrier to effectively engage in services for their child (Zuckerman et al., 2017). Studies have continuously emphasized the need for educating diverse families on ASD (Magaña, Lopez, Aguinaga, & Morton, 2013; Millau, Rivard, & Mello, 2018). Nonetheless, further investigation is needed as to how caregivers apply general ASD knowledge to their own children given the potential long-term implications for children with ASD (e.g., on parents’ service-seeking behaviors and overall child wellbeing). The goals for this project are 1) to characterize the ASD conceptualizations of mothers from culturally diverse backgrounds and 2) to explore how mothers apply knowledge gained to their children with ASD. Given that diverse cultural backgrounds are represented in this sample, we also determine if group differences exist among interview responses.

Method: Twenty culturally-diverse mothers of children with ASD participated in semi-structured qualitative interviews, lasting approximately 1.5 to 2 hours in length. Mothers in this sample were diverse in race/ethnicity identification (6 White, 8 Latina, 2 Black or African American, 3 Asian, and 1 mixed) and nationality (8 US-born mothers). Mothers born outside of the US represented countries such as Algeria, Dominican Republic, Honduras, Jamaica, India, and Vietnam. Mothers’ children ranged in age from 4 to 13 years old (mean age = 7). Data collection continued until thematic saturation was reached. Each interview was transcribed and coded in either English or Spanish, and approximately half of interviews were coded by two bilingual graduate students (97% reliability). Data was analyzed through content and thematic analysis. Data was stratified by nationality (i.e., immigrant vs. US-born) and ethnicity (i.e., Latina vs. non-Latina).

Result: All mothers emphasized increased ASD knowledge when compared to their knowledge before their child’s diagnosis. Mothers consistently discussed a new appreciation for the severity and heterogeneity of ASD symptoms. Prior to their children’s diagnoses, mothers would at most have a prototypical idea of ASD — either very low or high functioning. Group-based patterns of responses emerged when mothers described autism etiology; US-born mothers were overall unsure of what causes autism, but described that vaccines were certainly not the cause. Immigrant mothers though also uncertain, more readily identified a variety of possible parental (biological or accidental), environmental, or religious causes. Examples of causes endorsed include mishaps during their child’s delivery or contaminated food. No differences emerged here by ethnicity.

Responses differed by ethnicity, but not by nationality, regarding how mother’s applied gained knowledge to their children with ASD. Latina mothers were more likely to believe that their child no longer has, or ever had, ASD, despite reporting behaviors that are consistent with an ASD presentation. Many mothers doubted the validity of the initial diagnostic evaluation or believed that their child’s symptom improvements from services indicates that their child has “grown out” of ASD. Feelings of guilt and a lack of community acceptance for ASD diagnoses may contribute to mother’s not applying ASD knowledge to their own children.

Discussion: While there was one area of difference in mothers’ knowledge regarding ASD (i.e., etiology), mothers generally endorsed having grown to understand the existing diversity of ASD symptom presentations. Despite this increased knowledge, Latina mothers described experiencing difficulties in understanding how their children currently meet criteria for the disorder. These findings have implications for future ASD services utilized by families, as well as implications for maternal- and child-wellbeing for when symptoms remain present, but caregiver acceptance is limited.

References/Citations:
