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Maternal beliefs about autism: A link between intervention services and autism severity in White and Latino mothers

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ABSTRACT

Variation in parental beliefs about Autism Spectrum Disorder (ASD) may impact subsequent service use profiles. This study aimed to examine (1) variation in beliefs about ASD among English language proficient White (EP-W) mothers, English language proficient Latino (EPL) mothers, and limited English language proficient Latino (LEP-L) mothers of children with ASD; (2) variation in beliefs about ASD in the context of the child's ASD severity, among EP White mothers, EP Latino others, and LEP Latino mothers; and (3) potential links between maternal beliefs about ASD and children's current ASD treatment. This multi-site study included 305 English or Spanish-speaking parents of children with ASD, ages 2–10 years, who completed a survey about their beliefs about their child's ASD, their child's ASD severity, and treatments used by their children. Results showed that mothers in the EP-W, EP-L, and LEP-L groups differed in their beliefs about viewing ASD as a mystery. Only maternal views of ASD severity in the EP-W group were linked to their beliefs about ASD. Finally, maternal beliefs about ASD having major consequences on their child's life, and ASD being a mystery were strongly associated with a child's use of ASD intervention services. These findings provide new knowledge of how maternal beliefs about ASD vary in linguistically diverse groups, how a child's ASD severity may influence such beliefs, and how maternal beliefs correlate with the amount of therapy children with ASD receive. Future research should address how these beliefs or views are formed, what factors influence them, or whether they are malleable. Understanding parents' beliefs or views of having a child with ASD can potentially help us increase use of ASD intervention services in families of children with ASD.

Previous research has reported some variability in parental beliefs about their child's Autism Spectrum Disorder (ASD; Dale, Jahoda, & Knott, 2006; Silverman & Brosco, 2007). These parental beliefs about ASD might influence ASD-related treatment selection

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(Mandell & Novak, 2005). Understanding how variation in parental beliefs about ASD may be influenced by child and family characteristics could ultimately help increase optimal service utilization in children with ASD, as well as reduce racial, ethnic, and language-based disparities in care for children with ASD. Thus, this study sought to examine (1) variation in beliefs about ASD among English language proficient White (EP-W) mothers, English language proficient Latino (EP-L) mothers, and limited English language proficient Latino (LEP-L) mothers of children with ASD; (2) variation in beliefs about ASD in the context of the child's ASD severity, among EP-W mothers, EP-L others, and LEP-L mothers; and (3) potential links between maternal beliefs about ASD and children's current ASD treatment.

1. Parental beliefs about ASD

Super and Harkness (1986) and Harkness and Super (1994) advanced the developmental framework that posit that culture, which includes parents' beliefs about parenting practices and child development, influences the developing child. This view has been supported by research that reports parental beliefs about child's disability, causes of it, and treatment services to address that disability (Danseco, 1997). Previous research indicates that parents of children with ASD vary in their beliefs about their child's ASD in terms of causes, prognosis, and general ASD knowledge (Dale et al., 2006; Silverman & Brosco, 2007). Although limited, recent research also suggests that parents of different ethnic and cultural backgrounds may have different beliefs about their child's conditions. For instance, in one study, English-speaking parents of children with ASD were asked about beliefs regarding their child's "learning or developmental conditions" (Zuckerman, Lindly, Sinche, & Nicolaidis, 2015). In that study, parents, who had lower income, lower educational level, or were racial/ethnic minorities, were more likely to believe child's condition was a mystery, and less likely to believe their child's condition was lifelong and it could be prevented or decreased with treatment.

Overall, however, an understanding of the effects of language and ethnicity on parental beliefs about ASD specifically is still lacking. Such information is important because it will enable understanding of what meaning or views parents have about their experience of having a child with ASD (Woodgate, Ateah, & Secco, 2008).

2. Utilization of ASD related services

Most children with ASD do not receive the recommended amount of intervention services (National Research Council, NRC, 2001; Odom, Boyd, Hall, & Hume, 2010; Pringle, Colpe, Blumberg, Avila, & Kogan, 2012; Siller, Reyes, Hotez, Hutman, & Sigman, 2014). Children from minority groups tend to receive even fewer intervention services than their White peers (Levy & Hyman, 2005; Magaña, Lopez, Aguinaga, & Morton, 2013; Magaña, Parish, Rose, Timberlake, & Swaine, 2012; Parish, Magaña, Rose, Timberlake, & Swaine, 2012; Stevens et al., 2009; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). For example, compared to White children, Latino children received fewer specialty services and had more unmet intervention needs (Leigh, Grosse, Cassady, Melnikow, & Hertz-Picciotto, 2016; Liptak et al., 2008; Magaña et al., 2013; Magaña et al., 2013; Thomas et al., 2007). Specifically, Latino children often receive fewer speech and language and occupation therapy services than White children (Irvin, McBee, Boyd, Hume, & Odom 2012).

In general, Latino children tend to receive worse health care access, utilization, and quality of services than their White peers (Magaña et al., 2012; Parish et al., 2012). The reasons for these disparities are likely complex and multifactorial, but utilization of ASD related intervention services might be, in part, influenced by family characteristics, such as race/ethnicity, SES, parent income/education, and parental beliefs (Mandell & Novak, 2005; Siller et al., 2014).

3. Severity in ASD

Some research has been reported on parental views about the severity of their child's ASD. Parents who perceived their children's ASD as more severe reported less progress in adaptive skills and cognitive abilities (Reed & Osborne, 2012; Zachor & Itzchak, 2010), and increased behavioral problems (Jang, Dixon, Tarbox, & Granpeesheh, 2011; Jang & Matson, 2015; Matson, Wilkins, & Macken, 2008). Also, when parents viewed their children's ASD as more severe, they reported increased adjustment difficulties in siblings (Hastings, 2003; Meyer, Ingersoll, and Zambrick, 2011), and decreased parental satisfaction and maternal well-being (Hock & Ahmedani, 2012; Hoffman et al., 2008; Lyons, Leon, Phelps, & Dunleavy, 2010; Meirsschaut, Roeyers, & Warreyn, 2010; Moh & Magiati, 2012).

4. Parental beliefs, utilization of ASD related services, and ASD severity

Parental beliefs about ASD might be linked to parental decisions to use intervention services for their children (Bernheimer & Weisner, 2007; Mandell & Novak, 2005; Zuckerman et al., 2015). In two French studies, participation in parent training programs was found to be associated with the beliefs that ASD symptoms are permanent and that ASD has a genetic component (Al Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010); and parents who believed that early traumatic experiences caused ASD were less likely to use behavior therapy and PECS (Dardennes et al., 2011). In another study with English-speaking parents of children with ASD who were low functioning, parenting self-efficacy as well as parental understanding of their child development predicted the rate of change in the intensity (number of hours per week) of children's individual intervention services over time, such that greater understanding and parenting self-efficacy were associated with increased intervention services intensity among children with ASD (Siller et al., 2014). In the same study, parental knowledge about their child's development was found to be associated with higher

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