



# Treatment-related changes in children's communication impact on maternal satisfaction and psychological distress



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## ABSTRACT

**Background:** Parents of children with autism have been found to have reduced psychological well-being that has usually been linked to the stress related to managing their child's symptoms. As children's behavior and cognitive functioning are subject to change when suitable early intervention programs are put in place, it is plausible that positive treatment-related changes in the child will have a positive impact on parental distress.

**Aims:** We undertook an individual differences study to investigate whether maternal psychological distress is affected by the outcomes of children receiving intervention.

**Methods and procedures:** The participants comprised 43 mothers of preschool children with ASD enrolled in an early intervention program for 12 months.

**Outcome and results:** Child and family factors were linked to maternal psychological distress. However treatment-related changes in children's communication, as assessed on the Vineland Adaptive Behavior Scales II, and parenting satisfaction uniquely contributed to psychological distress above and beyond other factors. A mediation analysis indicated that mothers whose children make treatment gains in communication skills experience lower levels of psychological distress as a consequence of higher levels of parenting satisfaction.

**Conclusions and implications:** The findings highlight improvements in everyday adaptive communication skills in children with ASD impact on mothers' satisfaction and distress.

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## 1. Introduction

Autism Spectrum Disorder (ASD) is characterized by difficulties in social communication and restricted, repetitive patterns of behavior and interests (American Psychiatric Association, 2013). It is well established that parenting a child with ASD is stressful, impacting mental health and overall quality of life (Baker-Ericzn, Brookman-Fraze, & Stahmer, 2005; Davis & Carter, 2008; Eisenhower, Baker, & Blacher, 2005; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013). Compared with

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parents of children with other developmental disabilities and those of typically developing children, parents of children with ASD are more likely to report elevated levels of parenting related stress, psychological distress, and more mental health issues, such as anxiety and depression (Eisenhower et al., 2005; Estes, Munson, Dawson, & Koehler, 2009; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; McStay, Trembath, & Dissanayake, 2014). For example, Bitsika and Sharpley (2004) reported that half of the parents in their study were severely anxious and nearly two thirds were clinically depressed. Findings on the prevalence of anxiety problems however are mixed, with rates ranging from 15.6% to 50% (Bitsika & Sharpley, 2004; Kuusikko-Gauffin et al., 2013; Mazefsky, Folstein, & Lainhart, 2008).

### 1.1. Factors impacting parents' psychological distress

#### 1.1.1. Effects of ASD on parents

A number of factors negatively impact parents' psychological distress in this population, including the presence of severe challenging behaviors in their child with ASD, communication and social deficits, low cognitive functioning and severity of autistic symptoms (Bishop, Richler, Cain, & Lord, 2007; Hastings et al., 2005; Konstantareas and Homatidis, 1989; Lecavalier, Leone, & Wiltz, 2006; Lyons, Leon, Phelps, & Dunleavy, 2010; McStay et al., 2013, 2014; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). For example, lack of communication is a major cause of worry for parents from very early on (often before a diagnosis is made), and continues to impact quality of life and parental well-being throughout the lifespan, both directly (as difficulties in communicating can cause anxiety and confusion about the child's behavior; Marcus, Kuncze, & Schopler, 2005) and indirectly (children with poor social communication skills are more vulnerable to challenging behaviors, including aggression and self-injurious behaviors; Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007). Indeed, it has often been suggested that communication deficits make families of these children particularly vulnerable to stress (Bebko, Konstantareas, & Springer, 1987; Bristol, 1984; Ekas & Whitman, 2010). Parents of children with ASD (Lecavalier et al., 2006) as well as those who have children with Intellectual Disability (Hassall, Rose, & McDonald, 2005) who have better communication skills report less stress.

In addition to communication skills, the child's cognitive and adaptive behavior difficulties can also have an impact on parents' psychological distress. Indeed, child cognitive functioning has been found to be associated with maternal stress (Baker-Ericzn et al., 2005), and parents of children with ASD report that their children's cognitive problems are frustrating and stressful for them (Bebko et al., 1987). Regarding the role of adaptive behavior issues on psychological distress, low adaptive functioning in children with ASD has been found to be correlated with increased parenting stress (Hall & Graff, 2011) and high perceived negative impact (Bishop et al., 2007).

Importantly, however, the behavior of children with ASD (including communicative behavior) and cognitive functioning are subject to change with appropriate intervention (Dawson et al., 2010; Granpeesheh, Tarbox & Dixon, 2009; Koegel & Kern Koegel, 2006; Remington et al., 2007; Sallows & Graupner, 2005; Vivanti et al., 2014). Therefore it is plausible that intervention programs that target these difficulties (e.g., deficits in communication, cognitive functioning and adaptive behavior) may also impact parents' psychological distress. A number of studies have investigated the effects of different types of parent-focused interventions for children with ASD on parents' psychological distress (Estes et al., 2014; Karst et al., 2014; Keen, Couzens, Muspratt, & Rodger, 2010), finding that interventions had a positive impact on parental stress, as reflected in reductions of stress over time (Lieberman-Betz et al., 2014; Wong & Kwan, 2010). However, no research to date has investigated the extent to which treatment-related changes in children affect their parents' psychological distress.

#### 1.1.2. Effects of sense of competence on parents

Although caring for a child with disability is challenging, it has been shown that these challenges are not only possible to overcome but that the experience of having a child with a disability may strengthen families, expand their social network and lead to increased personal growth in parents and other family members (King, Zwaigenbaum, Bates, Baxter, & Rosenbaum, 2012; Turnbull, Behr, & Tollefson, 1986). Consistent with the notion that the link between life events and psychiatric symptoms is frequently moderated by individual characteristics (Belsky & Pluess, 2009), it is plausible that certain personal characteristics of parents of children with ASD might on one hand put them at increased risk for developing stress related symptoms, and on the other, protect them despite the problems they face in their everyday lives. One such factor, the sense of competence, appears important to understand parents' psychological distress (Johnston & Mash, 1989). Two dimensions, namely perceived self-efficacy as a parent and satisfaction derived from parenting have been found to be related to psychological distress in parents of children with ASD (Giallo, Wood, Jellett, & Porter, 2013; Hastings & Brown, 2002). Parents of children with ASD who are less satisfied report higher levels of stress (Ozturk, Riccadonna, & Venuti, 2014). Moreover, self-efficacy was found to mediate the impact of child behavior problems on anxiety and depression in mothers of children with ASD (Hastings & Brown, 2002). Interestingly, perceived parenting competence was found to differentiate mothers of children with ASD from mothers of children with other developmentally delays and typically developing children (Rodrigue, Morgan, & Geffken, 1990). Specifically, mothers of children with ASD reported lower perceived parenting competence suggesting that they may feel more uncertain about whether they possess the skills necessary to be a good parent. Therefore, parenting sense of competence (efficacy and satisfaction) might be an important factor affecting parents' psychological distress. Previous studies have not explored the potential role of parental sense of competence in examining change in children's symptoms as a result of intervention and parents' psychological distress. Taken together, a broad range of characteristics of children with ASD, including the presence of communication, cognitive and adaptive deficits, chal-

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