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Resolution of the child's ASD diagnosis among Arab–Israeli mothers: Associations with maternal sensitivity and wellbeing



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ABSTRACT

This study focused on Arab–Israeli mothers of children with ASD, and examined maternal resolution of the child's diagnosis, and its associations with mothers' sensitivity to the child, maternal psychological distress, parenting stress, social support, and family demographics. Forty-six mothers and their 2–8 year old sons participated in the study. Mothers were interviewed regarding their resolution of their child's diagnosis, their child's ASD symptoms and adaptive behaviors, and completed questionnaires to assess their psychological distress, parenting stress and social support. Maternal sensitivity was observed during two mother–child play contexts, didactic and social play. Resolved mothers were more sensitive to their child during social play, and reported less psychological distress and parenting stress, as well as fewer child ASD symptoms compared with unresolved mothers. Implications for cultural sensitive parental guidance for families of children with ASD are discussed.

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1. Introduction

Parents' resolution of their child's diagnosis refers to the process of coming to terms and accepting a diagnosis of a significant developmental disability or chronic illness of the child (Marvin & Pianta, 1996). Parents' resolution is presumably related to enhanced wellbeing (Sheeran, Marvin, & Pianta, 1997) and facilitates sensitive and attuned caregiving to the child (Marvin & Pianta, 1996; Pianta, Marvin, & Morog, 1999). Several researchers (e.g., Barnett et al., 2006; Marvin & Pianta, 1996; Oppenheim et al., 2007) have emphasized that resolution is a central aspect of family processes and therefore its assessment is vital for understanding parents' challenges and tailoring supportive programs for them. The associations between resolution, parental wellbeing and attuned caregiving were documented in research focused on families of children with varied disabilities, yet they were examined in only a few studies of children with ASD, with mixed results (e.g., Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010 versus Poslawsky, Naber, Van Daalen, & Van Engeland, 2014; and Hutman, Siller, & Sigman, 2009 versus Oppenheim, Koren-Karie, Doley, & Yirmiya, 2012).

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In addition, studying the applicability of parents' resolution of their child's ASD diagnosis in non-Western cultures is highly important as the prevalence of ASD is similar in Western and non-Western cultures (Elsabbagh et al., 2012). Yet, prior research of parents' resolution of varied child diagnoses focused mostly on Western families. To address these gaps the current study examined the generalizability of the links between parents' resolution, wellbeing, and sensitivity among Arab–Israeli families of children with ASD, whose society is considered traditional and collectivist, and is characterized by a high level of stigmatization of children with disabilities and their families (Duvdevany & Abboud, 2003).

Most parents whose child receives a diagnosis of a serious developmental disorder like ASD, experience strong emotional reactions such as shock, sadness, despair, or confusion. These feelings reflect parents' grief for losing the wished-for, typically developing child (Siegel, 1996). Marvin & Pianta (1996) suggested that the emotional and cognitive process of coping with the child's diagnosis is central to our understanding of parent–child relationships. Based on attachment theory and research regarding resolution of loss and trauma (Bowlby, 1980; Main & Hesse, 1990), Marvin and Pianta offered a model of resolution of the diagnosis, according to which, some parents come to terms with the reality of their child's diagnosis and are considered "resolved". These parents successfully cope with emotions evoked by their child's diagnosis and revise their hopes and expectations in light of their child's diagnosis, while seeing the individuality of the child beyond the diagnosis. Other parents who are considered "unresolved", deny the child's diagnosis, or see the child only through the prism of the diagnosis and are overwhelmed with grief, despair, or anger.

Resolved parents' refocus of attention on the child's current abilities and needs presumably facilitates sensitive caregiving, namely, accurate interpretations of the child's signals and appropriate responses to these cues (Ainsworth, Blehar, Waters, & Wall, 1978). Lack of resolution may serve as a major source of stress and hinder sensitive caregiving. Unresolved parents might present unrealistic expectations from the child, ignore or distort the child's signals, and inappropriately respond to the child by being overly intrusive, passive, or harsh (Marvin & Pianta, 1996). Thus, Marvin and Pianta (1996) suggested that parents' resolution should be assessed to identify at risk families and provide appropriate parental guidance.

Resolution may be particularly challenging for parents of children with ASD. First, children with ASD are usually diagnosed at a later age compared to children with other serious developmental disorders (e.g., Down Syndrome). Thereby parents might hold on to a perception of their child as typically developing for a longer duration, which may hinder their acceptance of the ASD diagnosis once it is given. Second, signals and cues of children with ASD are less consistent and predictable than those of typically developing children and are therefore more difficult to read (Wetherby, Watt, Morgan, & Shumway, 2007). This lack of a typical inter-personal feedback might leave parents feeling unrewarded for their parenting, which in turn might prevent parents' resolution. Finally, ASD is not characterized by external features, which might further challenge the process of coming to terms with the child's disorder.

To assess parent's resolution of their child's diagnosis, Pianta and Marvin developed the Reaction to Diagnosis Interview (RDI; Pianta & Marvin, 1993) in which parents are asked to reflect on their thoughts and feelings regarding the child's diagnosis, the process leading up to the diagnosis, and changes in these thoughts and feelings since receiving the diagnosis and up to the present. Resolved parents describe a positive change over time and suspend the search of reasons for the child's disability. They present a balanced portrayal of the child that includes both strengths and challenges, and express hopes for the child's future but not unrealistic expectations. Lack of resolution may take varied forms, including being emotionally overwhelmed; angrily preoccupied; depressed; emotionally disengaged; cognitively distorting; confused or disorganised, but all forms share difficulties in moving on in life and absence of positive change in thoughts and feelings regarding the child's diagnosis.

Over the past 20 years several studies focused on parental resolution of a wide range of pediatric and psychiatric child diagnoses, including CP (Rentinck et al., 2010; Schuengel et al., 2009), epilepsy (Marvin & Pianta, 1996), childhood phenylketonuria (Lord, Ungerer, Wastell, 2008), congenital disorder (Barnett et al., 2006), hearing loss (Adams, 2011), Type 1 diabetes (Goldberg, 2010), preterm birth (Shah, Clements, & Poehlmann, 2011; Yaari et al., 2015), developmental delay (Barak-Levi & Atzaba-Poria, 2013); intellectual disability (Feniger-Schaal & Oppenheim, 2013), ADHD, mood disorders, psychotic disorder, anxiety disorder (Kearney, Britner, Farrell, & Robinson, 2011), and ASD (Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2009). For the most part this body of work supports the conception that parental resolution plays an important role in family relationships and parents' wellbeing, and as such, above researchers suggested that the evaluation of parents' resolution should become an integral part of clinical care and a target for intervention (e.g., Barnett et al., 2006; Lord, Ungerer, & Wastell, 2008).

However, some inconsistent results have been documented, which require further research. First, several studies found that resolved parents of children with varied medical conditions (e.g., Phenylketonuria) developmental disorders (e.g., intellectual disability) or emotional disorders (e.g., anxiety disorder) report less psychological distress (Lord et al., 2008; although see Shah et al., 2011) and parenting stress (Kearney et al., 2011; Sheeran et al., 1997) compared with unresolved parents. Yet of the two studies of parents of children with ASD which examined these links, one documented that resolved parents report less parenting stress than unresolved parents (Milshtein et al., 2010), while the other did not find links between parents' resolution and parenting stress or distress (Poslawsky, Naber, Van Daalen, & Van Engeland, 2014).

Second, social support may be also closely related to resolution. Family, friends and professionals may provide practical help and emotional support to parents and thus facilitate the process of parental resolution. However, to the best of our knowledge only two studies examined these links, both in the context of CP. These studies suggested that resolved mothers report higher levels of support from their spouse (Rentinck, Ketelaar, Jongmans, Lindeman, & Gorter, 2009), extended family

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