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Couple relationships among parents of children and adolescents with Autism Spectrum Disorder: Findings from a scoping review of the literature



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ABSTRACT

To explore commonly-held assumptions regarding the risk of couple breakdown in families of children with Autism Spectrum Disorder (ASD), a scoping review of quantitative ($n=39$), qualitative ($n=15$), and mixed ($n=5$) studies was conducted. Findings include themes related to marriage and divorce rates, relationship satisfaction and conflict, and other significant variables. Parents and service providers of individuals with ASD will benefit from knowing that strategies such as developing common goals, increasing partner respect, securing social support, reducing stress, and instilling hope are all factors which support the development and maintenance of positive couple and co-parenting relationships.

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1. Introduction

A diagnosis of Autism Spectrum Disorder (ASD) is based on criteria identified in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; APA, 2013)*. While there is broad variation in the presentation of this disorder, affected individuals display difficulties engaging in social interaction and communication, and present with clinically distinct behavioural features such as resistance to change, adherence to nonfunctional routines, and stereotyped and repetitive behaviours. These symptoms significantly affect multiple areas of functioning such as in family, educational, employment or community settings (APA, 2013). The Centers for Disease Control and Prevention estimates the prevalence of ASD to be 1 in 68 children—an increase of 123% from data collected in 2002 (Baio, 2014).

Supporting people with ASD, as well as their families, has become an urgent priority for service providers and government organizations (Brookman-Frazee, Drahotka, Stadnick, & Palinkas, 2012; Harris, Durodoye, & Ceballos, 2010; Health Canada, 2007). While much of existing ASD research has focused on genetic factors, characteristics, treatment, and outcomes for diagnosed children, a significantly smaller number of reports have examined the experiences of parents of affected children and related need for effective supports and interventions for them across the lifespan (Gray, 2002; Harris, 1984; Stoddart, 1999; Stoddart, Burke, & King, 2012; Van Bourgondien, Dawkins, & Marcus, 2014).

Practitioners and parents commonly perceive that there is a high risk of divorce in parents of children with ASD (Freedman, Kalb, Zablotsky, & Stuart, 2012; Randall, 2009; Shumaker, 2013; Sobsey, 2004); the results of empirical analysis are not as clear, however. Family and couple relationship strain has been explored in research addressing families with children of varying disabilities which may provide some insight into couple and marital dynamics of parents of children with ASD specifically. A meta-analysis by Risdal and Singer (2004) found that between 2.9% and 6.7% more marriages end in divorce among parents of children with disabilities, compared with parents of children with no disabilities. Conversely, in a Norwegian study, Lundeby and Tossebro (2008) found that children with disabilities were more likely to live with two, married parents than children without disabilities. Another study found that among couples with satisfying relationships, the challenges of dealing with a child's disability can serve to strengthen and enrich relationships (Scorgie & Sobsey, 2000). In a Norwegian study, Lundeby and Tossebro (2008) found that children with disabilities were more likely to live with two, married parents than children without disabilities. Sabbeth and Leventhal (1984) reviewed 34 studies and found no increased risk of divorce rates in such families, but did find higher rates of marital distress and lower marital satisfaction for parents with children with ASD compared to parents of children with other disabilities.

The dominant theme of the family-focused research that does exist for families with a child with ASD is an exploration of the psychological health and well-being of parents, and has predominantly been based on data collected from mothers (Benson & Kersh, 2011; Hayes & Watson, 2013). Studies report high levels of stress (Davis & Carter, 2008; Hayes & Watson, 2013; Rivard, Terroux, Parent-Boursier, & Mercier, 2014; Rodrigue, Morgan, & Geffken, 1990; Sanders & Morgan, 1997) and rates of depression (Benson, 2006; Davis & Carter, 2008; Sharpely, Bitsika, & Efremidis, 1997; Zablotsky, Anderson, & Law, 2013). However, it has been noted that the presence of a child with an ASD may not exclusively account for parental depression as mental health problems may have existed before the birth of the affected child (Cohen & Tsiouris, 2006; Stoddart, 2003). In a study comparing parenting stress in mothers of children with Fragile X syndrome, Down syndrome, and ASD, mothers of children with ASD showed the lowest levels of psychological well-being and coping (Abbeduto et al., 2004). A number of researchers argue that diagnosis of a child with ASD can be more stressful for parents compared with other disorders due to the lack of clarity in diagnostic criteria, as well as the associated symptoms that may add to the complexity of an ASD diagnosis (i.e., sleep or eating difficulties) (Howlin & Moore, 1997; Lord & Risi, 1998; Martinez-Pedraza & Carter, 2011). Family and couple relationship strain can be intensified if a child with ASD requires more time and effort; most notably if the child exhibits problem behaviours (Brobst, Clopton, & Hendrick, 2009; Pozo, Sarria, & Brioso, 2014). Evidence of elevated stress among parents of children with ASD has been found across geographical regions, cultures, child age and cognitive level (Abbeduto et al., 2004), although it is of note that the research results may be gender-biased due to the skewed rate of female participants.

A number of positive outcomes can occur when families have found a way to adapt to the various stressors that are associated with parenting a child with ASD, and some parents have made the connection between having a child with ASD and quality improvement in their marital relationship. Hastings, Beck, and Hill (2005) suggest that this connection may be more likely to occur when parents are encouraged to consider the positive aspects of having a child with a disability. A review

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