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Maternal stress and family quality of life in response to raising a child with autism: From preschool to adolescence

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ABSTRACT

While the impact of raising a child with an Autism Spectrum Disorder (ASD) is well documented, with mothers reporting higher levels of stress than mothers of children with other disabilities, positive maternal outcomes have also been identified. What remains unclear, however, is the role of child age on maternal outcomes. We sought to clarify the role of child age in maternal stress and family quality of life (FQoL) in mothers raising a child with ASD. Participants included 140 mothers of children aged 3–16 years grouped to represent four key stages of childhood (preschool, early school years, middle school, early high school). Using a cross-sectional design, mothers completed questionnaires assessing potential risk (e.g., child problem behaviour, symptom severity) and protective (e.g., family characteristics) factors attributed to maternal outcomes. The results revealed significant age related group differences in child internalising behaviour and ASD symptomatology between the early and middle school years. Lower levels of adaptive social behaviour in older age groups were also found. Although mothers of older children reported significantly less support from professionals than mothers of younger children, no significant age effects were found to contribute to maternal reports of stress or FQoL. The current findings support the view that mothers appear to demonstrate stable levels of stress and FQoL despite fluctuations in key child variables and a reduction in supports, across age, highlighting the ongoing nature of maternal needs and heightened levels of child symptomatology during adolescence.

1. Introduction

Due to the complex and heterogeneous nature of Autism Spectrum Disorder (ASD) and the associated difficulties in diagnosis, treatment and support, research has focused on the experience of raising a child with ASD on maternal outcomes.

Mothers raising children with ASD report poorer wellbeing and greater stress than mothers of children with other disorders and typically developing children (e.g., Abbeduto et al., 2004; Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005; Estes et al., 2009; Quintero & McIntyre, 2010). However, research has also identified characteristics of resilience and wellbeing in mothers, such as satisfaction with their family quality of life (FQoL; Pozo, Sarria, & Brioso, 2014). A deeper understanding of child and family factors that mitigate risk, and those that promote resilience, is needed to drive the development of evidence-based supports and services for these families.

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1.1. Child factors

Research has highlighted the important role of syndrome-specific stressors, such as symptom severity and adaptive functioning, on negative outcomes in mothers of children with ASD (Ekas & Whitman, 2010; Hall & Graff, 2011; Hayes & Watson, 2013; Lyons, Leon, Phelps, & Dunleavy, 2010; Zablotsky, Anderson, & Law, 2012). However, the biggest impact on maternal stress and wellbeing appears to be the manifestation of problem behaviours, such as aggression, withdrawal, impulsivity, and attention problems (e.g., Lecavalier, Leone, & Wiltz, 2006; Manning, Wainwright, & Bennett, 2011; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013; Peters-Scheffer, Didden, & Korzilius, 2012). While child characteristics affect the experience of mothers raising children with ASD, they change as children grow (e.g., Eisenhower et al., 2005; McGovern & Sigman, 2005; Shattuck et al., 2007). Thus, the relationship between child age and maternal stress requires further consideration.

There is consistent evidence to suggest a decline in problematic behaviour as children with ASD age (e.g., Eisenhower et al., 2005). Such behaviour problems have been suggested to stabilise between childhood and adolescence (Chadwick, Cuddy, Kusel, & Taylor, 2005) before further improvement in adolescence and young adulthood (Lounds, Seltzer, Greenberg, & Shattuck, 2007; Taylor & Seltzer, 2010). However, ongoing high rates of behavioural and emotional concerns are evident in adult participants (Gray et al., 2012). There is also evidence that core ASD symptoms (i.e., repetitive behaviours and interests, social and communication impairments) may reduce as children age (Shattuck et al., 2007). These findings are consistent with research that has examined changes in adaptive behaviour over time (e.g., Anderson, Oti, Lord, & Welch, 2009; Baghdadli et al., 2012; McGovern & Sigman, 2005), suggesting that children with ASD display reduced levels of impairment in social interactions, daily living skills, and communication as they grow.

Collectively, these studies suggest evolving symptomatology at different time points. However, due to the use of different populations, at different ages, in different countries, with different educational systems, at different times, it is unclear whether similar outcomes are evident in children of different ages within one cross-sectional cohort. Such investigations would help validate previous findings and increase our understanding about patterns of development across children of different ages in one geographical area. Furthermore, future studies need to address the impact of family factors and their subsequent development over time.

1.2. Family factors

A number of internal and external family resources have been suggested to act as protective factors in mothers raising children with ASD, decreasing vulnerability to negative outcomes. These resources include the family environment (i.e., the expression of thoughts, feelings, and support within the family unit); family hardiness (i.e., the strength of the family unit, commitment, and sense of control); level of marital support; perception of social support; sense of coherence (i.e., seeing life as meaningful, ordered, and able to be managed); and the range of coping strategies mother's employ to cope with identified stressors.

Evidence suggests that these resources may buffer against the impact of stressors, lowering levels of distress, depression, negative affect, and general stress in mothers of children with ASD (Altiere & von Kluge, 2009; Benson & Karlof, 2009; Benson & Kersh, 2011; Greeff & van der Walt, 2010; Manning et al., 2011; Siman-Tov & Kaniel, 2011). Research examining the impact of these factors may help clinicians recommend strategies that are most fitting with, and appropriate to, the individual circumstances of each family.

Only two family resources have been tracked across child development in an attempt to capture changes in protective factors available to mothers raising children with ASD. These studies have highlighted adolescence as a period in which mothers report higher levels of support (Tehee, Honan, & Hevey, 2009) and engage in greater use of disengagement (detachment from stressors) to cope with raising a child with ASD (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). While such research advances our understanding of the potential impact of changes in support and coping over time, it is unclear whether such findings are unique to a particular geographical area or representative of the services and supports provided to parents of children with ASD more broadly. In addition, possible changes in the family environment and marital relationship as children with ASD age remain unknown.

1.3. Maternal outcomes

The fluctuations in identified child and family factors highlight the importance of taking a developmental approach to the assessment of positive and negative outcomes for mothers of children with ASD (Karst & Van Hecke, 2012). Some evidence suggests that maternal stress may change over time with mothers of older children reporting lower stress levels (e.g., Barker et al., 2011; Gray, 2002; Lounds et al., 2007; Osborne & Reed, 2009) while other studies report no age-related effects (e.g., Lecavalier et al., 2006; Manning et al., 2011; Peters-Scheffer et al., 2012). However, these studies tend to be conducted within a relatively short time frame (e.g., 2 years); focus on specific stages of development (e.g., preschoolers and school-age children, Hastings et al., 2005); or combine children within a wide age range (e.g., 2–18 years of age), limiting the specificity of study findings. In addition, limited research exists regarding the development of positive outcomes, such as maternal wellbeing, over time.