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Research Paper

Contributors to well-being and stress in parents of children with autism spectrum disorder



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ABSTRACT

Background: Parents of children with autism spectrum disorder (ASD) present more well-being and stress problems than parents of typically developing (TD) children. However not all parents present these problems. These problems can be due to a dynamic interaction between environmental antecedents, person antecedents, and mediating processes. Understanding how these factors separately contribute to explain parents' well-being and stress can have implications for intervention programs. The aim of this study was to explain parents' subjective well-being and physiological stress by considering whether they had a child with ASD or not and their child's negativity (environmental antecedents), their perception of their child's problems (person antecedents), and their use of reappraisal (mediating processes).

Method: Thirty-seven parents of children with ASD and 41 parents of TD children reported their subjective well-being and their physiological stress was assessed. Additionally, children's negativity was observed, parents rated their perception of their child's problems (autistic traits, emotion regulation ability, and lability/negativity), and parents reported their use of reappraisal.

Results: Compared to parents of TD children, parents of children with ASD reported having lower subjective well-being and had increased physiological stress. Parents' perceptions of children's lability/negativity and parents' use of reappraisal were better predictors of parents' subjective well-being than ASD and parents' perceptions of children's lability/negativity contributed to parents' physiological stress as much as ASD.

Conclusions: Prevention and intervention programs targeting parental well-being and stress will benefit from working with parents at the level of perceptual constructs and reappraisal ability.

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1. Introduction

Parents of children with autism spectrum disorder (ASD) are at a greater risk of increased stress and mental health problems than parents of typically developing (TD) children (Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011). ASD can, in fact, be one of the most demanding disorders in terms of threats to parents' well-being and mental health (Seltzer, Krauss, Orsmond, & Vestal, 2001). It has been repeatedly shown that parents of children with ASD report more stress and present more depressive symptomatology than parents of TD children (Duarte, Bordin, Yazigi, & Mooney, 2005; Lee, 2009)

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and parents of children with other disorders (Abbeduto et al., 2004; Dumas, Wolf, Fisman, & Culligan, 1991). They also report more anxiety (Bitsika & Sharpley, 2004; Lee, 2009), more mental health problems (Montes & Halterman, 2007), and decreased well-being (Nikmat, Ahmad, Oon, & Razali, 2008). However, even though families of children with ASD face serious difficulties (Dumas et al., 1991), not all concerned parents show problems with well-being and stress.

Past research has characterized the experience of parenting a child with ASD as stressful and as presenting a threat to parents' well-being (e.g. Seltzer et al., 2001). Past research has also described coping strategies used by these parents (e.g. Pottie & Ingram, 2008). However, to our knowledge, no studies have sought to understand how the different factors that have been recognized for years as predictors of stress (e.g. Lazarus & Folkman, 1984) can explain well-being and stress in parents of children with ASD. Identifying these processes in parents of children with ASD can offer outlets to intervene with these parents to improve their well-being and decrease their stress. Therefore, the aim of the present study was to explain why faced with the same life-event (i.e. having a child diagnosed with ASD) some parents present decreased well-being and stress while others do not.

The transactional model of stress and coping theory, proposed by Lazarus and Folkman (1984), defines stress as an emotional response to a situation or an event, that is important for the individual, and that is perceived as exceeding the individual's resources (Lazarus & Folkman, 1984). This model is based on the cognitive-relational theory of stress (Lazarus & Folkman, 1987) which conceptualizes stress as resulting from a recursive dynamic interaction between environmental antecedents such as a life-event or daily hassles (e.g. demands, constraints and resources, ambiguity, and imminence of a situation), person antecedents (e.g. goal hierarchies, attributions, and belief systems), and mediating processes (e.g. appraisal and coping). The interaction between these three aspects can be reflected in immediate and long-term effects such as the individual's subjective well-being, social functioning, stress, and somatic health. Using this model, differences on well-being and stress of parents of children with ASD could be understood as resulting from a dynamic contribution of (a) environmental antecedents such as the fact of having a child diagnosed with ASD and the child's negativity, (b) person antecedents such as parents' attributions and belief systems regarding their child, and (c) mediating processes such as parents' capacity to cognitively reappraise (see Fig. 1).

(a) Environmental Antecedents

Some of the environmental antecedents that can contribute to decreased well-being and increased stress in parents of children with ASD can be related to the life event of having a child diagnosed with ASD and to the daily hassles this represents. Parents need to adapt to new expectations regarding their child's future (Brogan & Knussen, 2003). Parents are also challenged by factors that are related to dealing with a chronic disorder (i.e. repeating strains) and they often describe themselves as being isolated and having to fight all the way (Woodgate, Ateah, & Secco, 2008). Furthermore, the fact that their children have normal appearances, which do not signal any disorder, but often present disruptive and sometimes antisocial behaviors, can lead to stigmatization and lack of understanding from others (Gray, 1993, 2002).

Daily hassles related to having a child with ASD can also be reflected at the level of the child's negativity and the difficult behaviors they often present. Children with ASD have more emotional and conduct problems compared to TD children (Pouw, Rieffe, Oosterveld, Huskens, & Stockmann, 2013; Rieffe, Camodeca, Pouw, Lange, & Stockmann, 2012; Russell & Sofronoff, 2005; Samson et al., 2014) as well as compared to children with other disorders (Bradley, Summers, Wood, & Bryson, 2004; Brereton, Tonge, & Einfeld, 2006; Eisenhower, Baker, & Blacher, 2005; Green, Gilchrist, Burton, & Cox, 2000). These difficult behaviors are also present in children with ASD who do not have intellectual disability (Pearson et al., 2006; Totsika et al., 2011).

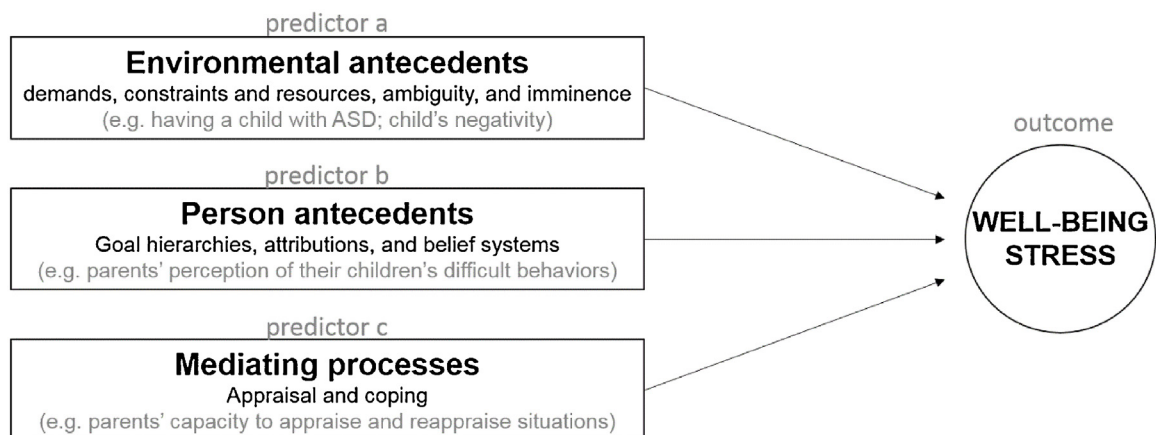


Fig. 1. Adaptation of the transactional model of stress and coping theory (Lazarus and Folkman, 1984) to explain well-being and stress in parents of children with ASD.

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