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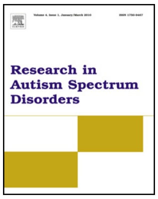

Caregiver stress during the first year after diagnosis of an Autism Spectrum Disorder

John H. McGrew *, Melissa L. Keyes [1]

Department of Psychology, Indiana University Purdue University Indianapolis, 402 N. Blackford Street, LD124, Indianapolis, IN 46202, United States

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ABSTRACT

Caregiver burden and marital adjustment of mothers of children diagnosed with Autism Spectrum Disorder (ASD) were assessed at baseline, i.e., within six months of diagnosis ($n = 79$), and again 12 months later ($n = 65$), using predictors from the double ABCX family adaptation model, e.g., life demands, social support, appraisal, coping. Although there were no changes over time in burden or marital adjustment, participants reported increased positive appraisals of having a child with autism, increased support from providers and decreased use of problem focused coping. Cross-sectionally at Time 2, hypothesized predictors of marital adjustment and caregiver burden derived from the literature and from stress and coping theory (Lazarus & Folkman, 1984) were largely confirmed. Longitudinally, after adjusting for baseline levels in the multiple regressions, better marital adjustment at 12 months was associated with changes over time in three predictor variables: decreased negative appraisal, decreased pile-up stress, and increased general social support. Predictors of increased caregiver burden at 12 months, after adjusting for baseline levels, were increased negative appraisal, increased avoidant coping and decreased problem focused coping.

1. Introduction

There is now considerable evidence that raising a child with a disability can be a source of increased family stress (Baker, Blacher, Kopp, & Kraemer, 1997; Lam & Mackenzie, 2002; Rodriguez & Murphy, 1997; Scott, Atkinson, Minton, & Bowman, 1997; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Wade, Taylor, Drotar, Stancin, & Yeates, 1998). However, compared both to typical children and to children with other disabilities, family stress tends to be highest in families raising a child with an Autism Spectrum Disorder (ASD) (Bouma & Schweitzer, 1990; Hayes & Watson, 2013; Perry, Harris, & Minnes, 2005; Silva & Schalock, 2012; Siman-Tov & Kaniel, 2011; Zablotsky, Bradshaw, & Stuart, 2013). Parents of children with ASD report increased burden and psychological distress, decreased marital satisfaction, lower self-confidence, increased helplessness and increased negative emotions including fear, anger and resentment (e.g., Benson & Kersh, 2011; Gray, 1994; Hayes & Watson, 2013; Higgins, Bailey, & Pearce, 2005; Leff & Walizer, 1992; Siegel, 1997). In part, these negative outcomes are related to the challenging nature of the problem behaviors and symptoms associated with ASD

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* Corresponding author. Tel.: +1 317 274 8672; fax: +1 317 274 6756.
E-mail addresses: jmcgrew@iupui.edu (J.H. McGrew), Melissa.l.keyes@gmail.com (M.L. Keyes).

[1] Present address: Director of Legal Services, Indiana Protection and Advocacy, 4701 N. Keystone Avenue, Indianapolis, IN 46205, United States. Tel.: +1 317 722 5555.

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(e.g., Khanna et al., 2011; Manning, Wainwright, & Bennett, 2011; Siman-Tov & Kaniel, 2011). Problem behaviors and symptoms associated with ASD can include sleep disruption, aggression, self-injurious behavior, hyperactivity, impulsivity, poor to absent communication skills, impairments in social relatedness, repetitive or stereotypic patterns of behavior, and hyper- and hypo-sensitivities to stimuli (American Psychiatric Association [APA], 2013).

The stress of caring for a child with a disability can be conceptualized as a process of ongoing adaptation and adjustment to change (e.g., Floyd, Singers, Powers, & Costigan, 1996; Lazarus & Folkman, 1984; McCubbin & Patterson, 1983). For families of children with disabilities, transition points pose particular challenges, e.g., transitioning from pre-school to kindergarten, from middle school to high school, from high school to post-high school (Lounds, Seltzer, Greenberg, & Shattuck, 2007). Of particular interest for the current study, the initial transition point, when a family first learns that their child has a formal diagnosis of ASD, was examined as a potential time of increased stress (Casey et al., 2012; Howlin & Asgharian, 1999; Leff & Walizer, 1992; Mihlstein, Yirmiya, Oppenheeim, Koren-Karie, & Levi, 2010; Moh & Magiati, 2012; Siegel, 1997; Sullivan, 1997; Taylor & Warren, 2012). Families must adjust to the loss of the child they hoped for, accept the child they have, and face the daunting task of learning about autism, while beginning to navigate a complex, confusing, expensive and sometimes unhelpful and inaccessible service system (cf., Ruble & McGrew, 2007).

There has been only limited research exploring how the initial diagnosis of ASD affects families over time. In general, prior cross-sectional studies indicate that receiving a diagnosis is a drawn out, frustrating, convoluted and highly challenging process for families and that burden, stress and depression may be elevated at the time of diagnosis (Bristol & Schopler, 1983; Goin-Kochel, Mackintosh, & Myers, 2006; Howlin & Asgharian, 1999; Howlin & Moore, 1997; Mandell, Novak, & Zubritsky, 2005; Mansell & Morris, 2004; Moh & Magiati, 2012; Stuart & McGrew, 2009; Taylor & Warren, 2012; Wiggins, Baio, & Rice, 2006). In addition, factors that exacerbate family stress generally (e.g., symptom severity, problematic behaviors, additional family stressors), may act similarly in exacerbating or moderating the stress of diagnosis (Hassall & Rose, 2005; Hassall, Rose, & McDonald, 2005; Minnes, 1988; Stuart & McGrew, 2009). However, prior research on the process and impact of initial ASD diagnosis on caregivers has been limited by the exclusive use of retrospective, cross-sectional designs and the reliance on samples collected well after the initial diagnosis, such that the average time since diagnosis is often measured in years (e.g., Howlin & Asgharian, 1999; Leff & Walizer, 1992; Mihlstein et al., 2010; Moh & Magiati, 2012; Siegel, 1997). Such retrospective designs suffer from potentially biased recall that increases with the length of time since diagnosis. In addition, in contrast to theoretical conceptualizations of adaption to stress as a process (e.g., Lazarus & Folkman, 1984), the reliance on assessment at a single point cannot provide an understanding of adaptation over time. To our knowledge, no published study has fully addressed these methodological concerns. Although studies have examined changes in caregiver functioning over time, e.g., how marital adjustment at time 1 impacts maternal well-being or psychological adjustment at Time 2 (Benson & Kersh, 2011; Lickenbrock, Ekas, & Whitman, 2011), none have focused on the impact of diagnosis. A recent cross-sectional study of maternal depression following ASD diagnosis did attempt to address many of these concerns, examining change over time and limiting the sample to those recently diagnosed, however, the sample still averaged 1.4 years since diagnosis and change was inferred retrospectively by comparing recalled depression to current depression both collected cross-sectionally (Taylor & Warren, 2012).

To begin to address these limitations, the current study used data collected at two time points, the first near the time of diagnosis (within 6 months) and the second one year later. In addition, the impact of diagnosis was assessed on multiple levels (individual, marital), and used a theoretical framework to help understand factors that might impact burden and stress, the Double ABCX model (McCubbin & Patterson, 1983). The Double ABCX model views family stress (i.e., the outcomes or reactions to events) as the interaction between demands (e.g., stressors or events) and available resources, coping style and cognitive appraisal (McCubbin & Patterson, 1983) and has been employed in prior cross-sectional studies of family adjustment to ASD (e.g., Bristol, 1987; Manning et al., 2011; Pakenham, Samios, & Sofronoff, 2005). For example Bristol (1987) found that mothers of children with autism or communication disorders had better adjustment when they had greater social support, fewer additional stressors and used more active coping. Similarly, Pakenham et al. (2005) found that maternal adjustment was highest with lower stressor severity, fewer pile-up demands and greater use of positive coping. More recently, Manning and colleagues (2011) reported higher parenting stress with increased child problem behaviors and decreased use of spiritual support coping, positive reappraisal and positive reframing of subjective social status.

The Double ABCX model can be applied flexibly; investigators can choose which factors to include and how to operationalize them. As shown in Fig. 1, we modeled caregiver outcomes (X) as a function of severity of the stressor (A) (e.g., severity of the child's autism), additional family stressors (aA) (e.g., additional illness in the family, divorce), family external resources (bB) (e.g., social support), caregiver appraisal of the situation (C) (e.g., positive and negative appraisals of raising a child with autism), and caregiver coping strategies (cC) (e.g., emotion-focused, problem-focused, and avoidant coping) (letters correspond to figure). A prior study reporting on the baseline sample at the time of diagnosis, found that individual and marital burden were increased at the time of a child's diagnosis, and that symptom severity, additional pile-up demands, lower levels of social support, and the use of passive avoidant coping strategies were strongly associated with increased burden (Stuart & McGrew, 2009). The following section briefly summarizes the empirical literature supporting the predicted associations between the specified elements of the Double ABCX model and caregiver outcomes in ASD and outlines our research questions and hypotheses.