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Using a model of family adaptation to examine outcomes of caregivers of individuals with autism spectrum disorder transitioning into adulthood

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ABSTRACT

Background: The study examined the burden of caring for individuals with autism spectrum disorder (ASD) transitioning from high school and factors associated with burden derived from the Double ABCX model of family adaptation (i.e., autism symptom severity, problem behaviors, pile-up life demands, personality traits, social support, cognitive appraisals, and coping strategies). In particular, we were interested in the potential association between the “big 5” personality traits and burden.

Method: Participants ($N = 105$) were caregivers of individuals with ASD within two years pre- or post-graduation from high school.

Results: Primary caregivers reported moderate levels of burden. As hypothesized, burden was significantly associated with both child (i.e., increased autism symptom severity and problem behaviors) and caregiver characteristics (i.e., greater neuroticism, lower levels of extraversion, conscientiousness, agreeableness, and social support, and increased use of threat appraisals and passive-avoidance coping strategies). Using multiple regression, increased child behavior problems and increased caregiver use of passive-avoidance coping were identified as independent predictors of burden. Passive-avoidance coping mediated the relationship between caregiver burden and individual personality traits (i.e., neuroticism, extraversion, conscientiousness).

Conclusions: The results suggest that proximal variables, such as caregivers’ use of maladaptive coping strategies, explain the associations between burden and personality. Suggestions for interventions to relieve burden are discussed.

Caregivers of individuals with autism spectrum disorder (ASD) report increased distress and poorer psychological outcomes (e.g., stress, depression, anxiety) compared to caregivers of typically developing children (Dunn & Burbine, 2001) and children with other developmental disabilities (Hayes & Watson, 2013). Several factors have been associated with this increased burden in caregivers of children with ASD. These factors can be organized using the four components of the Double ABCX model of family adaptation (McCubbin & Patterson, 1983). The first component (see Fig. 1) characterizes the total family demands and needs, starting with the focal stressor, raising a child with ASD (A; e.g., child symptom severity, problem behaviors), then adding general life stressors/pile-up demands affecting the family (aA). The second component characterizes the family/caregiver’s internal (B; e.g., personality traits) and external resources (bB; e.g., social support) to meet the demands. The third component characterizes the family/caregiver’s interpretation of the demands (C; e.g., threatening) and coping strategies (cC; e.g., problem-focused). Finally, the fourth component is

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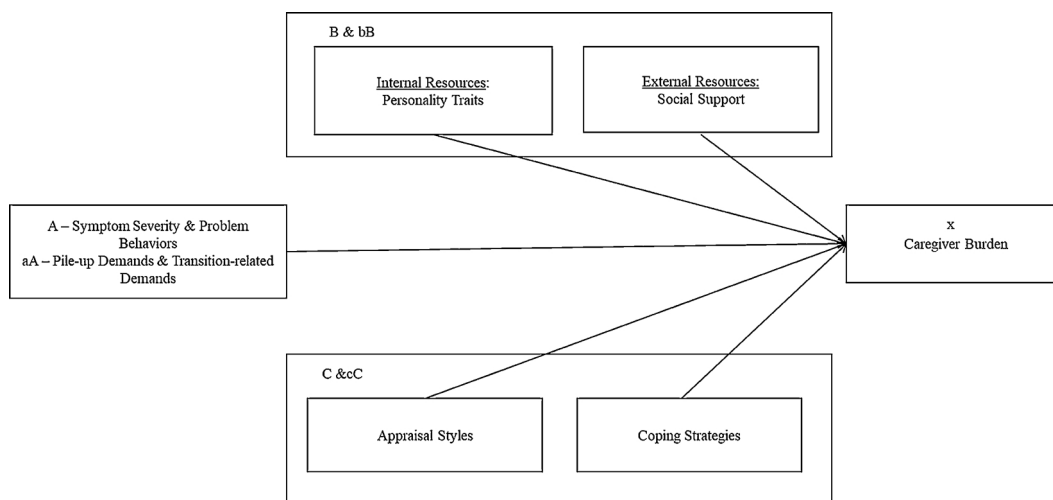


Fig. 1. The double ABCX model.

the outcome or the family/caregiver's overall adaptation (X; i.e., caregiver burden – the perception of the negative impact of caregiving on the caregiver's emotional, social, financial, and physical functioning; Zarit, Todd, & Zarit, 1986).

Results from studies using the Double ABCX model to examine family functioning when raising children with ASD are broadly consistent with the model (e.g., Hall & Graff, 2012; Manning, Wainwright, & Bennett, 2011). For example, variables representative of the first component, greater autism symptom severity, increased problem behaviors (A), and increased pile-up demands (aA) have been consistently associated with poorer family adaptation, e.g., increased parenting stress or burden (Davis & Carter, 2008; Stuart & McGrew, 2009). Similarly, elements representative of the second component, greater autism-specific (e.g., support from physicians, therapists, or others within the autism-community) and general social support (bB; Bekhet, Johnson, & Zauszniewski, 2012; Khanna et al., 2012) as well as personality style (B; e.g., optimism; Ekas, Lickenbrock, & Whitman, 2010) have been related to decreased caregiver burden and maternal distress in parents of those with ASD. Finally, elements from the third component, cognitive appraisals (C) and coping strategies (cC) have been associated as hypothesized to various measures of caregiver and family adaptation (e.g., caregiver burden, parent stress, well-being, depression, family functioning). Specifically, better psychological adaptation has been related to greater use of challenge appraisals and lower use of threat appraisals (Manning et al., 2011; Stuart & McGrew, 2009) as well as to increased problem-focused coping (e.g., initiating actions to alter the situation; Abbeduto et al., 2004; Benson, 2010) and decreased passive-avoidance coping (cC; e.g., denial, avoidance; Hastings et al., 2005) among caregivers of those with ASD. However, the association between emotional approach coping (e.g., positive reappraisal) and outcomes is inconsistent; it was unrelated to maternal depressed mood and caregiver burden (Benson, 2010; Khanna et al., 2011; Stuart & McGrew, 2009), but predictive of decreased parenting stress (Manning et al., 2011).

1. Personality traits

Lazarus and Folkman (1984) noted that personality factors can play an important role impacting appraisal, coping, and thus stress. Specifically, personal characteristics, such as values and beliefs about oneself and the world, help define individuals' interpretation of stressful encounters and the choice of appraisal style and coping strategy is also often related to personality. Despite the potential importance of personality in understanding caregiver burden, studies of personality and caregiver stress in ASD are sparse. Furthermore, the current literature has been largely limited to establishing the association between "healthy" personality traits (e.g., optimism) and stress (Ekas et al., 2010). Similarly, another individual difference variable examined in studies of caregivers' adaptation is the parent's broader autism phenotype (BAP). For example, BAP has been shown to be associated with parenting stress, coping strategies, and social support (Ingersoll & Hambrick, 2011). To our knowledge, however, no studies in ASD have embedded the exploration of stress and personality within a larger conceptual framework, such as the "big 5" personality traits. Although Jobe and Glidden (2008) examined the "big 5" personality traits in caregivers of individuals with developmental disabilities, reporting that high neuroticism and low extraversion were related to greater transition-related worries and fewer transition-related rewards, the authors did not separately analyze caregivers of those with ASD, limiting its relevance for ASD.

The potential importance of the "big 5" personality traits for understanding caregiver stress has been consistently shown in studies of the stress of caring for people with disabilities, generally. For example, in caregivers of adults with dementia and adults with multiple functional impairments, those high in neuroticism report greater caregiver burden, depression, and poorer mental and physical health (Melo, Maroco, & De Mendonça, 2011; Van der Lee, Bakker, Duivenvoorden, & Dröes, 2014); whereas, those high in extraversion and conscientiousness report better physical and mental health, social support satisfaction, and decreased burden (Löckenhoff, Duberstein, Friedman, & Costa, 2011; Melo et al., 2011). In contrast, the relationship between caregiver outcomes and agreeableness and openness has been inconsistent, with some studies reporting a weak association and others finding none (Jobe &

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