Title: The Outcomes of Caregivers of Individuals with Autism Spectrum Disorder in the Transition Period

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Introduction: Raising children with autism spectrum disorder (ASD) is a difficult challenge for the primary caregivers. Previous studies have identified child factors (e.g., number of problem behaviors) and parent factors (e.g., social support) related to caregiving stress (Stuart & McGrew, 2009). However, few studies have examined the impact of the “big 5” personality traits (Costa & McCrae, 1992) on caregiving stress although this is an area of active research in understanding caregiving in other disorders (e.g., cancer caregiving). In addition, caregiving stress in ASD tends to be greater during key transition points (e.g., entering or exiting school). Accordingly, the current study examined the potential impact of caregivers’ personality traits on stress during the period when individuals with ASD transition out of high school. The Double ABCX model was used as a framework (McCubbin & Patterson, 1983), which views caregiving stress as the additive impact of several independent factors: stressors, internal resources, and external resources.

Method: This was a cross-sectional observational study. A total of 117 participants, recruited via Amazon Mechanical Turk and other methods (e.g., parent support groups, autism listservs), were caregivers of individuals with ASD who either will graduate within two years or have graduated from high school within the past two years. Caregivers were asked to complete questionnaires online measuring their caregiver burden, stressors (i.e., ASD symptom severity, problem behaviors, pile-up demands), internal resources (i.e., personality traits, cognitive and coping strategies), and external resources (i.e., social support).

Results: Parents reported high caregiving stress in the transition period ($M = 2.06, SD = .75$). Greater caregiving stress was associated with increased problem behaviors ($r = .48, p < .001$), higher neuroticism scores ($r = .52, p < .001$), greater use of threat appraisals ($r = .45, p < .001$) and of passive avoidance coping ($r = .67, p < .001$). Lower caregiver burden was related to higher scores on extraversion ($r = .31, p < .001$), conscientiousness ($r = -.32, p < .001$), agreeableness ($r = -.22, p = .01$), greater use of challenge appraisals ($r = -.18, p = .03$), and higher levels of social support ($r = -.34, p < .001$), both general ($r = -.36, p < .001$) and contextual social support ($r = -.21, p = .01$). The double ABCX model explained 59% of the variance on caregiver burden, $R = .77, F(14, 102) = 10.45, p < .001$. Problem behaviors ($\beta = .24, p = .002$), general social support ($\beta = -.23, p = .015$), and passive avoidance coping ($\beta = .39, p < .001$) predicted over half of the total variance in caregiver burden.

Discussion: The results support the potential importance of personality traits in explaining differences in caregiver stress in families of those with ASD. In particular, parents high in neuroticism reported greater stress, whereas caregivers high in conscientiousness, extraversion, and agreeableness reported a lower level of stress. Additionally, parents reported high levels of stress in the transition period. Several factors were identified that could help alleviate the stress. With respect to personal factors that might contribute to stress, parents should be encouraged to use challenge appraisals and avoid using threat appraisals and passive avoidance coping strategies. Problem behaviors also were strongly related to increased caregiver stress during the transition period, suggesting that parent interventions could provide support or strategies to parents to handle behavioral problems and reduce stress. In addition, given that contextual support was related to reduced burden, providers of families raising children with ASD should be sensitive to parents’ stress and open to provide support.

References/Citations: