Title: Child and parent factors associated with strain among caregivers of children with developmental disabilities

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Introduction:

Caregivers of children who demonstrate externalizing and internalizing behaviors are at higher risk of experiencing caregiver strain (Bradshaw et al., 2021; Khanna et al., 2012). Parents may respond to certain behaviors by engaging caregiver accommodations, or daily adjustments that caregivers make to facilitate everyday functioning. Examples of accommodations include reducing the demands/expectations placed on a child, allowing the child to avoid novel or aversive situations, and adhering to child’s insistence on sameness (Maul & Singer, 2009; O’Nions et al., 2018). Accommodations may serve to alleviate or prevent short-term negative experiences or parent distress (Dai & Carter, 2023). However, accumulation of such accommodations could lead to caregiver strain (García-Grau et al., 2024; Woodgate et al., 2008). The current study aims to examine whether accommodations mediate the relationship between child behaviors and caregiver strain.

Method:

Participants were recruited from the Children’s Hospital of Philadelphia’s medical and research registries. A sample of 407 caregivers of youth (Mage = 11.7, 63% males) with ID (n= 161), ASD (n=193), or both (ASD+ID; n=53) completed the Caregiver Strain Questionnaire (CSQ; Brannan et al., 1997), Accommodations and Impacts Scale for Developmental Disabilities (AISDD; Udhnani et al., 2023), and Nisonger Child Behavior Rating Form (NCBRF; Aman et al., 1996). Six scales of the NCBRF were analyzed: Conduct Problem, Insecure/Anxious, Hyperactive, Self-Injurious/Stereotypic, Self-Isolated/Ritualistic, and Overly Sensitive. Descriptive analyses with Pearson correlations were conducted. Bonferroni corrections were applied to reduce the likelihood of Type I error. The mediating effect of accommodations were examined using PROCESS macro for R Version 4.3.1 (Model 4; Hayes, 2022). Each domain of the NCBRF was inputted one at a time as a predictor variable, while covarying for the other five subscales. Each mediation model employed 5000 resamples to generate bias-corrected bootstrapping confidence intervals (Hayes & Scharkow, 2013). Standardized indirect effects of the mediation analyses were considered significant if the 95% confidence interval did not contain zero (Hayes, 2015).

Results:

Table 1 displays the Pearson correlations between all variables. Correlations that withstood Bonferroni-correction are in bold. Accommodations significantly mediated the relationship between all NCBRF scales and caregiver strain. The standardized indirect effects of the AISDD on the relationship between NCBRF and CSQ Global Sum Score were as follows: Conduct Problem: β = .31 [.26, .36], Insecure/Anxious: β = .16 [.10, .21], Hyperactive: β = .35 [.30, .41], Self-Injurious/Stereotypic β = .31 [.25, .36], Self-Isolated/Ritualistic β = .22 [.16, .28], and Overly Sensitive β = .29 [.23,.34].

Discussion:

The current study found that caregiver accommodations mediated the relationship between child behaviors and caregiver strain. The NCBRF scales with the highest indirect effects were generally those measuring externalizing behaviors, such as Conduct Problem, Hyperactive, and Self-Injurious/Stereotypic. These findings support studies that show links between child behaviors (e.g., hyperactivity, social withdrawal), caregiver accommodations, and caregiver strain (Bradshaw et al., 2021; Dai & Carter, 2009; Khanna et al., 2012). Moreover, this study adds to the literature by revealing mediating relationships, and thereby a potential area of exploration to further investigate the association between child behaviors and caregiver mental health. It is worth noting that because data were collected cross-sectionally, no causal attribution can be claimed. Instead, this study is hypothesis-generating to better understand the interplay between child and parent functioning. As caregiver strain is associated with greater risk of mental and physical health problems (Ezzat, 2017; Masefield et al., 2020) and has a significant impact on how caregivers interact with their child, access services, and cope (Ezzat, 2017; Shivers et al., 2017), it is critical to understand the factors that contribute to caregiver strain.

**Table 1**

*Pearson correlations between age, caregiver accommodations, child behaviors, and caregiver strain*

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Variable | M | SD | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Child’s age
 | 11.7 | 3.9 |  |  |  |  |  |  |  |  |
| 1. AISDD
 | 59.9 | 14.9 | **-0.19** |  |  |  |  |  |  |  |
| 1. NCBRF Conduct
 | 11.8 | 10.5 | -0.17 | **0.51** |  |  |  |  |  |  |
| 1. NCBRF Insecure
 | 8.1 | 8.4 | 0.06 | **0.22** | **0.62** |  |  |  |  |  |
| 1. NCBRF Hyperactive
 | 12.4 | 7.3 | **-0.22** | **0.57** | **0.57** | **0.42** |  |  |  |  |
| 1. NCBRF Self-Inj/Stereotypic
 | 2.5 | 3.4 | -0.04 | **0.44** | **0.34** | 0.17 | **0.42** |  |  |  |
| 1. NCBRF Self-Isolated/Ritualistic
 | 6.3 | 4.9 | -0.03 | **0.31** | **0.44** | **0.48** | **0.44** | **0.36** |  |  |
| 1. NCBRF Overly Sensitive
 | 6.3 | 4.1 | **-0.21** | **0.43** | **0.60** | **0.66** | **0.58** | **0.30** | **0.50** |  |
| 1. CSQ Global Strain
 | 7.7 | 2.6 | -0.11 | **0.77** | **0.62** | **0.42** | **0.61** | **0.46** | **0.41** | **0.53** |

*Note.* Correlations in bold withstand Bonferroni correction.

References:

Aman, M. G., Tassé, M. J., Rojahn, J., & Hammer, D. (1996). The Nisonger CBRF: A child behavior rating form for children with developmental disabilities. Research in Developmental Disabilities, 17(1). https://doi.org/10.1016/0891-4222(95)00039-9

Bradshaw, J., Gillespie, S., McCracken, C., King, B. H., McCracken, J. T., Johnson, C. R., Lecavalier, L., Smith, T., Swiezy, N., Bearss, K., Sikich, L., Donnelly, C., Hollander, E., McDougle, C. J., & Scahill, L. (2021). Predictors of Caregiver Strain for Parents of Children with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 51(9), 3039–3049. <https://doi.org/10.1007/s10803-020-04625-x>

Brannan, A. M., Heflinger, C. A., & Bickman, L. (1997). The Caregiver Strain Questionnaire: Measuring the Impact on the Family of Living with a Child with Serious Emotional Disturbance. Journal of Emotional and Behavioral Disorders, 5(4). https://doi.org/10.1177/106342669700500404

Dai, Y. G., & Carter, A. S. (2023). Characterizing Accommodations by Parents of Young Children with Autism: A Mixed Methods Analysis. Journal of Autism and Developmental Disorders, 53(9), 3380–3393. https://doi.org/10.1007/s10803-022-05652-6

Ezzat, O. (2017). Quality of Life and Subjective Burden on Family Caregiver of Children with Autism. American Journal of Nursing Science, 6(1), 33. https://doi.org/10.11648/j.ajns.20170601.15

García-Grau, P., Martínez-Rico, G., González-García, R. J., Escorcia-Mora, C. T., & Cañadas-Pérez, M. (2024). Caregiver Burden and Family Quality of Life in Early Intervention: The Role of Mothers and Family Confidence. European Journal of Investigation in Health, Psychology and Education, 14(5), 1325–1337. https://doi.org/10.3390/ejihpe14050087

Hayes, A. (2022). Introduction to Mediation, Moderation, and Conditional Process Analysis (T. Little, Ed.; 3rd ed.). Guilford Press.

Hayes, A. F., & Scharkow, M. (2013). The Relative Trustworthiness of Inferential Tests of the Indirect Effect in Statistical Mediation Analysis: Does Method Really Matter? Psychological Science, 24(10), 1918–1927. https://doi.org/10.1177/0956797613480187

Khanna, R., Madhavan, S. S., Smith, M. J., Tworek, C., Patrick, J. H., & Becker-Cottrill, B. (2012). Psychometric properties of the Caregiver Strain Questionnaire (CGSQ) among caregivers of children with autism. Autism, 16(2), 179–199. <https://doi.org/10.1177/1362361311406143>

Masefield, S. C., Prady, S. L., Sheldon, T. A., Small, N., Jarvis, S., & Pickett, K. E. (2020b). The Caregiver Health Effects of Caring for Young Children with Developmental Disabilities: A Meta-analysis. Maternal and Child Health Journal, 24(5), 561–574. https://doi.org/10.1007/s10995-020-02896-5

Maul, C. A., & Singer, G. H. S. (2009). “Just Good Different Things”: Specific Accommodations Families Make to Positively Adapt to Their Children With Developmental Disabilities. Topics in Early Childhood Special Education, 29(3), 155–170. https://doi.org/10.1177/0271121408328516

O’Nions, E., Happé, F., Evers, K., Boonen, H., & Noens, I. (2018). How do Parents Manage Irritability, Challenging Behaviour, Non-Compliance and Anxiety in Children with Autism Spectrum Disorders? A Meta-Synthesis. Journal of Autism and Developmental Disorders, 48(4), 1272–1286. https://doi.org/10.1007/s10803-017-3361-4

Shivers, C. M., Krizova, K., & Lee, G. K. (2017). Types of strain among family members of individuals with autism spectrum disorder across the lifespan. Research in Developmental Disabilities, 68, 42–51. <https://doi.org/10.1016/j.ridd.2017.07.003>

Udhnani, M. D., Miller, J. S., & Lecavalier, L. (2023). Development and Preliminary Validation of the Accommodations & Impact Scale for Developmental Disabilities. Journal of Autism and Developmental Disorders, 54(5), 1870–1881. <https://doi.org/10.1007/s10803-023-05929-4>

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. Qualitative Health Research, 18(8), 1075–1083. https://doi.org/10.1177/1049732308320112