Title: Compound Sibling Caregivers of individuals with Intellectual and Developmental Disabilities

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Introduction: Siblings of individuals with IDD are often referred to as “compound caregivers” because they may simultaneously care for their: own children, parents, and brother/sister with IDD (Hodapp et al., 2016). Previous studies have focused on the caregiving roles of siblings in relation to their brothers/sisters with IDD (Lee & Burke, 2018). There has been little attention to assess whether sibling caregivers had multiple caregiving roles (Perkins & Haley, 2010). The purpose of this study was two-fold. Our first aim was to compare the demographic characteristics across sibling caregiving groups (i.e., non-caregivers [no caregiving roles], single-caregivers [caregiving for one individual], and compound caregivers [caregiving for more than one individual]). Our second aim was to determine whether the type of caregiving role related to differences in: the sibling relationship, future planning, advocacy, sibling involvement in training, and support needs. We hypothesized that compound caregivers (vs. non-caregivers and single caregivers) will be more engaged in future planning, advocacy, and trainings and have more support needs.

Method: Data have been collected from 241 participants (i.e., adult siblings of individuals with IDD) via a national web-based survey. Participants included: 99 non-caregivers, 115 single caregivers, and 27 compound caregivers. Compound caregivers were siblings who currently fulfilled caregiving roles to two family members (e.g., siblings, parents, their own child with disability). Participants completed the following measures: future planning (Heller & Caldwell, 2006); advocacy (Burke et al., 2015); sibling relationship (Hodapp et al., 2010); sibling participation in training and support activities (Burke et al., 2018); and sibling support needs (Burke et al., 2018). For aim one, univariate analyses were conducted. For post hoc analyses for the ANOVA, LSD analyses were conducted. For aim two, we conducted an analysis of covariance (ANCOVA) with sibling age as a covariate.

Result: Compared to non-caregivers, single caregivers and compound caregiver: were significantly older (p = .01) and had an older brother/sister with disabilities (p <.01). Also, non-caregivers reported less household income compared to compound caregivers (p = .02). There were no significant demographic differences between single caregivers and compound caregivers.

Compared to non-caregivers, single-caregivers and compound caregivers presented more positive sibling relationships (F = 8.89, p <.01), engaged in greater future planning activities (F = 3.24, p = .03), and engaged in greater advocacy activities (F = 13.12, p < .01). Further, single-caregivers reported greater support needs in sibling training compared to non-caregivers (F = 2.38, p = .04).

Discussion: In our study, we found that 11.2% of the caregivers were compound caregivers. Using a larger sample, future research may examine whether there are differences in relation to stress, depressive symptoms, and caregiving reciprocity. Given the potential compound caregiving responsibilities for siblings, further investigation is warranted.

References/Citations: