Importance of Community in the Development of Resilient Caregivers for Medically Complex Children

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Introduction. Children with medical complexity (CMC) have chronic health problems that significantly affect organ systems, limit function, and increase healthcare and medical technology needs. Few studies explore caregiver resilience. Research shows resilience helps caretakers overcome adversity and improve mental health. This study examines factors that influence caregiver resilience.

Methods. Caregivers completed anonymous surveys at healthcare clinics or through social media (10/2022-11/2023), collecting demographics, caregiving hours, and travel time. Resilience was measured using the 17-item Likert scale version of the Adult Resilience Measure Revised (ARM-R; total maximum score: 85). Personal and caregiver resilience scores were derived from the total score. Kruskal-Wallis tests, Dwass-Steel-Critchlow-Fligner methods, and Spearman rank correlation were used.

Results. Of the 200 participants, 187 were analyzed. Most were female (91.44%), biological parents (80.75%), and 40-49 years old (35.83%). The average total score was 68.08 (SD = 12.42). The total scores ($p = 0.007$) and caregiver resilience scores ($p < 0.001$) differed significantly across the five categories of hours spent sharing caregiving tasks with families. Sense of belonging correlated with higher total scores ($\rho = 0.80$, $p < 0.001$), personal ($\rho = 0.84$, $p < 0.001$), and caregiver ($\rho = 0.61$, $p < 0.001$) resilience scores. Furthermore, a sense of belonging shows a positive correlation with perceived fair treatment ($\rho = 0.73$, $p < 0.001$) and interpersonal relationships ($\rho = 0.59$, $p < 0.001$).

Conclusions. Most participants scored relatively high on resilience scores. Sharing caregiving tasks with families and feeling connected to the community were identified as factors improving resilience. Perceived fair treatment and interpersonal relationships had a positive impact on belongingness. Future interventions should enhance family involvement and focus on community-building.