**Title**: Caregiving for adults with Down syndrome: a qualitative assessment of experiences and support needs

**Authors**: Amy E. Bodde1, Joanna Brooks 2, Bethany Forseth3, Tara Wolfe1 & Lauren T. Ptomey1

**Introduction**: Down syndrome (DS) or trisomy 21 is caused by the triplication of the 21st chromosome and is the leading chromosomal cause of intellectual disability(1). Nearly all individuals with DS require support from a caregiver throughout their lifespan. Studies have shown that caregivers, often parents or siblings, experience high levels of stress, depression and anxiety(2). However, most of these studies have focused caregivers of youth with DS, and few have explored the experiences of caregivers of adults with DS(3). This is increasingly important as the prevalence of adults with DS is growing(4) due to the recent dramatic increase in their life expectancy(5, 6). Better understanding of the experiences and unmet support needs of caregivers of adults with DS will help researchers, clinicians, and health professionals to design targeted interventions to improve caregiver well-being.

**Method**: Semi-structured interviews were conducted with caregivers of adults with DS at the conclusion of a 12-month randomized controlled physical activity trial for adults with DS. Interviews took place either in-person or over ZoomTM videoconferencing. The interview guide included 8 open-ended questions designed to query both positive and challenging aspects of caregiving and perceived caregiver support needs. Transcriptions of the recorded interviews were coded by two members of the research team. Themes were identified using thematic analysis (7, 8) informed by the Transactional Theory of Stress and Coping(9).

**Results**: Seventeen caregivers completed the interviews. Thirty-seven codes were identified which led to 4 themes. The 4 major themes included: Constancy of caregiving; Future planning; Joys and rhythms in caregiving; and Significance of support. Caregivers expressed challenges of caregiving including behavioral challenges, time burdens, school transition challenges, concerns about future planning and challenges of compound caregiving. However, many also described great joy in the caregiving of their loved one with DS. Both informal (family, friends) and formal supports (county and state services) emerged as critical aspects of caregiving. Many caregivers expressed gratitude for the supports they had but voiced frustration at the lack of support they perceived, include long wait lists for state intellectual and developmental disability waivers and lack of respite options. Time for oneself with frequently cited as an unmet need.

**Discussion:** Our findings reflect that caregivers often feel the constant burden of caregiving, require both informal and formal supports and need trusted options for respite care. The expressions of both the joys and challenges of caregiving are reflective of other recent studies in this field(2). Intervening to support caregivers with formal or informal respite service options and help with future planning may help meet caregiver needs and improve their well-being.

University of Kansas Medical Center, Department of Internal Medicine

2 University of Kansas Medical Center, Department of Population Health

3 University of Kansas Medical Center, Department of Physical Therapy and Rehabilitation Science

**References:**

1. Bull MJ. Down Syndrome. New England Journal of Medicine. 2020;382(24):2344-52.

2. Rutter TL, Hastings RP, Murray CA, Enoch N, Johnson S, Stinton C. Psychological wellbeing in parents of children with Down syndrome: A systematic review and meta-analysis. Clinical Psychology Review. 2024;110:102426.

3. Koch LC, Lunsky Y, St. John L. Physical Activity, Sedentary Behaviour, Sleep and Mental Wellbeing in Family Caregivers of Adults With Intellectual and/or Developmental Disabilities. Journal of Applied Research in Intellectual Disabilities. 2025;38(1):e13310.

4. de Graaf G, Buckley F, Skotko BG. Estimation of the number of people with Down syndrome in the United States. Genet Med. 2017;19(4):439-47.

5. Glasson EJ, Dye DE, Bittles AH. The triple challenges associated with age-related comorbidities in Down syndrome. J Intellect Disabil Res. 2014;58(4):393-8.

6. Glasson EJ, Sullivan SG, Hussain R, Petterson BA, Montgomery PD, Bittles AH. The changing survival profile of people with Down's syndrome: implications for genetic counselling. Clin Genet. 2002;62(5):390-3.

7. Kiger ME, Varpio L. Thematic analysis of qualitative data: AMEE Guide No. 131. Med Teach. 2020;42(8):846-54.

8. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3(2):77-101.

9. Lazarus RS, Folkman S. Transactional theory and research on emotions and coping. European Journal of Personality. 1987;1(3):141-69.