137: Caregiver burden and support needs in caregivers of adults with 22q11.2 deletion syndrome

Lisa Palmer[1], Tracy Heung[1,2], Nikolai Reyes[1, 2, 4,5], Samantha D'Arcy[1], and Anne S. Bassett[1,2,3]

[1]The Dalglish Family 22q Clinic, University Health Network, Toronto, ON, Canada; *[2]Clinical Genetics Research Program, Centre for Addiction and Mental Health, Toronto, ON, Canada*; *[3]Department of Psychiatry, University of Toronto, Toronto General Hospital Research Institute, and Campbell Family Mental Health Research Institute, Toronto, ON, Canada*; [4]*Institute of Medical Science, Temerty Faculty of Medicine, University of Toronto, Toronto, ON, Canada;* [5]*Edmond J. Safra Program in Parkinson's Disease, the Rossy Progressive Supranuclear Palsy Centre, and the Morton and Gloria Shulman Movement Disorders Clinic, Toronto Western Hospital, Toronto, ON, Canada.*

Background: Adults with 22q11.2 deletion syndrome (22q11.2DS) often require lifelong support due to complex medical, cognitive, and psychosocial challenges. Caregivers play a critical role in managing these needs, yet the burden they experience, and their support needs, remain underexplored. **Methods:** We assessed caregiver burden using the standardized Zarit Burden Interview (ZBI) and examined current supports and anticipated future support needs using a brief survey created by clinical staff at our clinic for adults with 22q11.2DS. We assessed burden for unaffected caregivers (n=14, all relatives living with the adult with 22q) of 11 adults (median age 23.3, range 19.4-33.6 years; n=8 male) with a typical 22q11.2 deletion consecutively assessed at the clinic. We examined the relationship between caregiver burden and major features of 22q, including moderate-severe congenital heart defect (CHD, n=4), moderate-severe intellectual disability (ID, n=3) and psychotic illness (n=4) and explored common themes related to caregiver support needs. **Results:** Overall, ZBI scores indicated experience mild-moderate levels of caregiver burden (median score 37.5, range 14-61). There was no significant effect of ID or CHD on burden; however, caregivers of adults with 22q11.2DS and psychotic illness reported significantly higher burden (median score 51.5, range 35-61, vs 28.0, range 14-48 p=0.02). The most common current supports reported were family, friends, and the Adult 22q Clinic. The most frequently identified future support needs were related to housing and future planning for the adult with 22q. **Conclusions:** Caregivers of adults with 22q11.2DS experience substantial burden, particularly when psychotic illness is present. Although identifying many current informal supports, caregivers expressed significant concern about housing options and long-term care planning. These findings highlight the need for specialized support for caregivers and for targeted supports related to housing and long-term care planning for adults with 22q.11.2DS.