# 2021 Gatlinburg Conference Poster Submission

EXAMPLE

**Title**: Impact of Stress and Sleep in Caregivers of Children with Neurogenetic Syndromes during COVID-19

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**Introduction**: Caregivers of children with neurogenetic syndromes (NGS) often report elevated stress levels and poorer sleep quality (Gallagher et al., 2010; Gupta, 2007; Lee et al., 2018). These health challenges are likely amplified during the COVID-19 pandemic as protective measures such as physical distancing, home confinement, and closures disrupt many aspects of daily life. Caregivers of children with NGS are also facing unique stressors due to the higher risk for severe COVID-19 related complications in people with intellectual and developmental disabilities, as well as the higher dependence of people with NGS on medical, educational, and support services that have been altered. These dramatic changes pose risks to caregiver sleep, an essential function for well-being, quality of life, and physical health. For example, previous studies have suggested that high caregiver sleep quality may be protective against depressive symptoms in elderly caregivers of dementia patients and family caregivers of persons with cancer (Carter, 2006; Mccurry et al., 1998). However, to date, the impact of daily stress levels during COVID-19 on the duration and quality of caregiver sleep is unclear, including among NGS caregivers. The present study sought to use an experience sampling approach to examine how daily stress patterns during COVID-19 relate to sleep quality in caregivers of children with NGS.

**Method**: Data collection is ongoing as part of a longitudinal ecological momentary assessment (EMA) study on caregiver and child well-being in NGS families during COVID-19. Here, we focus on preliminary data on 50 caregivers of children with NGS (13 Angelman syndrome, 9 Down Syndrome, 4 Fragile X syndrome, 9 Prader Willi and 15 Williams syndrome) ages 1 to 14 years old ($M$ = 4.5) who were recruited into this study from the Purdue Early Phenotype Study. Caregivers were primarily white 96%, and 86% reported family income above $50,000. Across four biweekly assessment periods (7 weeks total), caregivers completed four daily surveys delivered via ExpiWell, an EMA smartphone application (Tay, 2015). The present study focuses on three variables from this broader study: (1) weekly ratings of the degree to which COVID-19 is causing them stress, (2) daily morning ratings of previous night sleep duration and quality and (3) momentary ratings of daily stress. Momentary stress levels were measured four times per day within a brief survey, "pinged" to the caregiver's cell phone, that included the question "How STRESSED are you feeling right now?".

**Results**: Final analyses will include mixed effects models to examine how previous night sleep predicts level and change in daily stress in the full sample. Preliminary results from the first week of data indicate that caregivers slept 6.98 hours on average, which is slightly low relative to national guidelines of 7 to 9 hours of sleep. However, sleep quality was generally "average" (55.14% on scale of 0 = "very poor" to 100 = "very good"). Caregivers who reported greater COVID-19 related stress on weekly surveys also reported shorter sleep duration ($r$= .109 p= .0009) and a trend toward poorer daily sleep quality ($r$ = -.053, p= .099). Final analyses will examine how sleep relates to stress reported across caregivers' days, which will inform the temporal association between stress and sleep.

**Discussion:** Sleep is important for caregiver psychological well-being**.** Our preliminary findings suggest that sleep quality and sleep duration may be impacted by COVID-19 related stress among NGS caregivers, with sleep quality and duration – measured immediately after waking – relating to caregivers' weekly self-reported levels of general stress caused by COVID-19. Future work is needed to validate self-reported sleep with more objective measures, such as actigraphy and polysomnography. However, our preliminary results suggest that COVID-19 may be enhancing overall caregiver stress levels. This information could be particularly useful when developing personalized interventions that consider individual caregivers' patterns of stress and health behaviours.

**References:**

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