

Title: Impact of COVID-19 on telemental health treatment outcomes among caregivers of children with Angelman syndrome

Authors: Riley Felicicchia¹, Meredith Bucher¹, Daniel Foti¹, Kelly LeMaire¹, & Bridgette Kelleher¹

Introduction: Caregivers of children with neurogenetic syndromes (NGS) are vulnerable to stress-related mental health challenges. However, NGS caregivers also frequently report that local providers are not adequately trained in their child's disability (Kelleher et al., 2020), which may make them less likely to engage their family in services. Telemental health may address this gap by connecting caregivers with providers who have specialized training in the needs of NGS families. These connections may be particularly important during COVID-19 because of the elevated stress caregivers are likely experiencing. However, it is also possible that the stress of COVID-19 itself limits caregivers' willingness and ability to engage in treatments to bolster their well-being and mental health, even when issues of travel and provider training are resolved via telehealth.

The present study addresses this issue by examining how NGS caregivers' stressors during COVID-19 relate to their treatment uptake in an ongoing trial of Acceptance and Commitment therapy (ACT; Hayes et al., 1999), an empirically supported treatment for improving quality of life and mental health. Our preliminary findings (Bucher et al., in preparation), indicate ACT treatment significantly improved depression symptoms at the group level, however, the success of treatment varied across individuals. Here, we asked two key questions to inform whether COVID-19 –related experiences impacted treatment effectiveness within this sample: (1) How did COVID-19 stress affect caregivers' abilities to participate in treatment as measured by number of completed sessions, missed sessions, and home practice assignment completion? and (2) Did both general stress related to COVID-19 and parenting stress during treatment relate to the magnitude of individuals' symptom reduction across treatment?

Methods: Participants were caregivers of children diagnosed with Angelman syndrome (n=18) who were recruited through the Angelman Syndrome Foundation to participate in a mental health intervention during the COVID-19 pandemic. Enrolled caregivers completed 9 weeks of telehealth ACT treatment with trained graduate student clinician coaches and completed weekly surveys. The present study focuses on three survey items administered post-treatment: (a) "How has your caregiving responsibility changed?" (b) "To what extent has the COVID-19 pandemic changed your daily life", and (c) "To what extent has the COVID-19 pandemic caused you stress?" We examined how these variables related to change in symptoms pre- to post-treatment, as measured by both the depression subscale from the Depression, Anxiety, and Stress Scale Short Form (DASS-21; Lovibond and Lovibond, 1995) and the overall parenting stress score from the Parenting Stress Index, Revised (PSI; Abidin, 1995).

Results: Data collection is still ongoing; here, we report available outcome data from 10 of 18 caregivers who have completed follow-up assessments to date. Of these caregivers, 7 reported that COVID-19 caused them "moderate" to "a lot" of stress, and 8 reported that COVID-19 changed their life "moderately" to "a lot". Six of the 10 participants reported that they are spending more time caring for children due to COVID-19, and their changes in depression symptoms appear to be smaller ($M=1.5$, $SD=1.4$) relative to those whose caregiving responsibilities remained stable ($M=4.7$, $SD=4.4$), preliminarily supporting our hypothesis that COVID-19 disruptions may constrain treatment efficacy. Final analyses will use nonparametric Wilcoxon tests and Spearman correlations to examine how these COVID-related variables relate to both treatment engagement (percentage of home practice assignments completed, number of completed sessions) and outcomes (depression symptoms post-treatment, controlling for baseline) in the full sample of 18 caregivers. We will also feature qualitative data from caregivers to contextualize these findings.

Discussion: Our preliminary findings suggest that caregivers are experiencing significant effects from COVID-19 that manifest across caregiver responsibility, changes in daily life, and stress. Telehealth-based treatments may be a solution for caregivers experiencing mental health concerns during COVID-19. However, our preliminary findings suggest that caregivers may still face barriers in receiving telehealth treatment. These findings parallel prior reports that telehealth treatment alone will not reduce health disparities in underserved populations (Park et al., 2018), and indicate that clinicians must still attend to access barriers, particularly during COVID-19. Our final results may inform the specific barriers and potential ways to address these barriers that providers should keep in mind when attempting to serve NGS caregivers and other highly impacted populations, both during COVID-19 and future public health crises.

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¹ Purdue University, West Lafayette, Indiana