INTRODUCTION

• Angelman syndrome (AS) is a neurogenetic disorder that causes a delay in developmental and cognitive abilities. The prevalence of this disorder is 1 in 12,000 to 20,000 individuals. Some characteristics of AS include a delay in development, intellectual disabilities, severe speech impairment, bouts of uncontrollable laughter, seizures, and problems with movement and balance. Due to these impairments, prior studies have suggested that children with AS exhibit elevated levels of challenging behaviors compared to typically developing peers. Thus, these behaviors require higher levels of care and may impact their caregiver’s mental health. Understanding which caregivers may be at risk for negative mental health outcomes is important for improving caregiver well-being and quality of life.

• This study examines the associations between challenging behaviors in children with AS and caregiver depression, anxiety, and stress levels. Using the Depression, Anxiety and Stress Scale (DASS-21) and the Child Behavior Checklist (CBCL 1 ½ - 5; Achenbach, 1991), we assessed depression, anxiety, and stress scores. This then leads us to ask, do children with more challenging behaviors correlate to higher levels of depression, stress and/or anxiety in their caregivers? We hypothesized that caregivers of children with more challenging behaviors would in fact have higher depression, anxiety, and stress scores.

• This hypothesis was based on previous research with similar results. For instance, a research study aimed to determine if stress, anxiety, and depression rates among parents of children with autism spectrum disorder (ASD) is elevated and concluded that their initial belief was correct. In another article, Amy Mendenhall claims that parents of children with mental illnesses show stronger signs of strain in all areas of their lives, including work, mental and physical health, and social and family relationships. This research shows that parents of children with mental illness may benefit from a strength-based, parent-focused interventions in order to help them care for both themselves and their families in a healthy and supported way. While other studies look at different aspects of mental health, this study contributes to the limited literature surrounding how challenging behaviors of children with AS impact caregiver mental health, with the potential to guide future intervention.

METHODS

• Data was derived from Project Well-CAT (Supporting Wellbeing of Caregivers in Angelman Syndrome Community via Telehealth), a telehealth intervention study focusing on how the depression, stress, and anxiety levels of parents of children with Angelman syndrome fluctuated before and after a 9-week ACT telehealth treatment course. Caregivers (n = 22) who completed the first session were included in the results, figures, and tables, even if they did not complete the study. Inclusion criteria for caregivers was as follows, (1) caregiver of a child ages 2-8 with Angelman syndrome, (2) primary language spoken at home is English, and (3) access to high-speed internet. Exclusion criteria for caregivers was if they appeared to be at high risk of suicide, bipolar 1, a moderate-severe eating disorder, or those exhibited more than very mild psychotic symptoms were also excluded. Caregivers were made aware of these guidelines at the start of treatment by their ACT coach. Additionally, only the (1+) survey was analyzed to examine caregiver’s depression, stress, and anxiety levels prior to treatment. The CBCL had a mean of 0.36 and a standard deviation of 0.44 while anxiety scores had a mean of 3.14 and finally stress scores had a mean of 2.26 depression scores and a mean of 24.04 while anxiety scores had a mean of 2.41 and a standard deviation of 4.03.

HYPOTHESES

• We hypothesized that caregivers of children with more challenging behaviors would in fact have higher depression, anxiety and stress scores.

RESULTS

Due to the small sample size, non-parametric Spearman’s test was used to analyze if challenging behaviors of children with Angelman syndrome are associated with higher parent anxiety, stress, and depression scores. According to the Bonferroni Correction, we will correct our alpha level to the p < (0.05/3) for the three subscales of the DASS-21 data which is p < (0.017). Doing this, corrects for inflated error. There was no statistically significant association between Child Behavior Checklist (CBCL) scores and parent depression (p = 0.091, r = 0.369), CBCL scores and anxiety (p = 0.082, r = 0.379), and CBCL scores and stress (p = 0.091, r = 0.369). However, the results trend towards significance suggesting that more participants might lead to statistically significant associations between CBCL scores and parent depression, anxiety, and stress.

DISCUSSION

Contrary to our predictions, we did not find a significant association between challenging behaviors in children with AS and caregiver depression, anxiety, and stress levels. Since our results did not signify a significant correlation, but were in the direction of our hypotheses, there is still a need for more research to investigate this finding and determine what would be most useful for improving caregiver mental health. Many caregivers are still experiencing high levels of depression, anxiety and stress and this should be explored.

• Mental Health America, the nation’s leading community-based nonprofit organization, claims that an estimated 1 out of 4 caregivers of a person with a mental illness is diagnosed with depression. This organization also claims that “stress [and] worry… felt while being a caregiver has consequences” so a caregiver should take time out for themselves, get enough sleep, exercise, and ask for help if needed. By following these tips, a caregiver can likely feel less stress, depression and anxiety within their daily life. While the data of our project is coherent, it does not align with our initial hypothesis, and there are certain limitations to our study. First of all, our sample size of twenty-two caregivers of children with AS is relatively small. If we had a larger sample size, we might have been able to establish a more significant difference. Furthermore, while the participants completed the surveys on their own, without the presence of the clinician, which allowed for less response bias, it does not eliminate this potential issue. Thus, there is the possibility that participants would answer the questions in favorably ways. Going forward with the experiment, recruiting more participants would be crucial in order to determine if there are statistically significant associations between child challenging behaviors and parent depression, anxiety, and stress scores. Future research should be explored with more diversity in race, marital status, and gender. Would the results vary if the participants in the data showed more diversity, more single or divorced individuals or more male caregivers? Overall, while the findings from this study were nonsignificant, it still contributes to the limited literature regarding how challenging behaviors of children with Angelman syndrome impact caregiver mental health. This study can also help stimulate the development of new research on children with Angelman syndrome and their caregivers.