
Authors: Olena Zyga, M.A., Ellen Doernberg, B.A., Sandra Russ, Ph.D., & Anastasia Dimitropoulos, Ph.D.

Introduction: Research has shown that children with Prader-Willi Syndrome (PWS) have deficits in social cognitive abilities that are similar to children with autism spectrum disorder (ASD), and impact domains relating to parent and peer interactions (Dimitropoulos, Ho, & Feldman, 2013). Parents of children with PWS also report difficult behaviors surrounding tantrums, compulsive behaviors, rigid and restrictive routines, pretend play behaviors, and ability to engage with peers. The use of parent training in other developmental disorders, such as ASD, has become an accepted and effective option for behavior change (Scahill et al., 2016). Developing a training program for parents of children with PWS could produce similar positive results and improve parent-child relationships early in development. However, given the low prevalence of PWS in the general population (approximately 1 in 12,000 live births), developing behavioral interventions for individuals with PWS is faced with the significant challenge of enrolling enough participants for local studies. The use of telehealth could provide a means to alleviate this barrier to accessing treatment. Research in ASD has shown that parent training for problem behaviors in young children is feasible via distance-learning methods (Vismara et al., 2013), however no study has yet to investigate the use of this modality in PWS.

Method: The current study aimed to deliver a 6-week parent-training intervention to primary caregivers of children with PWS, ages 3-6 years, twice a week, for 20-30 minute sessions. Thus far, 12 children with PWS (6 males; 6 females) and their primary caregiver have participated in the current study. This poster will report on (1) the feasibility and acceptability of a parent-training program for families with preschoolers with PWS and (2) what strategies may prove most beneficial for targeting certain problem behaviors in PWS and how they may compare to children with ASD. Participants completed in-person baseline and post-intervention visits. During the intervention period, the primary caregiver worked directly with the interventionist via video conferencing software to complete the Parent-focused Remote Education To ENhance Development (PRETEND) program, which centers on improving the quality of interactions, play, and social communicative ability in children and their parents. Parents of participants were asked to complete an anonymous, electronic version of the Behavioral Intervention Rating Scale (BIRs) after the post-intervention visit (5-point Likert scales: 1 = strongly disagree; 5 = strongly agree).

Results: Ten of the 12 families completed the intervention program (mean child age = 4.56 years). Overall, caregivers rated the program highly with an overall rating of 5.39/6.00 for the program’s acceptability, 5.53/6.00 program effectiveness, and 4.83/6.00 for the program’s usability. Parental attitudes towards telehealth as a treatment modality were also positive (4.83/5.00). Specific strategies that were reported to be most used by parents (i.e., behavior charts, reinforcement schedules, distraction and relaxation techniques, story cards to build play skills, visual schedules, and social stories) will be discussed.

Discussion: These preliminary findings are the first to provide evidence suggesting that parent training in young children with PWS may be a beneficial intervention option for targeting both behavioral and socioemotional domains of functioning. Further, telehealth, as a modality, may be an efficacious way to deliver this intervention option. Lastly, this research found that the type of strategy used by parents of children with PWS are similar to those used in ASD, however, the situations of when to use these strategies and how they are implemented may vary by disorder category.

References/Citations: