Symposium Title: Remote Delivery of Behavioral Intervention for ASD: Challenges, Successes, and Considerations Moving Forward

Chair: Carly Hyde

Discussant: Connie Kasari

Overview: While behavioral intervention is currently the gold-standard for autism treatment, various factors, including geographical dispersal and travel expense, lack of trained professionals and long waitlists, and a parent’s availability during business hours, make high-quality interventions challenging to access. Telehealth models are a promising way to disseminate empirically validated behavioral interventions to communities. This symposium surveys three preliminary efficacy trials for methods of remote delivery in children with neurodevelopmental disorders. The first presentation will examine parent engagement and feasibility of two alternative versions of a web-based reciprocal imitation training (RIT). The second presentation will address parent engagement and monitoring in a video-conference based parent-mediated training for children at high risk for autism due to Tuberous sclerosis complex. The final presentation will discuss the efficacy of a remote play-based intervention for children with Prader-Willis Syndrome. Collectively, these presentations will address the challenges and successes of remote behavioral interventions, as well as considerations moving forward in the era of telehealth.

Paper 1 of 3

Paper Title: Parent Engagement in a Self-Directed Vs. Therapist-Assisted Telehealth Program for Families of Young Children with Autism Spectrum Disorder (ASD)

Authors: Allison Wainer, Ph.D., Zachary Arnold, B.A., Caroline Leonczyk, Ph.D., Sarely Licona, B.A., Edith Ocampo, B.A., Latha Soorya, Ph.D.

Background: There is strong empirical and theoretical support for parent involvement in interventions for autism spectrum disorder (ASD) and related neurodevelopmental disorders, with corresponding growth in the development and evaluation of manualized parent-mediated early interventions (PMI). Despite purported benefits of PMI, such programs are highly under-utilized in community settings, due in large part to a lack of trained professionals, lengthy waitlists, child care, transportation, and reimbursement issues. These barriers compel examination of alternative service delivery methods, such as telehealth, to increase access to care. Benefits of telehealth include greater provider and patient coverage and opportunities for standardized yet individualized learning. Indeed, telehealth is well-suited to deliver interventions with different levels of support depending on the specific needs of an individual and family. While self-directed programs have strong potential for dissemination and a large public health impact, the extent to which therapist-consultation “coaching” influences program engagement and outcomes remains largely unknown. Our group developed a telehealth program, Mirror Me, to teach families of young children with ASD an evidence-based naturalistic developmental behavioral intervention called reciprocal imitation training (RIT). Mirror Me uses video modules to introduce the intervention strategies and was designed to be used in either a self-directed or therapist-assisted format. A goal of this pilot randomized control trial was to determine differences in parent engagement between the self-directed and therapist-assisted formats of Mirror Me.

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Methods: This 10-week pilot RCT compares two different formats of Mirror Me: self-directed to therapist-assisted. Participants include 21 families of young children, ages 16 to 49 months, with a diagnosis of autism spectrum disorder and deficits in social imitation skills. All families used the self-directed website for five weeks and then were randomized to continue on their own or receive remote therapist-assistance in the form of “coaching” once per week over the subsequent five weeks. Participants attended in person study assessment visits at baseline (pre-intervention), 10-weeks (post-intervention), and 15-weeks (follow up). Parent engagement with the website, intervention and study assessments was tracked across the active treatment and follow up phases.

Results: One hundred and thirty young children and families were screened over the phone for interest and eligibility in the current study. Twenty-eight enrolled in the study, with 21 (75%) meeting eligibility criteria. Of those 21, four families withdrew during the initial five weeks of the trial, while another three withdrew during the second five weeks of the trial. None of the nine families who withdrew had been randomized to the coaching condition. On average, parents rated Mirror Me as highly acceptable, relatively easy to use, and easy to “see” and “explain to others” the benefits of the program. However, the seven families who withdrew reported “feeling uncertain,” having difficulties finding the time to use the website, and challenges determining how to prioritize Mirror Me with respect other concurrent services and interventions. Follow up interviews indicated that for those families who withdrew, initial enthusiasm was dampened by experiencing a lack of support and feeling overwhelmed upon receiving an ASD diagnosis.

Discussion: Results from this pilot study suggest that integration of support, in the form of remote therapist-assistance, may be beneficial for increasing sustained parental engagement with telehealth interventions. Identifying optimal timing and format of remote therapist assistance will be an important next step, along with understanding characteristics that might indicate which families are most likely to require that support. These lines of research will help build a foundation for the development of more adaptive and personalized approaches to telehealth.
indicating they see strong changes in their child). Parents were grouped as high- and low- perception of change based on the average score of 3.6.

Independent t-tests were used to determine differences in perception of change grouping based on demographic factors (parent education, distance from test site), parent-reported variables from the TAND checklist (overall distress, perception of autism symptoms), and individual characteristics (epilepsy status at the start of intervention, hours spent in outside intervention, developmental assessment scores).

**Results:** Overall compliance the intervention protocol was high. 82% of parents responded to at least 75% of text messages, and 92% completed the full 12 weeks of intervention. Fourteen parents reported a high Perception of Change; these participants tended to be farther from the testing site (p = 0.031), have fewer outside interventions (p = 0.017), and score lower on developmental assessment (p = 0.001).

**Discussion:** Overall, this system of parent monitoring was tolerable for parents, and produced informative data on parent engagement and perception of change. This data will inform future adaptations to the intervention design such as streamlining online and phone-based metrics to enhance compliance to study protocol. When considering parent reporting (a key component of remote intervention), it is critical to consider the impact of parent perception of change, as well as potentially influential factors. Those with more at stake (higher time and financial investment due to travel distance, access to fewer local services, and more severely impacted children) may perceive greater change in their children over the course of intervention.

**References:**


**Paper 3 of 3**

**Paper Title:** Show Me What Happens Next! Efficacy of a Pilot Study of Remote Play-based Intervention for Children with Prader-Willi Syndrome

**Authors:** Ellen Doernberg⁴, BA, Anastasia Dimitropoulos⁵, PhD, Olena Zyga³, PhD, Sandra Russ⁴ PhD

**Introduction:** Prader Will-Syndrome (PWS) is a rare congenital genetic neurodevelopmental disorder characterized by impactful social-cognitive and socio-emotional deficits, related to overall cognitive and behavioral rigidity and impaired adaptive functioning (Dykens & Kasari, 1997; Holland et al., 2003). Additionally, research from the Dimitropoulos Lab has demonstrated that children with PWS, ages 6-9, showed deficits in pretend play ability similar to an age-matched ASD sample (Zyga et al., 2015). However, the addition of a play partner led to significant increases across play-based domains (imagination, organization, and affect in play) for children with PWS (Zyga et al., 2015). In typically developing children, pretend play is related to many positive outcomes, including social awareness, emotion regulation, and idea generation/cognitive flexibility (Bergen, 2002; Lillard, 1993; Hoffman and Russ, 2012; Moore and Russ, 2006; Wallace & Russ, 2015). Therefore, targeting skill building through play in children with PWS may increase socio-emotional understanding and cognitive flexibility, while decreasing rigidity and repetitive behaviors. Developing behavioral interventions for individuals with PWS is faced with the significant challenge of enrolling enough participants for local studies, but telehealth methodology allows for the reduction of barriers such as distance.

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and cost of in-person trials (Wainer & Ingersoll, 2015). Previous reports by our group (Dimitropoulos, Zyga, & Russ, 2017; Zyga, Russ, and Dimitropoulos, 2018) were the first to show the feasibility of a remote play-based intervention for children in the PWS population. This presentation is a follow-up to the previous report on the Play-based Remote Enrichment To ENhance Development (PRETEND) program for school-aged children with PWS (Dimitropoulos, Zyga, & Russ, 2017), reporting on the efficacy of the intervention in regards to its impact on children’s pretend play ability and cognitive flexibility.

Method: The current pilot study evaluated a 6-week play-based remote intervention administered directly to children with PWS, ages 6-12 years, twice a week, for 15-20-minute sessions. Thus far, 18 children with PWS have completed the program, with ongoing recruitment. All participants completed in-person baseline and post-intervention visits, where measures were used to assess children’s pretend play skills (the Affect and Play Scale (APS); Russ 1993, 2014) and cognitive fluency/flexibility (the Multidimensional Stimulus Fluency Measure (MSFM); Moran, 1983). During the intervention period, participating children worked individually and directly with their interventionist via videoconferencing software to complete the PRETEND program. The intervention program was adapted from a play-based program aimed at increasing imagination and emotional expression in typically developing children (Moore & Russ, 2008). Interventionists followed manualized procedures to ensure fidelity in targeting specific skills throughout the program.

Results: At baseline, the PWS group fell within the deficient range (1 SD below) as compared to a norm reference group on all 5 original APS variables (Imagination, Comfort, Organization, Affect Frequency, and Affect Categories). Additionally, the PWS group fell significantly below a norm reference group for their performance on the MSFM at baseline. From pre to post intervention, the PWS group made significant changes in their play skills such that core elements of their play were in the normative range post intervention. From pre to post intervention, the PWS group also significantly improved in their flexibility and fluency in thought.

Discussion: Results from the current report are the first to support preliminary efficacy of this intervention in school-age children with PWS. Findings confirm that: 1) children with PWS have deficits in pretend play and cognitive flexibility, evidenced by rigid thought patterns (i.e. getting stuck on a topic) and repetitive behavior (i.e. replaying the same storylines), and 2) the remote play-based intervention significantly improved children’s pretend play, and positively impacted their flexibility and fluency in thought. A limitation from the present study was the lack of control group for comparison, though current data collection includes a waitlist control group. Results from this pilot study indicate an important new avenue of feasible and accessible behavioral intervention for school-age children with PWS.

References:


