Synopsis / Abstract

Cortical visual impairment (CVI) is the leading cause of bilateral visual impairment in children in United States and is very common in children with cerebral palsy. Children with CVI have difficulty using their eyes to process the world around them which negatively impacts all aspects of learning and development. CVI is a neurological disorder caused by an insult to the posterior visual pathway making it difficult to process and interpret visual information. The most recent published incidence rate for childhood CVI indicates a rise from 36 per 100,000 people in the 1980s to 161 per 100,000 people in 2003, an increase of over 400%. However, a definite understanding of incidence, prevalence, etiology, prognosis, and associated neurological and ophthalmological problems associated with CVI are lacking. Early identification and treatment of CVI is imperative. In 2010, Lantzy and Lantzy completed a retrospective study indicating that 95% of the children with CVI who received intervention exhibited clinically significant changes in their visual abilities following the intervention. Rehabilitation programs for individuals with CVI should focus on maximizing the use of a child's functional vision. Strategies such as simplifying the environment, using single color objects, and incorporating movement to engage visual attention are some of the strategies incorporated to help a child with CVI use their vision more efficiently.

Up to 60 children with CVI, aged 12 months to 6 years, 11 months and their caregivers will be recruited to participate in this study. The proposed project has two aims. The first aim is to compare the efficacy of a novel, in-home telehealth-based intervention approach for children with CVI and their caregivers to standard of care. Participants will be randomized into two group: intervention group and control group. All participants will be evaluated at three time points; an initial evaluation, post intervention evaluation (4 months after the initial evaluation +/- 2 weeks), and follow-up evaluation (12 months following the initial evaluation +/- 2 weeks). The primary outcome is the CVI Range which assesses a child's functional vision. The secondary outcome is the Canadian Occupational Performance Measure (COPM) which measures progress on individualized goals set by the caregiver. All participants in the intervention group will receive 9 in-home, telehealth-based intervention sessions over a 3 month period. Our hypothesis is that children who participate in the in-home, telehealth-based intervention sessions will exhibit a higher change in their functional vision and individualized goals as compared to standard of care. The second aim is to assess the feasibility and acceptability of the in-home telehealth-based intervention approach for children with CVI and their caregivers through the use of interviews and questionnaires. Our hypothesis is that an in-home, telehealth-based intervention will be feasible and produce a high level of caregiver satisfaction.

The results of this study will inform practice on many levels. The results could improve the outcome of children with CVI and their caregivers, increase caregiver confidence in implementing the intervention and provide initial pilot data on the efficacy of a novel, telehealth-based intervention. In the ten rules for healthcare redesign, the Institute of Medicine states that patients should receive care in many forms, not just face-to-face visits. This project addresses this issue directly. Additionally, data from this pilot study will be used to inform a larger scale, multi-site, randomized control trial in the future.

Please share this information with the families of your children in that age group and let me know by September 22nd who is interested in participating. We are hoping to have the first clinic to do the

assessment in October. Location will be determined once we see who we have participating. Thanks! And let me know if you or your families have questions.

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