**Title**: Understanding Medical Event Heterogeneity During Intervention: Infants with Tuberous Sclerosis Complex (TSC) Enrolled in a Caregiver-Mediated Telehealth Program

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**Introduction**: Tuberous Sclerosis Complex (TSC) is a rare genetic disease in which the formation of benign tumors in areas like the brain, spinal cord, and other areas of the body (NIH). The heterogeneity of the seizures experienced by those with TSC can have the potential to significantly impair the child’s learning capabilities if left unchecked, but their subsequent manifestations remain obscure (Zamora & Narothama, 2022). The incidence of medical events during an active intervention is poorly understood and underreported (Camfield & Camfield, 2015).

**Aim:** The present study used a mixed-methods coding system to investigate medical event type, frequency, and consequence in a group of infants enrolled in a 12-week caregiver-mediated telehealth intervention program.

**Method**: Parent-child dyads participated in an evidence-based caregiver-mediated program via telehealth that aims to improve child communication and play skills (JASPER; Kasari, et al., 2012). Eligible infants had a TSC diagnosis, were 1-3 years old, and had no planned surgery during the intervention period. Dyads were randomly assigned to either only receive intervention materials or receive the materials and active coaching (n=21) through twice-weekly online sessions for twelve weeks. One of the weekly sessions was an information-based discussion with just coach and parent and the other coaching session entailed a thirty minute zoom session in which the infant joined their caregiver to practice intervention strategies. Session notes from both types of sessions (n=387) were coded in order to characterize medical event information. Coding was developed from the methods used by Capal et al. in their 2017 study and included categories noting seizure type, number of seizures, hospitalizations, unrelated illness, behavior improvement or other behavior change, medication changes, service hour changes, and travel occurring in a given intervention period.

**Results**: Nearly half (n=10) of the active intervention group experienced at least one seizure during active intervention, most being partial or focal seizures (n=21). The seizure frequency across participants ranged from zero to four times, the latter of which occurred in two different participants. There was a total of 14 hospitalizations during the intervention. One participant needed to travel multiple times (n=2) for medically related reasons, whereas others traveled on scheduled occasions in order to receive treatment. Within the active intervention group, patterns observed both before and after seizures such as heightened overstimulation, agitation, and gravitation towards certain toys were also observed.

**Discussion:** Overall, there was a high rate of participants in the active intervention group who had at least one seizure during their active intervention period. Additionally, caregivers had to manage hospital visits and medical-related travel while participating in the intervention program. This range of participant experience should be further examined to connect seizure patterns and environmental stressors to behavioral changes.

**References:**

Camfield, P., & Camfield, C. (2015). <https://doi.org/10.1684/epd.2015.0736>

Capal, J. K., Bernardino-Cuesta, B. et al, (2017).<https://doi.org/10.1016/j.yebeh.2017.02.007>

*Tuberous Sclerosis Complex | National Institute of Neurological Disorders and Stroke*. <https://www.ninds.nih.gov/health-information/disorders/tuberous-sclerosis-complex>

Zamora, E. A., & Aeddula, N. R. (2024).<http://www.ncbi.nlm.nih.gov/books/NBK538492/>

1. [↑](#footnote-ref-1)
2. [↑](#footnote-ref-2)