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Scholarly & Creative Works Conference

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Presenter: Pamela Avalos

Session & Time: Oral I

Room/Time: GUZ 104 / 10:40-11:00

Discipline: Occupational Therapy

Faculty Mentor: Laura Hess

Digital Portfolio URL: https://sites.google.com/view/pamela51o/home

Title: Pediatric Hemorrhagic Stroke: An Analysis of Outcome Measures and Lived Experiences

Abstract:

Background: Pediatric hemorrhage stroke (PHS) is defined as a â€œprolonged or permanent dysfunction of the brain activity due to interruption of normal vascular flow or due to hemorrhage within the brainâ€ (Molofsky, 2006, p.1). Survivors of a PHS often experience neurological, physical, cognitive, and psychosocial deficits that impact participation in daily occupations (Gordon et al., 2018). A comprehensive battery of clinical outcome measures is essential when assessing PHS survivor functioning across domains and contexts. However, there is limited empirical understanding focused on how traditionally employed clinical outcome measures align with the lived experiences of well-being from PHS survivors and caregivers. Therefore, our research question is: Is there alignment between commonly used PHS outcome measures and well-being lived experiences as voiced by families and survivors?

Research Design and Analyses: This qualitative research analyzed 16 PHS outcome measures from the multidisciplinary PHS Outcome Toolkit by Nesbit et al. (2024). The Domain and Process from the Occupational Therapy Practice Framework (OTPF) (American Occupational Therapy Association [AOTA], 2020) was used to design outcome measure specific codes. Analyses also included well-being codes from Bonk et al. (2025) to examine whether there was alignment with survivor and caregiver voices. Rigor and reliability of coding was completed to 100% consensus across the research team and faculty and coding was completed utilizing the constant comparison method developed by Corbin & Strauss (Corbin & Strauss, 2015) in DedooseÂ©(Dedoose, Version 9.2.22, 2022).

Preliminary Findings and Implications: Preliminary results from this current study suggest that the traditionally used PHS outcome measures focus more on specific disabling impairments and few align with well-being as expressed by survivors and caregivers. Examining the lived experiences of PHS survivors and caregivers side by side with existing PHS outcome measures highlights opportunities to unpack the strengths and limitations of assessments. The implications of this study provide an opportunity to expand upon current assessment batteries and consider more client-centered assessments that reflect the realities of life and recovery after PHS.