

Investigators:



Sucheta Joshi, MBBS for period 2021-2023*



Nicholas Beimer, MD for “no cost extension” period (2023-2024)

Grant Award Year: 2021

Amount of PERF[®] Grant: \$200,000

Investigator Institution: C.S. Mott Children’s Hospital – University of Michigan

* Dr. Joshi transferred project leadership to Dr. Beimer effective 9.1.2023 as she was assuming a new faculty position at Children’s Hospital Los Angeles effective January 2024.

Project Title: Developing a transition registry for Adolescents and Young Adults with Epilepsy

Project Description: Traditionally, after being cared for in pediatric specialty clinics, adolescents with epilepsy are transferred to adult neurology care. This happens at an age designated as the clinic’s standard policy, often 18 or 21 years. However, some adolescents are not adequately connected with an adult epilepsy specialist, while others fail to establish a consistent pattern of care in an adult system that offers less outreach and social support than the pediatric setting. Many hospitals now have transition clinics, but best practices for successful transition are still lacking. Yet, there is paucity of evidence demonstrating the success of transition programs as it relates to health care outcomes. Recognizing the need for a tool to support a transition program for youth with

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epilepsy, a transition readiness screening tool called EpiTRAQ was developed and validated at Michigan Medicine for youth and young adults with epilepsy ages 16-26 years. In the current project, we have used EpiTRAQ across 6 sites (3 Pediatric and 3 Adult Epilepsy clinics) to establish a multisite registry to prospectively study EpiTRAQ scores, transition support, and transition readiness in specific cohorts of youth with epilepsy. Since its inception, the registry has completed enrollment across all sites, and sites are engaged in data analysis to examine transition readiness in youth with epilepsy. The project has provided valuable data to consider future funding to examine interventions that would improve transition and compare cohorts of patients with such interventions vs those without.

Project Goals/Objectives: 1) Develop and refine systems to (a) administer EpiTRAQ every 6 months for youth and young adults ages 16-26 with epilepsy and (b) generate a summary for providers to inform transition activities during visits with youth and young adults with epilepsy. 2) Create a patient registry of transition age youth and young adults with epilepsy, including protocols to populate the registry with EpiTRAQ scores, transition support efforts and transition-relevant clinical outcomes. 3) Analyze the relationship of EpiTRAQ results, transition support activities, and epilepsy-related clinical outcomes.

Outcome of Research: 1. Our project team members have learned better how to collaborate and coordinate with multi-center groups for health-service research, such as finding common times and formats of meeting, spanning periodic virtual meetings and in-person discussions at national conferences. 2. As a team, we have established a secure and reliable mechanism for sharing cross-site data, which will be useful in future projects. 3. All project sites have successfully implemented a standardized transition readiness assessment tool (EpiTRAQ), the majority of which are using an electronic format that will endure beyond the end of the grant period. 4. Development of common data elements across sites for studying transition-related clinical outcomes enabled a better understanding for all co-investigators of what data are needed to successfully perform multi-center research. 5. We appreciate the power of the EMR for automated data extraction for clinical and health-services research. For example, at Michigan Medicine for adult and pediatric clinics, the local transition registry continues to automatically accumulate additional subjects based upon completion of EpiTRAQ questionnaires. Although all transition outcome relevant common data elements are not automated in this process, the Michigan Medicine registry has the potential for future health-services related projects and as of 9/30/2024 contains 1,326 unique subjects and 2,459 unique transition-related clinic counters for future study. Of note, the project period and funding of this grant allowed data extraction and analysis of only a subset of subjects (n = 292) of the overall registry at the Michigan Medicine site.

Subsequent Funding None to report.

Subsequent Publications None to report.

Subsequent Presentations

1. Zahid MJ, Shemme AJ, Bolden Q, Johnson P, Plegue M, Fletcher L, Beimer NJ, Joshi SM. Folic Acid Supplementation in Young Women in an Epilepsy Clinic, University of Michigan Neuroscience Day, Ann Arbor, MI, 2023 (awarded best fellow poster).
2. Fong S, Nurre E, Joshi SM, Child Neurology Society Webinar (2022).
3. S Joshi: "Transition of Care for Adolescents with Epilepsy-navigating the journey" (CHLA Pediatrics Grand Rounds 2024).
4. S Fong: "Collaborative care between care teams: Preparing adolescents and young adult patients in neurology for transition of care." Grand Rounds, Neurology, University of Connecticut, Storrs, CT, Sep 5, 2024.
5. AES Poster: Hornbach A, Cho E, Horn P, Fong SL. Factors influencing transition readiness in epilepsy. American Epilepsy Society. Dec 2023; Orlando, FL.