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Major Scientific Publication from the Pediatric Epilepsy Research Consortium (PERC)

New Research Published in the Top-Tier Scientific Journal “*Annals of Neurology*” - A Scoping Review of Health and Healthcare Disparities in Pediatric Epilepsy in the United States
(<https://onlinelibrary.wiley.com/doi/10.1002/ana.26862>)

Niwot, Colorado- Members of the Health Equity Special Interest Group (SIG) of the Pediatric Epilepsy Research Consortium (www.pediatricerc.com) conducted a comprehensive scoping review of 307 publications, revealing 769 unique disparity/equity findings.

Health disparities impact epilepsy care in children. Previous efforts to summarize data in this population have been limited. This study sought to understand how this information exists in the literature and identify gaps in knowledge.

This comprehensive scoping review of health disparities in pediatric epilepsy found that specific disparity populations like Sex and Race/Ethnicity were robustly explored, while Language/Immigration was under-represented, despite a high rate of disparities. Health-related outcome categories were also unequally investigated. Disparity findings were often difficult to access within publications.

According to Dr. Karen Skjei, lead author, “One of the most important findings of our scoping review is that the impact of certain disparity factors that most providers experience on a day-to-day basis, including limited English-proficiency and education barriers, have been largely overlooked in health disparities research. This may be due, in part, to the fact that they have not been designated high risk populations for health disparities by the NIH. While these patients may also experience socioeconomic and racial and ethnic barriers to care, interventions addressing those disparity factors may not affect the care that we provide to patients with education, English-proficiency and nativity barriers. Disparity populations do not exist in isolation of each other. This data must be collected more routinely when patient demographics are obtained. And researchers must be incentivized to include these factors in their study design and statistical analyses, whether through government funding and/or publication guidelines. PERC’s Health Equity SIG is currently in the process of exploring some of these disparity factors in more depth, with a focus on potential interventions.”

Epilepsy is the most frequent potentially fatal neurologic condition of childhood, affecting nearly half a million U.S. youth (<18 years of age) by 2015 estimates.

About the Pediatric Epilepsy Research Consortium

The Pediatric Epilepsy Research Consortium (PERC) is a national collaboration of more than 75 pediatric epilepsy programs and over 350 pediatric epileptologists, pediatric neurosurgeons, pediatric neuropsychologists, and other pediatric epilepsy researchers. Founded in 2010 by physicians and scientists determined to find better treatments for their patients, PERC has grown to become the leader in pediatric epilepsy research by providing a network and infrastructure to facilitate collegial, collaborative, practice-changing research. Through thirteen special interest groups, PERC works to improve the care of every child with epilepsy. We are particularly committed to fostering development of future pediatric epileptologists by providing opportunities for junior investigators to join ongoing efforts and develop research skills.

Our vision is a world in which all children with epilepsy benefit from the most recent advances in scientific knowledge and technology, regardless of geographic or economic resources. Through large multicenter registries, as well as multicenter retrospective and prospective analyses, we hope to identify preferred diagnostic evaluations and treatments for specific epilepsy syndromes, etiologies, and comorbidities.

Learn more at www.pediatricerc.com

