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# Health Disparities in Pediatric Epilepsy: Methods and Lessons Learned

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## Abstract

Epilepsy affects 1% of youth and is associated with neurocognitive and psychosocial comorbidities, increased risk of mortality, and poor health-related outcomes. Health disparities in children and youth with epilepsy (CYE) have been understudied. A Special Interest Group (SIG) within the Pediatric Epilepsy Research Consortium is conducting a scoping review to systematically assess the literature and highlight the gaps in access to clinical care and management of pediatric epilepsy. The methodology for this review is presented. In conducting a peer-reviewed assessment of the scope of health disparities in pediatric epilepsy, we learned that developing the methodology for and conducting a comprehensive scoping review with multiple contributors resulted in a time-intensive process. While there is an evidence to suggest that health disparities do exist in CYE, very few studies have focused on these disparities. Disparity results are often not included in key elements of articles, lending them to be underemphasized and underrecognized. Preliminary conclusions inform several important research considerations.

**Keywords** Health Disparities · Pediatric Epilepsy · Social Determinants of Health · Health Related Outcomes

## Introduction

### Overview of Epilepsy

Epilepsy affects 1% of the US population, including 750,000 youth aged birth to 17 (Institute of Medicine, 2012; Russ et al., 2012). It is a common chronic neurological condition characterized by recurrent, unprovoked seizures. Despite treatment, 30–40% of CYE experience medically refractory

epilepsy (i.e., continued seizures) (Chen et al., 2018; Geerts et al., 2010). CYE are 3–6 times more likely to have neurodevelopmental (e.g., autism spectrum, intellectual) and/or psychological (e.g., depression, anxiety) disorders than the general youth population and youth with non-neurological conditions (Ekinci et al., 2009; Jensen, 2011; Wagner et al., 2015); however, only 30% of CYE receive mental health care (Caplan et al., 2004; Ott et al., 2003). CYE are also at fourfold increased risk for premature death (Selassie et al.,

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2015). Combined with the burden of comorbidities and increased risk of death, a number of CYE are living in poverty (55%), reside in a rural area (32%), have public insurance (53%), and/or low health literacy (64%) (Paschal et al., 2016; Widjaja et al., 2013; Wilson et al., 2016). Though epilepsy is more prevalent than other neurological conditions in the U.S. population and is associated with other physical and mental disorders, increased morbidity and mortality, and risk of additional exposure to determinants that drive poorer health outcomes, epilepsy receives considerably less federal funding for research and support programs (Meador et al., 2011). While individual studies have demonstrated health disparities and inequities in CYE and their families, there has been no peer-reviewed assessment of the scope of these disparities.

### **Pediatric Epilepsy Research Consortium (PERC) and the Development of the Health Disparities SIG (See Table 1)**

PERC is a non-profit organization modeled roughly on the Pediatric Oncology Group, created in 2010 to mobilize and organize U.S. pediatric epilepsy centers into a collaborative, practice-changing research network to define and deliver the best possible care to CYE. Today, PERC comprises more than 70 U.S. pediatric epilepsy programs (<https://pediatricrc.com>). In June 2020, in response to multiple high-profile events in the news involving violence against Blacks, PERC formed a Health Equity SIG, with the initial goal being to craft a response to the NINDS request for information (RFI) regarding health disparities and inequities in neurology (RFI-NOT-NS-20-026; <https://www.ninds.nih.gov/RFI-NOT-NS-20-026>). The literature searches/response were categorized by known disparity populations and factors, lending a unique perspective to the NINDS response

by highlighting the current state, needs, gaps in knowledge, and potential future health equity research that is specific to pediatric epilepsy care. The goal was to provide additional knowledge to ultimately improve equity and outcomes. The response was submitted to the NINDS on July 15, 2020.

## **Summary of Response to NINDS**

### **Methods for Collecting and Organizing the Information**

Four key points were identified and addressed in the RFI: (1) known disparities and inequities in pediatric epilepsy and gaps in knowledge, (2) determinants that help explain these health disparities and/or inequities, (3) evidence-based research strategies, health services, policies, and other interventions that address these disparities/inequities, and (4) potential approaches for addressing these neurological disparities and/or inequities through ongoing or new research collaborations or interventions.

This framework was used to proceed with a literature search on the relationship between disparity factors and outcomes. Preliminary PubMed and Google Scholar searches were performed to identify disparity factors (e.g., race/ethnicity, socioeconomic status (SES)/insurance, gender, education, geography, and nativity/language). Multiple searches were then performed, and findings were categorized into four domains: prevalence, access to care, management, and outcomes.

### **Findings Included in the Response**

Few studies focused on health disparities (7 pediatric, 34 adult/mixed adult, and pediatric) (Wagner et al., 2021; Skjei et al., personal communication, 2020); most results came from studies with other aims that incidentally

**Table 1** Timeline for Pediatric Epilepsy Research Consortium (PERC) Health Equity Special Interest Group (SIG) Activities

December 2019	Formation of a PERC SIG focusing on health disparities and inequities proposed but tabled due to tepid response
June 2020	PERC Health Equity SIG forms after several high-profile acts of violence against Blacks highlighted structural racism in the U.S
July 2020	The SIG crafts and submits PERC response to the NINDS's request for information on U. S. health disparities/inequities in neurological diseases
August 2020	The SIG begins work on the Scoping review, focusing on the type of review and approach to literature search based on lessons learned from the NINDS RFI experience
September 2020	University of Texas librarian joins for guidance and assistance with the literature search
November 2020	Abstract review begins on more than 9000 articles and theses utilizing Rayyan online application
March 2021	Abstract review complete and several practice runs of rapid article scan begin
May 2021	Rapid article scan begins on more than 2500 articles and theses potentially containing health equity/disparity data (pediatric and/or adult) based on title/abstract review
September 2021	Detailed article review and data extraction begins on more than 250 articles with pediatric epilepsy data relating to health equities/disparities

PERC Pediatric Epilepsy Research Consortium, SIG Special Interest Group, NINDS National Institute for Neurological Disorders and Stroke

reported disparities in outcomes based on socio-demographic factors. Race and ethnicity are the strongest and most consistently documented areas of disparity related to epilepsy outcomes, such as access to pediatric epilepsy surgery and other forms of advanced epilepsy care and mortality (Sánchez-Fernández et al., 2017; McClelland et al., 2007; Greenlund et al., 2017; Wilson et al., 2016). Further, CYE from households with lower SES are exposed to additional harms that impact poorer health outcomes, such as mortality, lower adherence to anti-seizure medication (ASM) regimen, reduced routine healthcare utilization, and increased emergency visits (Begley et al., 2011; Loiselle et al., 2015; Puka et al., 2016). Health insurance is also a clear determinant of access to care and outcomes in pediatric epilepsy. Studies show that uninsured individuals and those with public insurance programs have significant gaps in access to specialized epilepsy services, including video electroencephalogram (vEEG) monitoring, surgery, and more frequent visits to the emergency department, even after controlling for prior use and ASMs (Grinspan et al., 2018; McClelland et al., 2007). Data regarding gender disparities within pediatric epilepsy in the U.S. are limited (e.g., McClelland et al., 2007; Sánchez Fernández et al., 2017). Even less is known about possible disparities secondary to sexual orientation or gender identity.

Sociocultural factors, such as level of education and health literacy, geographic region, and language/nativity/immigration status, are predictors of epilepsy outcomes. For example, pediatric epilepsy prevalence is higher in households with lower levels of parental educational achievement (Kroner et al., 2013), and pediatric access to care and adherence are both influenced by parental health literacy (Rahma & Khasro, 2010). Furthermore, there are data to suggest that lower levels of parental education may be associated with worse psychosocial outcomes for both CYE and their caregivers (Cui et al., 2015). Limited data on access to care among epilepsy patients based on limited English proficiency, nativity, or immigration status do suggest disparities in outcomes for adults (Myers et al., 2015; Thompson et al., 2014); however, no pediatric studies were identified. Few studies examine geographic region as an independent area of health disparity in epilepsy, and these studies are largely with adult patients (e.g., Szaflarski et al., 2020).

In summary, findings of the RFI indicated that there are very few pediatric studies that focused on socio-economic health disparities, no studies examining racial disparities in long-term outcomes, and very little information on inequities related to gender, limited English proficiency (LEP), nativity or immigration status, and geographic region for CYE.

## Rationale for a Scoping Review

The ad hoc RFI did find evidence of health disparities but was not a systematic review of the literature and did not assess equities. In addition, there is a paucity of pediatric studies that *focused* on health disparities in pediatric epilepsy. Therefore, we are performing a scoping review to systematically assess the literature and highlight the gaps in access to clinical care and management of pediatric epilepsy (Sucharew & Macaluso, 2019) for our most prohibited patients (e.g., those living in poverty, racial and ethnic minorities; Buchanan et al., 2020). Through the scoping review, we aim to promote equitable epilepsy care for CYE.

## Methods of Scoping Review

### Definition of Scoping Review

A scoping review is a systematic assessment of the existing literature in a particular area that informs a comprehensive description of the findings from studies included based on formal criteria (Sucharew & Macaluso, 2019). It does not formally evaluate the quality of evidence, provide a synthesized result, or answer a specific research question. The framework for a scoping review includes 1) describing the question, 2) identifying relevant studies, 3) selecting papers based on inclusion criteria, 4) charting data from the studies according to formalized abstraction procedures, and 5) collating, summarizing, and reporting the results (Sucharew & Macaluso, 2019). Steps one through four and lessons learned through the process of those four steps provide the scope for the present paper.

### Definitions of Disparities and Social Determinants of Health (Step 1)

The first step of the scoping review for the present project entailed adopting definitions for health disparities and social determinants of health (SDH). Historically, the term “disparities” has been used in the context of racial differences; however, there are many global dimensions of disparities in medicine and healthcare that are directly or indirectly related to the historical and current inequities in the distribution of educational, socio-political, economic as well as environmental resources (i.e., SDH).

For the purposes of the scoping review, we adopted a comprehensive description of health disparities provided by *Healthy People 2020*, which defines a health disparity as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage.” Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health

based on their racial or ethnic group; religion; SES; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or “other characteristics historically linked to discrimination or exclusion” (U.S. Department of Health and Human Services, 2021). Further, an Institute of Medicine (IOM) report on the epilepsies (2012) found that despite all the recent advances in healthcare, disparities exist and often in the context of broader inequalities. Disparities are often perpetrated by sources within the medical system (providers, ancillary non-medical staff), sometimes a result of their biases and prejudices.

SDH are considered environmental conditions, such as where people are born, live, learn, work, play, worship, and age, that affect a wide range of health, functioning, and quality-of-life outcomes and risks (U. S. Department of Health and Human Services, 2008). A framework of SDH takes into account the interactions of environmental, psychosocial factors in addition to the historic structural and systemic factors that have been linked to racial disparity (Braveman et al., 2011). In other words, there may be downstream and upstream (e.g., SES is an upstream and transportation a downstream factor for access to specialty care) determinants of health. Generally, SDH are grouped into five domains: Economic stability, education, health system and health care access, neighborhood and built/physical environment, and social and community contexts.

### **Selection of Factors and Outcomes (Step 1 Continued)**

These definitions for health disparities and SDH provided the framework for developing a common and uniform set of criteria for reviewing and organizing the literature (i.e., selection of factors and outcomes) in the scoping review. The five domains were used to identify “*SDH factors*” that may be associated with disparity or inequity in CYE. For example, socioeconomic and insurance status are considered measures of economic stability. Caregiver education and health literacy levels fall within the domain of education. Gender, race/ethnicity, language, and immigration status are examples of SDH involving social and community contexts. Geographic location (e.g., rural vs. urban) is surrogates for neighborhood/physical environment. For the purposes of the scoping review, we categorized “*SDH factors*” as race/ethnicity, sex/sexual orientation/gender identity, regional/geographic residence, caregiver education, SES, insurance type, English fluency, and nativity status.

There are also a number of factors related to pediatric epilepsy care that may contribute to disparities and inequity in health-related and clinical outcomes. We coined these as “*outcome factors*”: (1) Prevalence/incidence of pediatric epilepsy; (2) Access to care (i.e., whether a patient has

been seen by a specialist, the opportunity to have advanced diagnostic testing (e.g., vEEG)); (3) Utilization of care (i.e., ability keep appointments or attend visits, frequency of visits to the emergency department); (4) Epilepsy evaluation and diagnosis (i.e., time to diagnosis, receiving a vEEG test, treatment with ASM, referral to an epilepsy center, epilepsy surgery); (5) Epilepsy treatment and management (i.e., ASMs, diet, other methodologies); Economic factors (i.e., health care costs); and (6) Clinical outcomes—ability to adhere to epilepsy treatment regimen, epilepsy severity (i.e., seizure frequency, seizure severity, types of seizures, seizure remission), epilepsy surgical outcomes, adverse events or complications, psychiatric comorbidity (i.e., depression, anxiety) and quality of life, and mortality outcomes, including sudden unexpected death in epilepsy patients or SUDEP.

### **Search Brainstorming, Strategy, and Process (Step 2)**

The help of a health sciences librarian with experience in scoping and systematic review work was enlisted. Following the guidelines outlined by the PRISMA standards for scoping reviews (<http://www.prisma-statement.org/Extensions/ScopingReviews>), she began the selection of search terms by identifying MeSH vocabulary (Medical Subject Headings in PubMed), keywords from the PubMed records of a list of relevant articles provided by the research team, and terms from the “Health Disparities and Minority Health Search Strategy” developed by the National Library of Medicine (2019). All proposed search terms for each of the concepts—epilepsy, health disparities, and unmet social needs—were shared, discussed, and debated among the team members, resulting in a draft set of search terms. Search strategies were generated and then validated against a set of relevant articles, to arrive at a final PubMed search strategy. The search strategy was translated and adapted for use with each library database, registry, and website. The United States search hedge was developed by the University of Alabama at Birmingham Library (<https://guides.library.uab.edu/pub-med/hedges>).

The following electronic library databases were searched: PubMed (NLM), Web of Science (Clarivate), CINAHL (EBSCO), Cochrane (Wiley), PsycINFO (EBSCO), and Dissertations & Theses Global (ProQuest). The ClinicalTrials.gov study registry was mined to identify relevant ongoing or completed studies and their posted results and publications, if any. In addition, conference abstracts were sought via the websites of epilepsy and neurology societies including the American Epilepsy Society (AES), the Child Neurology Society, and the American Academy of Neurology. To round out the discovery of scholarly and gray literature, several focused searches were conducted in Google Scholar with a cutoff of the first 200 of each result set. In all searches, no limits were set on publication type or publication year;

however, searches were limited to studies published in English and conducted, at least in part, within the US.

The health sciences librarian stored and deduplicated results using EndNote, a reference management tool (<https://endnote.com/>). Deduplicated result sets were then imported in Rayyan, an open source title/abstract screening tool (<https://www.rayyan.ai/>), which was used for the initial screening of abstracts. All search strategies are documented in full in the Open Science Framework registry (<https://osf.io/7b8ed/>); the PubMed search strategy is documented in Table 2.

### Review of Literature (Steps 3 & 4)

A virtual meeting was held to identify criteria for reviewing abstracts and articles (e.g., review of definitions of disparities and SDH, selected SDH and outcome factors, and other criteria e.g., article written in English, research conducted in the US). Reviewer pairs then examined abstracts in Rayyan, and if reviewer responses were discordant on include vs. exclude, a third reviewer voted. If an abstract was selected, the full article was then pulled. Abstracts were reviewed from November 2020 through March 2021.

For the second round of evaluation, rapid article review, seven practice trials were completed (i.e., all reviewers evaluated the same ten articles). Interrater agreement was evaluated, and additional training and discussion was provided. For example, clarity was again provided on expected comorbidities of epilepsy, SDH vs. outcome factors, inclusion of determinants of health beyond social ones (e.g., developmental disability, whether transportation is a proxy for SES), significant vs. non-significant results, clinical meaningfulness. Full text articles were scanned to determine if they had original data from the US. Search terms were identified (Table 3), and the following statement: “Among epilepsy patients, differences in \_\_\_\_\_ (factor) are associated (or not associated) with differences in \_\_\_\_\_ (outcome)” was provided to guide reviewers in their evaluation of whether the article contained data on health disparities and/or inequities in CYE. Provision of these parameters for reviewers supported consistency and standardization in their searches as well as consideration for the variability in how health inequities are reported in the literature.

Articles were coded by *SDH factors*: gender, race/ethnicity, SES, insurance, language/immigration, education, geography, other and *outcomes*: prevalence/incidence, access, utilization, epilepsy severity, epilepsy evaluation/diagnosis, epilepsy treatment/management, quality of life/psychological comorbidities, epilepsy surgery, adverse events/complications, adherence to epilepsy treatment, economic, mortality/SUDEP, other. Articles were also coded as “pediatric only” and “mixed pediatric and adult” or “adult only” samples. Articles were divided into seven

“batches” and reviewed from April 2021 through August 2021. Reviewer pairs were assigned articles to review within 2–3 weeks. Reviewers independently reviewed articles and then discussed and resolved discrepancies. If a discrepancy could not be resolved, a third reviewer voted. With each of the seven batches of articles assigned, the reviewer pairs were varied. Data were entered into an excel spreadsheet.

The next step is mapping the pediatric and mixed pediatric and adult articles, which is currently in process. In mapping, reviewer pairs independently review full articles and evaluate them. Data are reported on study design, population, SDH factors, outcome factors, statistical data, and whether the results of the study indicate equity or disparity, description of findings, whether the paper’s focus was on disparity, and in which sections of the paper (e.g., title, abstract, results, etc.), the disparity/equity was mentioned. Reviewer pairs then meet and resolve any discrepancies in their evaluation of the articles. With each of the “batches” of ten articles assigned (currently on batch six), the reviewer pairs are varied. Data are entered into an excel spreadsheet.

## Lessons Learned

### Preliminary Findings

In our experience with the Response to NINDS and the scoping review to date, we have found very few articles that directly address health disparities in pediatric epilepsy. More frequently, papers include SDH such as race/ethnicity, insurance, SES, and gender as socio-demographic information for the study sample, but do not conduct analyses and report findings for these variables. Further, studies frequently categorize race/ethnicity as homogeneous (e.g., “White vs. Non-White” or “Other”). In many cases, direct links are reported between the disparity and health-related outcomes instead of acknowledging the system-level influences. For example, “CYE with low socio-economic status are less likely to receive epilepsy surgical evaluations.” We are also discovering that many articles contain data that support the existence of health disparities in pediatric epilepsy; however, these data are not reported in the abstract, text of the results, or the discussion. In these situations, these data are likely to be overlooked and underemphasized.

As the SIG has reviewed papers, additional questions have arisen. For example, we are interested in exploring whether older studies reflect more disparities compared to more recent studies and if newer studies highlight disparities in the paper by mentioning in the abstract more routinely than older studies (i.e., Have the times truly changed?). Specific to epilepsy, we recognize that gender disparities may be somewhat unclear as a gender difference may be inherent

**Table 2** PubMed search parameters

	Concept	Search strategy
A	Epilepsy	epileps* [Title/Abstract] OR "seizure disorder*" [Title/Abstract] OR epilepsy [MeSH Terms] OR "infantile spasm*" [Title/Abstract] OR epileptic syndrome* [Title/Abstract] OR Landau-Kleffner syndrome [Title/Abstract] OR Landau Kleffner syndrome [Title/Abstract] OR "acquired epileptic aphasia*" [Title/Abstract] OR "acquired epileptiform aphasia*" [Title/Abstract] OR "Acquired Aphasia with Convulsive Disorder" [Title/Abstract] OR "Acquired Childhood Aphasia with Convulsive Disorder" [Title/Abstract] OR Lennox Gastaut syndrome [Title/Abstract] OR Panayiotopoulos Syndrome [Title/Abstract] OR "partial seizure*" [Title/Abstract] OR "subclinical seizure*" [Title/Abstract] OR "uncinate seizure*" [Title/Abstract] OR "jacksonian seizure*" [Title/Abstract] OR "versive seizure*" [Title/Abstract] OR "clonic seizure*" [Title/Abstract] OR "tonic seizure*" [Title/Abstract] OR "sensory seizure*" [Title/Abstract] OR "neonatal convulsion*" [Title/Abstract] OR "infantile seizure*" [Title/Abstract] OR "infantile convulsion*" [Title/Abstract] OR "Myoclonic Encephalopath*" [Title/Abstract] OR "Dravet syndrome*" [Title/Abstract] OR "Doose syndrome" [Title/Abstract] OR "akinetik petit mal" [Title/Abstract] OR pyknoleps* [Title/Abstract] OR "lightning attack*" [Title/Abstract] OR "west syndrome" [Title/Abstract] OR Hypsarrhythmia* [Title/Abstract] OR "jackknife seizure*" [Title/Abstract] OR "salaam attack*" [Title/Abstract] OR "salaam seizure*" [Title/Abstract]
B	Health disparities OR unmet social needs	"Substance-Related Disorders" [Mesh] OR "mental health" [Mesh] OR anxiety [Title/Abstract] OR depression [Title/Abstract] OR "housing stability" [Title/Abstract] OR "housing instability" [Title/Abstract] OR transportation [Title/Abstract] OR "child abuse" [Title/Abstract] OR "unmet social needs" [Title/Abstract] OR "basic needs" [Title/Abstract] OR "resource needs" [Title/Abstract] OR "basic life needs" [Title/Abstract] OR "social needs" [Title/Abstract] OR "economic insecurity" [Title/Abstract] OR "economic security" [Title/Abstract] OR "economic need*" [Title/Abstract] OR "financial insecurity" [Title/Abstract] OR "financial security" [Title/Abstract] OR "financial need*" [Title/Abstract] OR "financial strain" [Title/Abstract] OR employment [Title/Abstract] OR unemployment [Title/Abstract] OR employed [Title/Abstract] OR unemployed [Title/Abstract] OR "family support" [Title/Abstract] OR "community support" [Title/Abstract] OR "education status" [Title/Abstract] OR "educational status" [Title/Abstract] OR "educational attainment" [Title/Abstract] OR "substance abuse" [Title/Abstract] OR "drug abuse" [Title/Abstract] OR alcoholism [Title/Abstract] OR "mental health" [Title/Abstract] OR "mental illness" [Title/Abstract] OR "psychiatric disorder*" [Title/Abstract] OR (disabilit* [Title/Abstract] NOT "developmental disabilit*") [Title/Abstract] OR "cognitive impairment" [Title/Abstract] OR "cognitively impaired" [Title/Abstract] OR "Health Status Disparities" [MeSH Terms] OR "Healthcare Disparities" [MeSH Terms] OR "Culturally Competent Care" [MeSH Terms] OR "Health Services Accessibility" [MeSH Terms] OR "Health Services for Persons with Disabilities" [MeSH Terms] OR "Health Services for Transgender Persons" [MeSH Terms] OR "health services, indigenous" [MeSH Terms] OR "United States Indian Health Service" [MeSH Terms] OR "Socioeconomic Factors" [MeSH Terms] OR "Social Determinants of Health" [MeSH Terms] OR "Population Groups" [MeSH Terms] OR "Race Relations" [MeSH Terms] OR "Disabled Persons" [MeSH Terms] OR "Emigrants and Immigrants" [MeSH Terms] OR "Medically Underserved Area" [MeSH Terms] OR "Medically Uninsured" [MeSH Terms] OR "Cultural Diversity" [MeSH Terms] OR "Minority Groups" [MeSH Terms] OR "Social Marginalization" [MeSH Terms] OR "Minority Health" [MeSH Terms] OR "Race Factors" [MeSH Terms] OR "Refugees" [MeSH Terms] OR "Rural Health" [MeSH Terms] OR "Rural Health Services" [MeSH Terms] OR "Rural Population" [MeSH Terms] OR "Social Discrimination" [MeSH Terms] OR "Social Segregation" [MeSH Terms] OR "Drug Users" [MeSH Terms] OR "Sexual and Gender Minorities" [MeSH Terms] OR "Vulnerable Populations" [MeSH Terms] OR "Working Poor" [MeSH Terms] OR "Urban Health" [MeSH Terms] OR "Urban Health Services" [MeSH Terms] OR "Urban Population" [MeSH Terms] OR "Gender Identity" [MeSH Terms] OR "Homosexuality" [MeSH Terms] OR "Medical Indigency" [Mesh] OR "Insurance Selection Bias" [Mesh] OR "Health Literacy" [Mesh] OR "Limited English Proficiency" [Mesh] OR disparit* [Title/Abstract] OR cultur* [Title/Abstract] OR inequalit* [Title/Abstract] OR inequit* [Title/Abstract] OR disadvantaged [Title/Abstract] OR "health services accessibility" [Title/Abstract] OR "social determinants of health" [Title/Abstract] OR socioeconomic* [Title/Abstract] OR socio-economic* [Title/Abstract] OR "african american*" [Title/Abstract] OR "alaska native*" [Title/Abstract] OR "american native*" [Title/Abstract] OR nativity [Title/Abstract] OR "black American*" [Title/Abstract] OR Caucasian* [Title/Abstract] OR white* [Title/Abstract] OR "asian American*" [Title/Abstract] OR disabled [Title/Abstract] OR "population diversity" [Title/Abstract] OR ethnic* [Title/Abstract] OR Hispanic* [Title/Abstract] OR immigrant* [Title/Abstract] OR undocumented [Title/Abstract] OR "american indian*" [Title/Abstract] OR latina [Title/Abstract] OR latino [Title/Abstract] OR latinas [Title/Abstract] OR latinxs [Title/Abstract] OR latinx [Title/Abstract] OR "latin American*" [Title/Abstract] OR "Mexican American*" [Title/Abstract] OR Mexican* [Title/Abstract] OR minorit* [Title/Abstract] OR "native American*" [Title/Abstract] OR "people of color" [Title/Abstract] OR multiracial [Title/Abstract] OR mixed-race [Title/Abstract] OR "mixed race" [Title/Abstract] OR poverty [Title/Abstract] OR "poor people" [Title/Abstract] OR "poor person*" [Title/Abstract] OR discrimination [Title/Abstract] OR "racial prejudice" [Title/Abstract] OR segregation [Title/Abstract] OR racism [Title/Abstract] OR microaggression [Title/Abstract] OR stigma [Title/Abstract] OR refugee* [Title/Abstract] OR "rural health" [Title/Abstract] OR "rural population*" [Title/Abstract] OR sexism [Title/Abstract] OR marginalization [Title/Abstract] OR marginalized [Title/Abstract] OR migrant* [Title/Abstract] OR underserved [Title/Abstract] OR underinsured [Title/Abstract] OR uninsured [Title/Abstract] OR insurance [Title/Abstract] OR medicaid [Title/Abstract] OR CHIP [Title/Abstract] OR "Children's health insurance program" [Title/Abstract] OR Medi-Cal [Title/Abstract] OR "urban health" [Title/Abstract] OR "urban population*" [Title/Abstract] OR "vulnerable population*" [Title/Abstract] OR "working poor" [Title/Abstract] OR poverty [Title/Abstract] OR bisexual* [Title/Abstract] OR bigender [Title/Abstract] OR homosexual* [Title/Abstract] OR gay [Title/Abstract] OR gender [Title/Abstract] OR queer [Title/Abstract] OR lesbian [Title/Abstract] OR transgender [Title/Abstract] OR intersex [Title/Abstract] OR asexual* [Title/Abstract] OR non-binary [Title/Abstract] OR "non binary" [Title/Abstract] OR pansexual [Title/Abstract] OR "sexual orientation" [Title/Abstract] OR "Medical Indigency" [Title/Abstract] OR interpret* [Title/Abstract] OR literacy [Title/Abstract] OR "Limited English Proficiency" [Title/Abstract] OR "English as a second language" [Title/Abstract] OR "language concord*" [Title/Abstract] OR "language discord*" [Title/Abstract] OR "language proficien*" [Title/Abstract] OR "language barrier*" [Title/Abstract]

**Table 2** (continued)

Concept	Search strategy
C United States	United States [mh] OR "united states" OR usa OR u.s.a. OR Appalachia* OR "great lakes" OR mid-atlantic-state* OR mid-atlantic-region* OR middle-atlantic-state* OR middle-atlantic-region* OR midwestern-us* OR midwestern-u.s* OR Midwestern-state* OR Midwest-state* OR Midwest-us* OR Midwest-u.s* OR "great plains" OR heartland OR "new england" OR northeastern-us* OR northeastern-u.s* OR northeastern-state* OR northeast-state* OR northeast-us* OR northeast-u.s* OR "pacific northwest" OR northwestern-us* OR northwestern-u.s* OR northwest-u.s* OR northwest-us* OR northwestern-state* OR northwest-state* OR pacific-state* OR southeast-state* OR southeastern-state* OR southeast-region OR southeastern-region OR southeast-us* OR southeastern-us* OR southeast-u.s* OR southeastern-u.s* OR southern-state* OR southern-us* OR southern-u.s* OR southwest-state* OR southwestern-state* OR southwest-us* OR southwestern-us* OR southwest-u.s* OR southwestern-u.s* OR "deep south" OR "black belt" OR "rust belt" OR "district of Columbia" OR "Washington dc" OR Washington-d.c. OR Alabama OR (Birmingham [ad] AND al [ad]) OR Huntsville [ad] OR (Montgomery [ad] AND al [ad]) OR Alaska OR anchorage [ad] OR fairbanks [ad] OR Arizona OR Phoenix [ad] OR Tucson [ad] OR Flagstaff [ad] OR Arkansas OR "little rock" OR California OR "los angeles" OR "san diego" OR "san francisco" OR Berkeley [ad] OR Stanford [ad] OR Colorado OR Vail [ad] OR Denver [ad] OR Connecticut OR Farmington [ad] OR "new haven" [ad] OR Hartford [ad] OR Delaware OR Wilmington [ad] OR Newark [ad] OR Florida OR Miami [ad] OR Gainesville OR Jacksonville OR Tampa OR Tallahassee OR Georgia OR Atlanta OR (Athens [ad] AND ga [ad]) OR (Augusta [ad] AND ga [ad]) OR Hawaii OR Hawai'i OR Honolulu OR Idaho OR Boise [ad] OR Illinois OR Chicago OR Urbana [ad] OR Evanston [ad] OR Indiana OR Indianapolis OR "West Lafayette" OR Iowa OR Kansas OR Wichita OR Kentucky OR Lexington [ad] OR Louisville [ad] OR Bardstown [ad] OR Louisiana OR "new Orleans" OR "baton rouge" OR Shreveport OR Maine OR Orono OR (Scarborough [ad] AND me [ad]) OR Maryland OR Bethesda [ad] OR Baltimore [ad] OR Rockville [ad] OR "johns Hopkins" OR Massachusetts OR Boston OR Harvard OR (worchester [ad] AND ma [ad]) OR Burlington [ad] OR Michigan OR Detroit OR "ann arbor" OR "east lansing" OR Minnesota OR Minneapolis OR Rochester OR "st paul" [ad] OR "saint paul" [ad] OR Mississippi OR (Jackson [ad] AND ms [ad]) OR Missouri OR (Columbia [ad] AND mo [ad]) OR Montana OR Bozeman [ad] OR Missoula OR Nebraska OR Omaha [ad] OR Lincoln [ad] OR Nevada OR "Las Vegas" OR "New Hampshire" OR "New Jersey" OR "New Mexico" OR "New York" OR "North Carolina" OR "North Dakota" OR Ohio OR Columbus [ad] OR Cleveland [ad] OR Cincinnati OR Oklahoma OR Oregon OR Portland [ad] OR Pennsylvania OR Philadelphia OR Hershey [ad] OR "Rhode Island" OR providence [ad] OR "South Carolina" OR "South Dakota" OR Tennessee OR Nashville OR Memphis OR Texas OR Houston OR Utah OR Vermont OR Virginia OR Richmond [ad] OR Washington [tiab] OR Washington [ad] OR Seattle OR "West Virginia" OR Wisconsin OR Wyoming
Final Search	A AND B AND C
Limits	English language

**Table 3** Article search terms

Disparit	Rac	Gender	Econom	Insur	Geogra	Education	Immig
Inequit	Ethnic	Sex	Poverty	Medicaid	Rural	Langu	Emply
Bias	Color	Male	Poor		Distance	Literac	
Demogra			Income				

to a certain epilepsy syndrome (e.g., Jeavons syndrome is more common in girls).

**Challenges**

We have found a few aspects of this process challenging. For example, it was difficult to decide on a set of search terms for the disparity concept; we sought a set of terms that encompassed mental health disorders, substance abuse disorders, racial/ethnic/minority identities, gender/sexual identities, financial insecurity, unemployment, and many additional marginalized statuses in pediatric epilepsy. This made for much discussion and decision making as we tried to be inclusive with disparity search terms. We also learned that the entire process is more time intensive than expected. Some of the SIG members had an optimistic initial goal to publish the review within two months of submitting the NINDS response, and to date, it has taken 15 months. Other factors that impacted the time were working around the group members’ schedules and personal styles. These

types of efforts are often dependent on the flexibility and willingness of our expert volunteers to meet in the evenings and/or on weekends to complete work that is time intensive and above and beyond typical workload. In addition, intentionally “casting the net” wider to ensure that potentially relevant studies were not excluded from the review resulted in an increase in false positives and additional work. There is always a balance between specificity and sensitivity that must be negotiated when search strategies are determined. Erring on the side of sensitivity increased the total number of results from the database searches.

**Quality Evaluation and Reflection**

Comprehensive search activities and screening process are expected for a high-quality scoping review, and the SIG intentionally developed processes to improve the quality of this review. Indeed, consensus on methodologies (e.g., what you are doing and how you want to do it) took additional time to deliberate and agree upon but resulted



in a streamlined, standardized, and clear process. We also executed multiple review trials to improve inter-rater concordance and reduce bias. For example, we elected to add some additional practice trials when the group was initially learning to scan and code articles. Through this practice, as members of the team became more familiar with the scoping review methodology, reviews required less time and inter-rater agreement improved.

## Future Research Considerations

### Methodology and Reporting

Our preliminary conclusions and lessons learned inform several important methodological considerations in the exploration and reporting of health disparities in pediatric epilepsy moving forward: (1) research question and study procedures, (2) recruitment of more diverse samples, and (3) reporting of research (Buchanan et al., 2020). The initial research questions and subsequent study design should consider heterogeneity of the pediatric epilepsy population. In addition, research aims are encouraged that explore how the intersectionality of youth identities (gender, race, sexuality, disability status, SES, etc.) impacts health-related outcomes in youth with epilepsy. Using methods such as community-based participatory research (CBPR) can enhance the engagement of marginalized populations, including Black, Indigenous, and Other People of Color (BIPOC) populations (Forsythe et al., 2019). Creating a community advisory board and soliciting their input in study design and implementation recognize a partnership between researchers and the epilepsy community. Throughout the research process, this collaborative partnership can involve community feedback on study measures and tools, recruitment and consent strategies, and behavioral health intervention components and delivery methods (Forsythe et al., 2019). Addressing cultural barriers, recruiting more diverse and underrepresented samples of youth with epilepsy (e.g., LGBTQIA+, Hispanic, youth with developmental comorbidities) (Musto et al., 2019), and tailoring resources to these specific populations (e.g., Hmong families, rural families, youth with cognitive impairments and/or autism) (Wagner et al., 2013) are necessary. Finally, considerations for collection and reporting of data with pediatric epilepsy populations include disclosing the ethnicity for all participants and the heterogeneity within BIPOC populations. To fully examine the full range of heterogeneity in race and ethnicity and potential racial and/or ethnic disparities, multi-site projects may be necessary (e.g., KIDS inpatient database, the Pediatric Epilepsy Learning Healthcare System, Pediatric Hospital Information System, <https://www.hcup-us.ahrq.gov/kidoverview.jsp>). Inclusion of disparities in the

key words, titles, and abstract of articles will highlight and increase the exposure to and dissemination of these findings.

### Key Content Areas

There is an increasing recognition of language, nativity status, and immigration status as important and independent, though commingled, determinants that may contribute to, and/or confound healthcare disparities attributed to race/ethnicity, education, and SES. For example, if a Black child has intractable focal epilepsy, there are several barriers to surgery, such as access to care, cultural distrust of medicine, and implicit bias of epilepsy health care providers—which of these are the most important to the family vs. most robustly related to surgery outcomes? However, there remains a dearth of literature on this subject as it relates to pediatric epilepsy. Additional work is necessary to develop survey tools that assess seizure semiology and frequency by asking culturally relevant questions. For example, one survey administered in Spanish in the U.S. demonstrated that “the vast majority of Hispanics use the term *convulsiones* [convulsions] or *ataque* [attack] to describe a seizure” (Sirven et al., 2005).

Dedicated studies focusing on geographic disparities in pediatric epilepsy access to care and outcomes are needed. With the rise of telemedicine in the United States as a direct result of the Covid-19 pandemic, there now exists a unique opportunity to address geographic barriers to care with virtual platforms (e.g., REACT; <https://www.childrensmercy.org/childrens-mercy-research-institute/studies-and-trials/epilepsy-in-adolescents-and-children-telemedicine/>). Assessment of the impact of SES on pediatric epilepsy care must extend beyond evaluations of income, material deprivation, and insurance and into the complex interplay between SES and other social factors, including access to education, living conditions, and patient-oriented community support (i.e., upstream SDH).

Funding for research to examine some known biological determinants of epilepsy outcomes is warranted. For example, a recent paper discussing the neuroendocrine basis of sex differences in epilepsy demonstrated the need for future research to focus on the role of hormones in the pathophysiology and treatment of epilepsy and its comorbidities in both children and adults (Reddy, 2017).

## Conclusions

While there is an evidence to suggest that health disparities do exist in CYE, very few studies have focused on these disparities. In addition, disparity results are often underemphasized and thus underrecognized. Developing the

methodology for and conducting a comprehensive scoping review with multiple contributors from different professional backgrounds and time zones resulted in a time-intensive process. Preliminary conclusions inform several important research considerations moving forward, including study design, recruitment, and reporting of findings.

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## Declarations

**Conflicts of Interest** Janelle Wagner, Sonal Bhatia, B. Oyinkan Marquis, Imelda Vetter, Christopher W. Beatty, Rebecca Garcia, Charuta Joshi, Gogi Kumar, Kavya Rao, Nilika Singhal, Karen Skjei have no relevant financial or non-financial interests to disclose.

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