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The SocioBioCognitive Epilepsy Framework: Integrating Social and Biological Risk to Improve Cognitive and Neurobehavioral Outcomes Across the Lifespan

Abstract

Cognitive and psychiatric comorbidities are among the most persistent and disabling challenges experienced by people with epilepsy (PWE), often persisting despite seizure control. Up to 80% of PWE experience cognitive impairments, and one in three meet criteria for a psychiatric diagnosis. These issues affect both adults and children with epilepsy, with significant implications for daily functioning, health care utilization, academic/educational progress, quality of life, and general life performance.

Traditionally, research has focused on epilepsy-specific biological risk factors (e.g., seizure frequency, age ~~of~~ at seizure onset, epilepsy syndrome), but growing evidence demonstrates that social determinants of health (SDOH) significantly shape neurodevelopmental and cognitive trajectories. This critical review explores how individual- and neighborhood-level SDOH—including income, education, healthcare access, housing stability, and systemic inequities—contribute to disparities in cognitive, behavioral, and emotional outcomes across the lifespan in epilepsy. Drawing on empirical data from pediatric and adult cohorts, we show that SDOH independently predict cognitive and behavioral challenges, even after accounting for epilepsy factors including severity. We propose the SocioBioCognitive Epilepsy (SBC-E) Framework, which integrates biological and social determinants to better explain the heterogeneity of neurobehavioral outcomes in epilepsy, emphasizing critical developmental windows and the cumulative impact of adversity. We also provide recommendations for addressing the social causes of epilepsy to improve cognitive outcomes, including epilepsy self-management programs, the integration of community health workers, and policy-level strategies aimed at addressing social needs in clinical settings. Our work highlights the need for a paradigm shift in epilepsy care—from a seizure-centric model to one that embraces holistic, equity-focused approaches across medical, educational, and community domains. Future research should investigate the reversibility of SDOH-related deficits, explore biological

mechanisms linking adversity to brain outcomes, and evaluate the real-world impact of integrated interventions. Addressing SDOH is essential to improving long-term outcomes for individuals with epilepsy and reducing disparities in care and well-being.

Introduction

Cognitive and psychiatric comorbidities are very prevalent in people with epilepsy (PWE). Up to 80% of people with epilepsy (PWE) experience some degree of cognitive impairment,¹⁻⁵ with those who have pharmacoresistant seizures exhibiting the most significant cognitive deficits. Additionally, 1 in 3 PWE meet criteria for a DSM-diagnosed mental health disorder, with depression and anxiety being two of the most common.⁶⁻⁸ These comorbidities are also frequently observed in children with epilepsy (CWE), who often present with developmental delays, cognitive impairments, academic difficulties, and behavioral challenges.⁹⁻¹² Importantly, these comorbidities extend beyond the challenges posed by seizures and their treatment, further impairing daily functioning, quality of life, and overall well-being.¹³⁻¹⁶ Notably, survey data demonstrate that cognitive and behavioral issues are reported by patients to be some of the most concerning aspects of their condition, second only to unexpected seizures and driving restrictions.¹⁷ Given the profound impact of these issues, the fields of neurology, neuropsychology, and psychiatry have long sought to understand the factors contributing to cognitive impairment and psychiatric complications in epilepsy, with a body of research spanning over a century.

The classic paradigm that has driven much of this research emerged from the primary interest in the effects of epilepsy on cognition and behavior.¹⁸ Since the middle of the last century a primary focus has been on so-called “disease-related” factors or variables reflective of the cause, treatment, and syndromes of the epilepsies (Figure 1A). For instance, those relationships linked to an increased risk of cognitive impairment include earlier age at seizure onset, increasing duration of epilepsy, poorer seizure control, symptomatic epilepsies, number of lifetime generalized tonic-clonic seizures and episodes of status epilepticus, number and type of medications, and the type, frequency and severity of EEG

abnormalities.^{4, 18} These relationships have been further interrogated with a number of neuroimaging techniques resulting in a clearer understanding of the altered neurobiology of the comorbidities.¹⁹⁻²¹ Work of this type is, and has been, consistent with the longstanding view that epilepsy serves as a “window to the brain”, a perspective that remains undeniably valid. However, epilepsy is not solely a neurological condition, it also encompasses social, genetic, somatic, and other dimensions that to date have been relatively under-investigated in relation to the neurobehavioral comorbidities of epilepsy (Figure 1B). In fact, the 2005 Task Force of the International League Against Epilepsy (ILAE), now defines epilepsy as *“a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures, and by the neurobiologic, **cognitive, psychological, and social consequences of this condition.**”*²² Here, we focus squarely on the social dimensions of epilepsy and particularly those factors linked to disadvantage and disparities in health outcomes.

The impact of social disadvantage, particularly social determinants of health (SDOH), on healthcare access and health outcomes has been extensively studied. The World Health Organization (WHO) defines SDOH as the conditions in which people are born, grow, work, live, and age, as well as the broader social, economic, and political forces shaping these conditions. These nonmedical factors include structural determinants—such as governance, economic systems, and social policies—that influence the distribution of resources across society.^{23, 24} Structural determinants, in turn, shape downstream factors like education, employment, income, neighborhood environments, healthcare access, and social networks. These interconnected factors play a critical role in shaping health outcomes and driving disparities.

While successful seizure control is achievable through pharmacological and surgical treatments, many individuals with epilepsy continue to experience significant cognitive and behavioral comorbidities. Despite stable seizure control, these persistent challenges suggest that other factors—beyond biological disease mechanisms—play a critical role in long-term outcomes. A growing body of evidence implicates SDOH as important contributors to the heterogeneity observed in cognitive and behavioral outcomes

amongst those with epilepsy (studies described below). Recognizing the influence of these non-medical factors, a holistic approach to patient care—one that integrates SDOH into clinical management—can help optimize outcomes, particularly for those already facing social disadvantage. In this review, we describe the social outcomes of PWE, provide an overview of available SDOH models and their relevance to health outcomes, and highlight recent studies demonstrating the impact of both individual- and neighborhood-level disadvantage on clinical, cognitive, and behavioral outcomes in pediatric and adult epilepsy. Additionally, we propose an updated framework for studying cognitive and psychiatric comorbidities in epilepsy, integrating social determinants and their interactions with epilepsy-related factors and treatment. Lastly, we offer recommendations for addressing cognitive and neurobehavioral outcomes at the patient, institutional, research, and policy levels, with a focus on integrating the social factors associated with epilepsy.

Social Outcomes in PWE and their Impact on Epilepsy Care

Individuals with epilepsy often face significant social challenges that can adversely affect their QOL. Studies have documented lower educational attainment,²⁵ occupational achievement,²⁶ and income²⁷ among individuals with epilepsy—factors that, in the general population, are known to negatively impact health status and contribute to accelerated brain and cognitive aging. In fact, over 40% of adults with either active or inactive epilepsy in 2010 and 2013 reported an annual household income of less than \$25,000,²⁷—approximately 47% below the U.S. national median household income of \$52,700 in 2013. Additionally, PWE are less likely to perceive their neighborhoods as safe, which may reflect broader limitations in available community resources.²⁵ Beyond socioeconomic challenges, epilepsy is also associated with stigma and discrimination, including workplace discrimination, due in part to public perceptions of seizures.^{28, 29} Many individuals with epilepsy report a lack of a strong social support system and are less likely to be married, more likely to live alone, and have higher divorce rates compared to the general population,^{30, 31} which can significantly hinder effective disease management.

The economic challenges faced by PWE and their families have a downstream impact on healthcare access and are closely linked to poorer epilepsy-related outcomes.³²⁻³⁸ Lower socioeconomic status (SES) in PWE is associated with a range of negative outcomes, including higher rates of emergency room visits,³⁹ polypharmacy and adverse antiseizure medication (ASM) effects,⁴⁰ longer time to surgical intervention, lower likelihood of seizure control post-surgery,⁴¹ and a higher incidence of Sudden Unexpected Death in Epilepsy (SUDEP).⁴² Lower educational attainment is associated with higher rates of seizure-related hospitalizations,⁴³ while higher education is linked to greater access to specialist care and better medication adherence;⁴⁴ similarly, lower occupational attainment is correlated with increased emergency department visits and higher seizure frequency.⁴⁴ PWE are more likely to be on public health insurance, under-insured, or uninsured,^{40, 45} which can significantly compromise both access to and quality of care. Inadequate insurance coverage is a significant barrier to optimal epilepsy care, as it is associated with delayed referrals for surgical evaluation, postponed diagnostic procedures, prolonged duration of unmanaged epilepsy, reduced access to advanced diagnostic tools and newer antiseizure medications (ASMs), limited specialist care, and inconsistent ASM use—all of which are critical to achieving seizure control.^{32, 36} In the U.S., access to comprehensive epilepsy care is further exacerbated by the limited availability of Level IV epilepsy centers in rural areas, and counties with greater neighborhood disadvantage are significantly less likely to have these centers.⁴⁶ Globally, the largest treatment gaps for epilepsy are observed in low- and lower-middle-income countries, where they can range from 95% to 100% in the lowest-income countries.⁴⁷

Lastly, certain populations in the U.S. face persistent challenges that are closely tied to the socioeconomic barriers previously described. Ethnoracially diverse groups—including Black/African American,³⁵ Hispanic/Latinx,³⁵ and American Indian/Alaska Native individuals⁴⁸—experience a higher prevalence and incidence of epilepsy, yet face significant disparities in care, including lower rates of epilepsy surgery (even after accounting for socioeconomic status SES), higher emergency room utilization, longer delays in diagnosis, and decreased likelihood of seeing an outpatient neurologist.^{35, 36,}

⁴⁹ Individuals with limited English proficiency in the U.S. face language-related challenges due limited availability of translation services, inadequate use of interpreters, and language-discordant care.^{36, 37} In epilepsy, language barriers are associated with lower rates of ASM use, reduced likelihood of undergoing epilepsy surgery, and decreased treatment of comorbid conditions.^{35, 36}

Frameworks of the Social Aspects of Health

Given the complexity and interrelated nature of SDOH and their impact on health outcomes, numerous frameworks have been developed to guide research, interventions, and policy efforts. One widely recognized model is the Healthy People 2030 SDOH framework, which organizes key determinants into five domains: Education Access and Quality, Economic Stability, Social and Community Context, Neighborhood and Built Environment, and Health Care Access and Quality.⁵⁰ Similarly, the National Institute of Neurological Disorders and Stroke (NINDS) SDOH Framework organizes determinants into five major domains: Structural, Social Status, Intermediate, Intrapersonal, and Biological—each encompassing a range of factors that contribute to health disparities and neurological outcomes.⁵¹ There are also several disease-specific models that integrate both biological and social determinants, highlighting their cumulative impact on disease risk and associated comorbidities. A recently proposed model by Stites et al.⁵² organizes the influences of biological factors and lived experiences on Alzheimer’s disease and related dementias (ADRD) risk cross the lifespan (prenatal, early life, midlife, and late life), and it includes parental factors such as parent/caregiver well-being and childhood adversity.

In the context of epilepsy, Szaflarski³² proposed a specialized SDOH framework that incorporates epilepsy-specific factors, including access to epilepsy care, epilepsy epidemiology and outcomes, and public policy related to treatment regulation, research funding, and anti-discrimination laws. More recently, Bensken et al.³⁴ proposed a conceptual model comprising four major domains—structural, socio-cultural, health care, and physiological—each centering on epilepsy risk and outcomes. While existing frameworks provide valuable insight into the social determinants associated with epilepsy

risk, care access, and outcomes, there is a growing opportunity to build on this work by integrating cognitive and neurobiological health. Importantly, epilepsy is one of the few chronic conditions that can occur at any age, with increased prevalence in childhood and older age, highlighting the need for a lifespan approach to capture the cumulative impact of biological and social risk factors. A comprehensive conceptual model that combines these dimensions would enhance our understanding of the dynamic interplay between epilepsy, cognitive development and trajectories, and social determinants, providing an opportunity to better address some of the most challenging comorbidities for PWE. Below, we review empirical studies that examine both individual- and community-level determinants of health and conclude with a proposed framework for investigating cognitive and neurobehavioral outcomes within the broader biological and social context of epilepsy, highlighting the unique lifespan dimension of epilepsy that distinguishes it from other neurological disorders.

Cognitive and Behavioral Comorbidities in Pediatric Epilepsy and the Role of SDOH

Children with epilepsy frequently experience academic struggles, cognitive deficits, emotional dysregulation, and disruptive behaviors.⁹⁻¹¹ These challenges persist despite reductions in seizure frequency, highlighting the complexity of pediatric epilepsy management.⁵³ These findings are not limited to the U.S. and have been noted globally.^{54, 55} The long-term effects of SDOH ~~and on~~ epilepsy outcomes are not well understood at this time; ~~however, l-~~Long-term effects can be gleaned from assessing adults with a history of childhood epilepsy and suggest that social factors can indeed play a role.⁵⁶ To investigate the cognitive and neurobehavioral trajectories of children with epilepsy and the factors associated with these trajectories, our group has ~~leveraged~~investigated a longitudinal data from a cohort of 332 children aged 6-16 years with new-onset seizures ~~were analyzed to~~ comprehensively characterize SDOH and associated ~~these~~ comorbidities associated with epilepsy.⁵⁷ Comprehensive neuropsychological evaluations—including standardized measures of language, executive functioning, memory, and processing speed—were administered at baseline, 18 months, and 36 months after epilepsy diagnosis. Behavioral outcomes were assessed through parent-reported Child Behavior Checklist (CBCL) scores and self-reported

measures of depression ([Children's Depression Inventory: CDI](#)) and anxiety ([Multiple Affect Adjective Check List: MAACL](#)).

Compared to typically developing controls, CWE demonstrated significantly lower cognitive scores across all domains over the 3-year period, with persistent impairments in language, executive functioning, verbal memory, and processing speed.^{58, 59} Behavioral difficulties, including internalizing and externalizing problems, were also significantly elevated in CWE and remained stable over time. These findings underscore the high prevalence and chronicity of cognitive and behavioral comorbidities in pediatric epilepsy, even in the context of controlled seizures.⁵⁷ We then extended traditional biomedical investigations by incorporating SDOH into the analysis of epilepsy outcomes with a focus on how baseline social, economic, and environmental conditions may shape these health outcomes long-term (Table 1).^{57, 60-62} We employed a Sociodemographic Disadvantage Index (SDI), which was developed from four key variables: household income, parental education level, parental employment status, and neighborhood disadvantage. Higher SDI scores indicated greater socioeconomic adversity. SDOH-related disparities were evident in both cognitive and behavioral outcomes. Children from socioeconomically disadvantaged backgrounds exhibited lower cognitive scores at all time points and showed greater declines over the 3-year follow-up. These cognitive deficits persisted even after controlling for seizure frequency and epilepsy severity, suggesting that SDOH exerts an independent influence on neurodevelopmental trajectories. Behavioral outcomes followed a similar pattern. Children from disadvantaged backgrounds exhibited higher CBCL scores (indicating more severe behavioral problems) and higher self-reported depression and anxiety scores across all assessment points. Importantly, SDOH-related disparities in behavior were evident at baseline—[assessments took place](#) within 6 weeks of epilepsy diagnosis—highlighting the early and pervasive influence of social context on behavioral and cognitive health in CWE. In a separate cohort, Struck et al.,⁶³ examined the role of parental factors (education, employment, and marital status) on cognitive outcomes in young adults with juvenile

myoclonic epilepsy and found that lower parental education was associated with poorer performance on measures of general mental ability and speed/executive function (Table 1).

Potential Mechanisms Linking SDOH and Neurobehavioral Outcomes

The mechanisms through which SDOH influences cognitive and behavioral outcomes in pediatric epilepsy are complex and multifactorial. Chronic stress appears to play a significant role as a central mediating pathway. Children living in disadvantaged environments are exposed to cumulative stressors, including economic instability, food insecurity, neighborhood violence, housing instability, and reduced access to high-quality healthcare and education. These stressors could potentially activate the hypothalamic-pituitary-adrenal (HPA) axis and the autonomic nervous system, resulting in dysregulated stress responses. Neuroimaging, neurovascular, and neuroendocrine studies demonstrate that chronic stress alters brain structure and function, particularly in regions involved in emotional regulation (e.g., amygdala) and executive function (e.g., prefrontal cortex).⁶⁴⁻⁶⁷ Long-term stress exposure is associated with increased amygdala reactivity and dysfunctional connectivity between the amygdala and prefrontal networks. These neural alterations may contribute to the heightened emotional lability, anxiety, and externalizing behaviors observed in socially disadvantaged CWE. Moreover, chronic stress impacts sleep regulation, immune function, and metabolic health, creating a cascade of physiological disruptions that further compromise cognitive and emotional resilience. Understanding these pathways is critical for developing targeted, multidisciplinary interventions that promote resilience and improve long-term neurodevelopmental outcomes in vulnerable pediatric epilepsy populations.

Cognitive and Mood Comorbidities in Adult Epilepsy and the Role of SDOH

Adults with epilepsy often experience widespread cognitive deficits and mental health challenges, with those who had childhood-onset epilepsy exhibiting the greatest levels of cognitive impairment and psychiatric comorbidities.^{2, 68} Furthermore, older adults with epilepsy are at a significantly increased risk for dementia, with studies indicating up to a threefold higher risk for AD/AR among older adults with epilepsy.⁶⁹ Although adults with epilepsy often experience poorer social

outcomes—such as lower socioeconomic status, educational attainment, and occupational achievement—which are known to impact access to care and epilepsy-related outcomes, only recently has the literature begun to explore how these social factors influence cognitive outcomes in epilepsy. Higher educational and occupational attainment are widely recognized as contributors to cognitive reserve—a protective mechanism that mitigates the impact of brain pathology on cognition by enhancing the brain’s ability to compensate for deficits.⁷⁰ The impact of educational attainment has been the most investigated determinant in epilepsy, with studies demonstrating that lower levels of education in adults and older adults with epilepsy is associated with worse cognitive outcomes (Table 2).^{5, 71-74} In a cohort of older adults with late-onset epilepsy, we found that higher occupational complexity was associated with more impaired cognitive profiles at baseline and greater cognitive decline over a five-year follow-up period.⁷² Hohmann et al. showed that in a young-to-middle aged cohort with pharmacoresistant focal epilepsy, unemployment was associated with worse performance on verbal learning.⁷⁴ Postoperative studies have also shown that poorer employment status is associated with worse cognitive outcomes after epilepsy surgery (Table 2).⁷⁵ Income level has been less extensively studied; however, existing research has shown negative associations between lower income and cognitive performance.⁷⁴ Lastly, in the U.S., the absence of universal health insurance contributes to a two-tier healthcare system, where individuals with public insurance or no insurance often receive lower-quality epilepsy care and experience poorer outcomes. Our work has shown that older adults with epilepsy on public health insurance (e.g., Medicare, Medicaid) demonstrate poorer performance on range of cognitive measures including learning, memory, processing speed, and executive function (Table 2).⁷⁶

Despite early-life environmental factors such as childhood experiences and parental background (e.g., parental education and occupation) being associated with adverse health outcomes⁷⁷ and with late-life cognition and risk of dementia,^{78, 79} the role of these factors in epilepsy outcomes has been examined only in pediatric populations. For the first time, our group provided evidence that early-life environmental factors, including parental education, occupational attainment, and childhood employment, are associated

with late-life cognitive outcomes in individuals with epilepsy (Table 2).⁷⁶ Beyond cognitive outcomes, social factors have been associated with adverse mental health, reduced quality of life, and poorer overall well-being. The presence of depression in PWE has been associated with lower household income, food insecurity, and a lower likelihood of less likely to being married.⁸⁰ Lower education,⁸¹ unemployment,⁸² and lower socioeconomic status⁸³ have been associated with poor quality of life in adults with epilepsy. Most importantly, attitudes and beliefs about epilepsy lead to PWE experiencing stigma and discrimination, which have a downstream impact on education, employment, access to care, and social capital.⁸⁴ Together, these findings underscore the critical need to consider both early-life and adult social determinants in understanding the cognitive and mental health trajectories of PWE, and highlight the importance of addressing social disadvantage as part of comprehensive epilepsy care across the lifespan.

Neighborhood Disadvantage in Epilepsy: Cognitive and Neural Correlates

The neighborhoods in which people live, work, and interact play a crucial role in shaping the quality and availability of resources accessible to them. Extensive research has shown that neighborhood environments significantly influence health outcomes, with individuals living in materially deprived areas experiencing some of the poorest health outcomes.⁸⁵ Deprivation indices provide a national ranking of neighborhood socioeconomic disadvantage based on the geographic location in which one lives. The components of these indices vary based on the specific index used, but generally include factors like education, income, employment, housing, and household characteristics^{86, 87} Over the past decade, a number of studies have shown that neighborhood deprivation is associated with brain morphology, volume, and connectivity as well as cognitive performance and decline and depressed mood in healthy controls as well as in a number of medical and neurological disorders.⁸⁸⁻⁹¹

In epilepsy, there is a growing body of literature using deprivation indices to examine the relationship between neighborhood environment and neuropsychological and quality of life comorbidities in both adults and children (Table 3). More specifically, in adults with pharmacoresistant focal epilepsy, neighborhood deprivation has been found to be strongly negatively correlated with general cognitive

ability and domain-specific cognitive performance (i.e., attention, visuomotor processing speed, language, visuospatial skills, and verbal and visual memory),^{63, 74, 92, 93} as well as with the overall pattern of cognitive performance across domains (i.e., intact, single-domain impairment, bi-domain impairment, generalized impairment).⁹⁴ Similar findings have been observed in older adults with focal epilepsy with higher Area Deprivation Index (ADI) associated with poorer cognitive performance across a number of cognitive domains.⁷⁶ Greater neighborhood deprivation has also been associated with increased mental distress,⁷⁴ depression and anxiety,⁹⁴ and perceived stigma⁹⁵ in adults with pharmaco-resistant epilepsy. A strong relationship has also been observed between ADI and general cognitive ability (i.e., FSIQ, VIQ, PIQ), specific cognitive functions (i.e., naming, phonemic fluency, passive inattention, delayed verbal recall), and academic performance in children and adolescents with recent onset epilepsy.^{93, 96} Interestingly, these same relationships were not apparent in a control group of healthy first-degree cousins.^{93, 96} A recent study also demonstrated correlations between ADI and health related quality of life in children and adolescents with epilepsy.⁹⁷ Interestingly, not only did neighborhood disadvantage independently predict quality of life, but it was the sole predictor of quality of life after familial factors were taken into account. Notably, greater neighborhood disadvantage has been associated with more pronounced structural neuroanatomical in juvenile myoclonic epilepsy⁶³ and white matter connectivity abnormalities in temporal lobe epilepsy,⁹⁸ offering insights into the potential mechanistic pathways through which social determinants further contribute to cognitive outcomes in epilepsy.

SocioBioCognitive Epilepsy (SBC-E) Framework

The evidence presented above clearly demonstrates that cognitive and neurobehavioral outcomes in epilepsy are shaped by factors beyond the disorder itself and-or its treatment. Therefore, a framework for studying these outcomes that incorporates both the biological and social determinants of epilepsy is warranted. Our proposed framework (Figure 2), the **SocioBioCognitive Epilepsy (SBC-E) Framework**, conceptualizes both epilepsy-related medical risk and social risk across key developmental stages, highlighting critical age periods in which epilepsy shows varying prevalence and incidence, as well as

increased vulnerability to developmental disorders in childhood and cognitive disorders of aging in older adulthood. The grey boxes represent social factors that influence epilepsy and cognition across the lifespan. These include neighborhood environment, ~~socioeconomic status~~ SES (both individual and family), and the broader cultural (e.g., cultural beliefs), political (e.g., policies), and social (e.g., public perceptions) contexts surrounding epilepsy. The yellow boxes represent the social factors that uniquely influence each age period. For example, as outlined by Oyegbile-Chidi and her team, parental education and income play a critical role on cognitive, academic, and behavioral outcomes in CWE, ~~w~~ W While insurance status may be more critical for older adults with epilepsy who are often managing multiple comorbidities beyond the epilepsy. Lastly, the dark green arrows represent epilepsy-related factors that influence cognition ~~and extend~~ across the lifespan. The aim of the SBC-E Framework is to guide the investigation of cognitive and neurobehavioral outcomes in epilepsy by incorporating both biological and social factors that may help explain differential risk for adverse outcomes. Furthermore, this framework can support investigations aimed at identifying the mechanistic pathways underlying poor cognitive outcomes in epilepsy, ultimately informing the development of pharmacological, surgical, behavioral, and social interventions.

Evidence Based Epilepsy Self-Management to Improve Cognitive Outcomes

Over the past decade, evidence supporting the benefits of Epilepsy Self-Management (ESM) programs has grown, with fifteen randomized controlled trials highlighting the positive impact of self-management interventions.⁹⁹⁻¹⁰² However, bringing these programs into clinical settings has proven challenging. There is a significant need for ESM programs to be supported by an infrastructure that enables real-world access and delivery. Without such infrastructure, ESM programs will remain underutilized, access will be limited, and the needs of people with epilepsy will remain unmet, further disadvantaging the most vulnerable populations.¹⁰³

Increasing healthcare system capacity to provide equitable access to quality epilepsy care that includes as a best practice standard the integration of the telehealth deliverable ESM intervention,

HOBSCOTCH (*H*OmE *B*ased *S*elf-Management and *C*Ognitive *T*raining *C*Hanges Lives), for people with epilepsy and cognitive challenges carries with it promise to reach people broadly, without geographic restriction, in their homes and diverse communities.¹⁰⁴ Recent efforts to develop a translational network of diverse epilepsy centers (Figure 3) championing the HOBSCOTCH Intervention for their patient communities has provided insight into how a coordinated and collaborative approach to intervention delivery relevant and meaningful to patients and providers can extend support equitably to people in communities with disparate levels of disadvantage across the United States.

Integration of a Nontraditional Skilled Healthcare Workforce

Cultivating a nontraditional health-care professional workforce to address SDOH in epilepsy carries with it much potential for addressing disparities in epilepsy care.^{105, 106} Community Health Workers (CHWs) are non-medical personnel who can be trained to offer a valuable set of skills that have proven effective in managing multiple health conditions, including more recently epilepsy. By expanding models of CHW integration into both clinical and community aspects of epilepsy care, pathways to address disparities become possible. A pilot program at Dartmouth Health has shown that a CHW trained in epilepsy, and integrated into a multidisciplinary epilepsy center care team, can conduct standardized SDOH screenings and address non-medical needs by connecting patients to community, state, and federal resources. CHWs can also be trained to effectively deliver evidence-based epilepsy self-management programs ~~that~~^{which} grow health literacy through their core educational modules and enhance patient self-efficacy for managing epilepsy and related comorbidities.

A Necessary Multi Sector Approach

Collaboration across multiple sectors—including healthcare professionals at various levels, public health leaders, community organizations, advocacy groups, policymakers, and individuals affected by epilepsy—is crucial for ensuring equitable access to quality epilepsy care.^{37, 107, 108} This collaborative approach is key to addressing disparities in cognitive and neurobehavioral outcomes. Equally important is advancing data-driven outcomes research in the real-world that focuses on the unique contextual

challenges faced by people with epilepsy in diverse communities and geographical settings. To effectively address healthcare disparities and improve outcomes for the most vulnerable populations, current and future SDOH data, as outlined in Figure 3, must be routinely collected as a standard part of care – and the workforce to address [these](#) needs must be trained, integrated into epilepsy care streams, and at the ready to best assist people and families facing the medical and social challenges [associated with](#) epilepsy ~~is-known-to-bring~~.

Implications for Intervention and Policy

Pediatrics. Understanding the role of SDOH in pediatric epilepsy highlights the urgent need for multidimensional care models that address both medical and social needs. Predictive models incorporating SDOH data could identify children at highest risk for poor cognitive and behavioral outcomes, enabling targeted early interventions. Comprehensive interventions that integrate medical care, family-centered psychosocial support, educational advocacy, and community resource linkage have the potential to mitigate the adverse effects of socioeconomic disadvantage. Moreover, addressing structural drivers of health disparities—such as systemic racism, under-resourced schools, and limited access to pediatric subspecialty care—will be critical for improving long-term outcomes in children with epilepsy. Policies promoting health equity, economic stability, and access to early childhood education may ultimately reduce the burden of cognitive and behavioral comorbidities in this vulnerable population.

Adults. Young-to-middle-aged adults with epilepsy would benefit from programs that expand access to higher education, support stable and meaningful employment, and provide essential resources such as reliable transportation. State-based vocational programs are especially valuable, as they can help people with [epilepsy \(PWE\)](#) find jobs that align with their cognitive and epilepsy-related needs, ensuring a better fit between individual abilities and job demands. Strengthening and enforcing workplace anti-discrimination policies is also crucial to ensure that PWE are treated fairly, have equal opportunities for advancement, and are protected from stigma or bias. In addition, expanding access to mental health services tailored for PWE is a key intervention. Integrating mental health care into epilepsy management

—through co-located services or telehealth—can help address common comorbidities such as depression and anxiety. Policies should support comprehensive insurance coverage, mental health parity, and provider training in epilepsy-informed care. Together, these initiatives can reduce social and economic barriers, promote independence, and improve long-term health and cognitive outcomes for individuals living with epilepsy.

Older Adults: To improve cognitive outcomes in older adults with epilepsy, policies should target individual-level SDOH that influence brain health in adulthood and later life. Expanding access to comprehensive, interdisciplinary care—particularly through public insurance programs like Medicare and Medicaid—is essential. Policy actions can include improving coverage for neurological and cognitive services, increasing provider participation in underserved areas, and enhancing care coordination for older adults with chronic conditions. Education-related policies should also focus on adult learning. Supporting adult literacy programs and incorporating cognitive health education into community learning initiatives can help strengthen cognitive resilience. Community-level investments play a key role in promoting healthy aging. Mobile health clinics, accessible telehealth services, and local programs that encourage physical activity, cognitive training, and social engagement can help address the impact of neighborhood disadvantage. Infrastructure improvements in underserved areas—such as better transportation, access to green spaces, and community health resources—can create environments that support cognitive well-being. Financial insecurity is another critical factor. Supplemental income programs for low-income older adults with epilepsy—such as expanded social security benefits or direct financial support—can reduce stress and improve cognitive and overall health. Together, these policy strategies can reduce disparities and promote better cognitive health outcomes by addressing the social and structural challenges faced by older adults with epilepsy.

Strengths and Limitations of SDOH Work to Date

A major signal in SDOH research to date is the consistently observed effect of disparities across a) age groups throughout the lifespan including youth, middle aged and older aged groups, b) diverse

neurobehavioral outcomes of interest including cognition (including ~~both~~ global cognition [intellectual function intelligence], specific cognitive domains, and cognitive phenotypes), academics, behavior (depression, anxiety, distress), and quality of life, c) epilepsy syndromes (focal and generalized epilepsies in youth and adults), d) the chronicities of epilepsy (new and /or recent onset, chronic, late onset), e) metrics of SDOH (personal, structural), and nations. SDOH factors either explain more variance in neurobehavioral outcomes compared to traditional seizure-related variables (age of onset, seizure control, number of medications) or remain significantly associated with diverse comorbidities after controlling for epilepsy-related variables across various study designs.

Weaknesses of available SDOH metrics and the broader literature include: a) reported high cost of living bias, geographic aggregation issues, limited consideration of contextual factors, and impact of high housing costs on the ADI as well as uncertainty regarding which of the 17 indicators included in the ADI ~~of underlying factors~~ drive the SDOH-comorbidity relationships, b) variable cut points and definitions of disadvantage across studies with need for standardization, c) largely, but not completely, cross-sectional and correlational literature with one measurement in most studies, d) competing hypotheses for the etiology of disadvantage (e.g., social drift) and broader SDOH driving forces, and d) the impact of SDOH and its consequences on brain structure and connectivity.

Taken together, the existing literature underscores the powerful and consistent role of SDOH in shaping cognitive and neurobehavioral outcomes in epilepsy, while also revealing important methodological and conceptual gaps that must be addressed to advance a more comprehensive and precise understanding of these relationships.

Future Directions

Based on the above, a roadmap for future directions for SDOH-comorbidity research and clinical practice become clear. On the research side, larger scale longitudinal controlled cohort studies with causal modeling are needed. This would best involve people with epilepsy throughout the lifespan, including a comprehensive array of personal and structural markers of disadvantage. Relatedly, we need ~~needed is~~

research ~~on the impact of into the~~ early intervention of identified modifiable SDOH factors ~~and monitoring of the impact of intervention on~~ outcomes. Also needed is movement to model the integration of SDOH factors into clinical care along with strategies for developing and implementing interdisciplinary care ~~to address these factors~~. More broadly, policy recommendations for addressing disparities in epilepsy care. Healthcare systems should routinely screen for social needs using tools like ICD-10 Z-codes or the Epic SDOH Toolkit. By identifying and addressing social risks such as housing instability, food insecurity, or transportation barriers, providers can offer more comprehensive care and connect patients with essential community resources.

In response to limited research in this area, our group established the **IMPACT** (Initiatives for Mobilizing Equitable Patient Access, Care, and Treatment) **Epilepsy** to address health disparities through community collaboration and tailored, lifespan-focused solutions. We focus on identifying the most critical social factors affecting access to epilepsy care by actively engaging multilevel stakeholders—including individuals with epilepsy, their families, providers, and organizational leaders. This insight drives the development of practical resources and innovative tools that empower individuals across the lifespan and connect patients, providers, researchers, and leaders with localized support. The mission of **IMPACT Epilepsy** is to advance equitable, accessible, and impactful outcomes in epilepsy care, education, and social well-being.

Conclusion

The ~~body of work reviewed is work~~ underscores the profound influence of SDOH on cognitive and behavioral outcomes in epilepsy. Despite advances in seizure management, those with epilepsy—particularly those from disadvantaged backgrounds—remain at elevated risk for chronic neurodevelopmental/neurocognitive challenges. Addressing these disparities will require a paradigm shift toward holistic, equity-focused care models that address both ~~the~~ biological and social determinants. The proposed **SocioBioCognitive Epilepsy Framework** aims to guide future research and interventions in this area. Further studies should explore the effectiveness of integrated interventions in adult epilepsy and

assess the reversibility of SDOH-related deficits. In addition, assessing the reversibility of SDOH-related deficits, and exploring the biological mechanisms linking social adversity to brain development in pediatric epilepsy is imperative. Such efforts can contribute to creating more stable conditions for managing chronic illness.

Acknowledgement

Funding

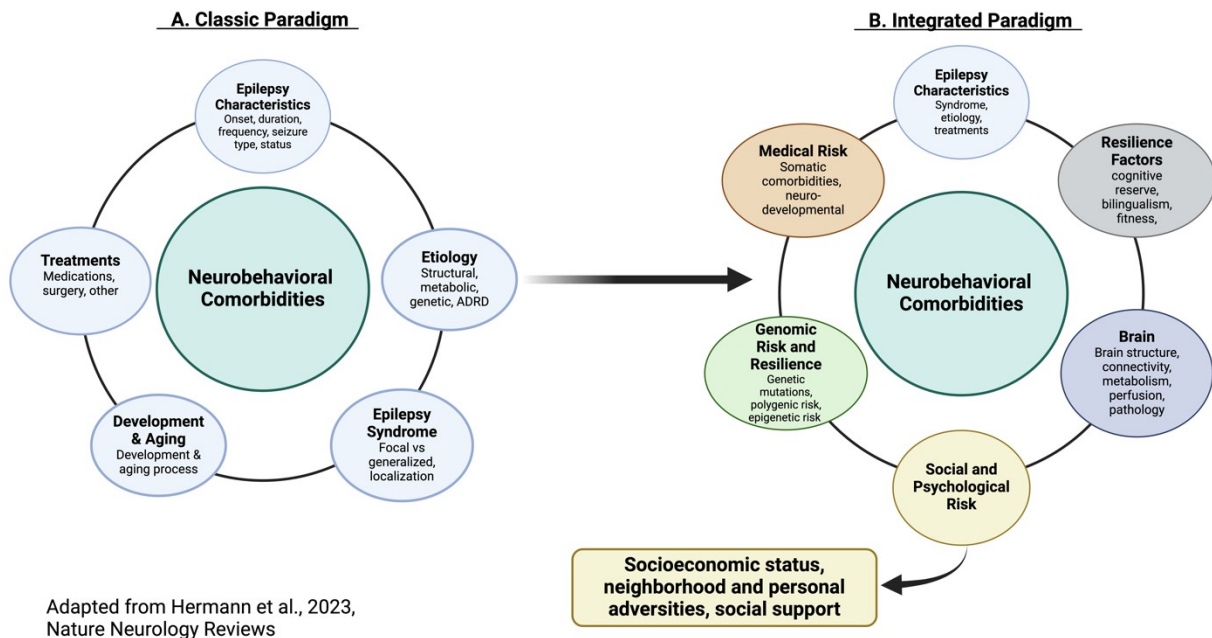


Figure 1: Shift in Conceptual Framework of the Causes of Cognitive and Neurobehavioral Comorbidities in Epilepsy.

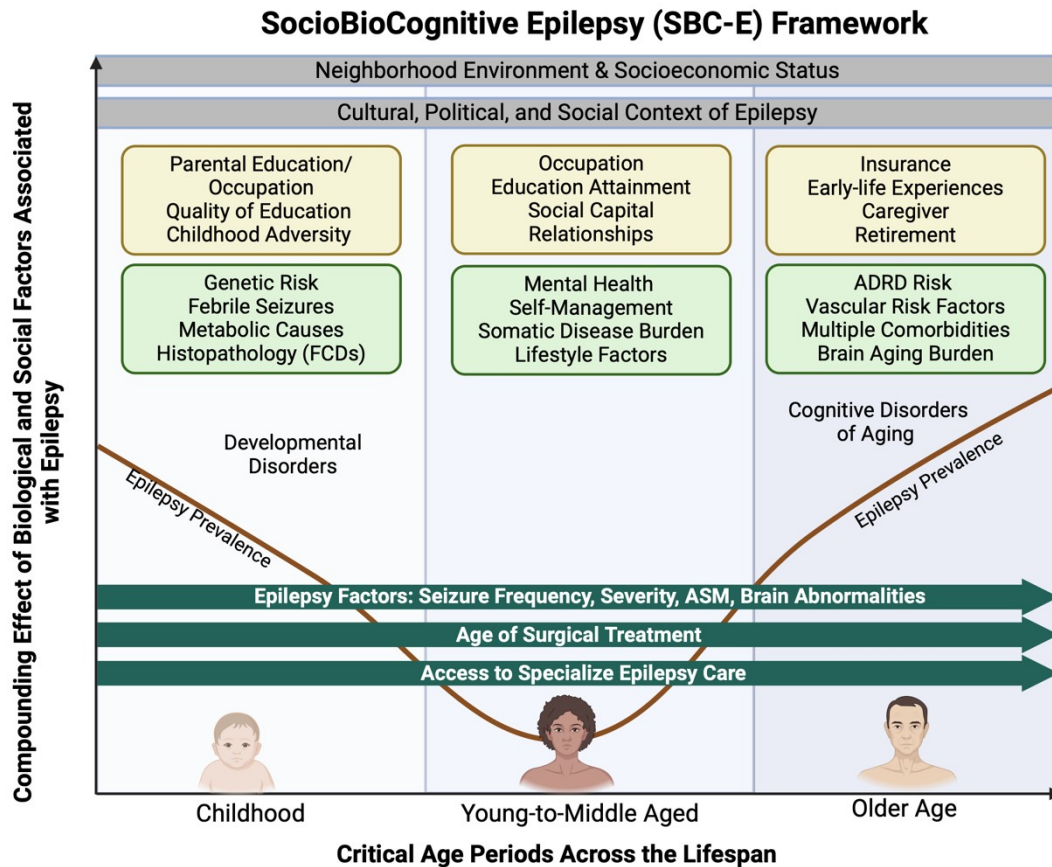


Figure 2: *Proposed SocioBioCognitive Epilepsy Framework to Investigating Cognitive and Neurobehavioral Comorbidities in Epilepsy.* Top gray boxes include social factors that span across the lifespan. Yellow boxes include social factors that are most influential to each age period. Green boxes include clinical factors most relevant to each age period. Green arrows include relevant clinical factors that span across the lifespan. FCD: focal cortical dysplasia; ADRD: Alzheimer's disease and related dementias

HOBSCOTCH Institute Translational Network

Hub & Spoke Model for Epilepsy Self-Management Delivery

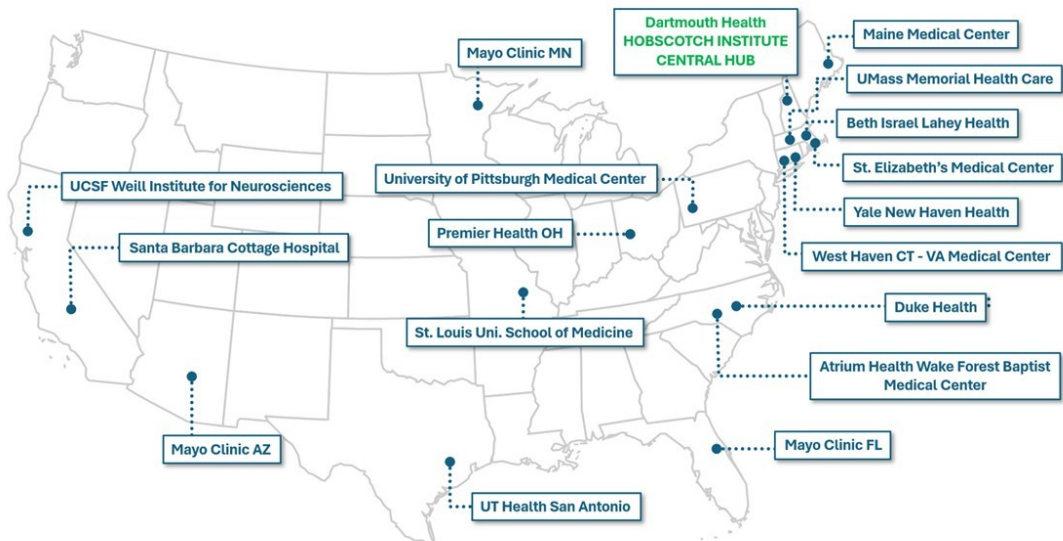


Figure 3: A network of 18 epilepsy centers across the United States participate in the HOBSCOTCH Institute Translational Network. The hub and spoke model aims to increase capacity for equitable patient and provider access to evidence-based epilepsy self-management. The hub at Dartmouth Health provides standardized patient materials, accredited provider training, standardized treatment manuals, implementation support, and telehealth referral pathways to support growth and access throughout the network.

Table 1

Table 1: Examples of Studies Examining Individual Social factors in Pediatric Epilepsy						
Author, Year, Country	Type of Study	Population	Age Range	Cognitive/ Neurobehavioral Domains	SDOH Examined	Findings
Oyegbile-Chidi, et al., 2023 ⁶⁰ , USA	Longitudinal	Newly diagnosed epilepsy and their siblings (controls)	6-16 years	Child Behavior Checklist; Teacher Report Form; Children's Depression Inventory; Multiple Affect Adjective Check List	Social disadvantage score: caregiver's education level, self-identified race, household income, parents' marital status	Children with the highest level of disadvantage showed greater anxiety, depression, hostility, neurobehavioral problems compared to those with lower disadvantage. Findings remained consistent over a 3-year period.
Oyegbile-Chidi et al., 2024 ⁶² , USA	Longitudinal	Newly diagnosed epilepsy and their siblings (controls)	6-16 years	IQ, language, processing speed, executive function, verbal memory, and academic performance	Social disadvantage score: caregiver's education level, self-identified race, household income, parents' marital status	Children with epilepsy and their siblings with the most disadvantage had the lowest scores on measures of IQ, language, processing speed, executive function, and verbal memory, and poorer academic performance. Findings remained consistent over a 3-
Struck et al., 2024, USA	Cross-sectional	Juvenile myoclonic epilepsy	16-24 years	General cognitive abilities, speed/response inhibition, and verbal learning and memory	Parental education, employment, and marital status.	Lower parental education was associated with poorer performance on measures of general mental ability, and speed/executive function.
Morales, et al., 2025 ⁵⁷ , USA	Longitudinal	Newly diagnosed epilepsy and their siblings (controls)	6-16 years	Child Behavior Checklist; Children's Depression Inventory; Teacher Report Form	Social disadvantage score: caregiver's education level, self-identified race, household income, parent's marital status	Three behavioral clusters were identified. Social disadvantage score was a significant predictor of more behavioral problems for both internalizing and externalizing behavior clusters.
Morales et al., 2025 ⁶¹ , USA	Longitudinal	Newly diagnosed epilepsy and their siblings (controls)	6-16 years	IQ, language, verbal and visual Memory, executive function, fine motor dexterity, and academic performance	Social disadvantage score: caregiver's education level, self-identified race, household income, parent's marital status	Children that who demonstrated at risk behavior and lower cognitive scores on had lower household income, lower mothers' maternal education, a higher rate of unmarried parents, fewer had parents that were married, and had overall the highest disadvantage.

Table 2

Table 2: Example of Studies Examining the Association between Individual Social Factors and Cognition in Adult and Older Adults with Epilepsy

Author, Year, Country	Type of Study	Population	Age Range	Cognitive/Neurobehavioral Domains	SDOH Examined	Findings
Oyegbile et al., 2004, USA	Cross-sectional	Temporal lobe epilepsy	25-49 years	Intelligence, language, verbal and visual memory visuospatial, executive function, motor dexterity, and processing speed	Educational level	Longer epilepsy duration was associated with poorer outcomes in patients with less than 12 years of education; this relationship was not observed in patients with 12 years or greater
Wang et al., 2020, China	Cross-sectional	Focal and generalized epilepsy	12-62 years	Mini-Mental State Examination; Montreal Cognitive Assessment; processing speed; verbal fluency; and simple attention	Educational level	Higher education levels were linked to lower cognitive impairment, with education beyond high school associated with higher cognitive scores.
Hohmann et al., 2021, Germany	Cross-sectional	Pharmaco-resistant focal epilepsy	24-50 years	Psychomotor speed, verbal learning, and mental distress	Educational level, employment, income, marital status	Unemployment was linked to poorer verbal learning but better psychomotor speed. Worse psychomotor speed was seen in patients with low income. Both low income and medium education levels were associated with higher mental distress.
Partanen et al., 2020, Finland	Longitudinal (pre/post surgery)	Surgical		Reasoning, memory, language, and executive function.	Employment status	Better working memory and executive functions were associated with improvement in employment status post epilepsy surgery.
Reyes et al., 2023, USA	Longitudinal	Late-onset epilepsy	72-83 years	Verbal memory, language, processing speed, and executive function	Educational level and occupation attainment	Lower education and occupation attainment was associated with a more impaired cognitive phenotype. Lower education attainment was associated greater cognitive decline at 5-year follow-up.
Reyes et al., 2023, USA	Cross-sectional	Focal temporal and frontal epilepsy	60-73 years	Montreal Cognitive Assessment, Alzheimer's Disease Assessment Scale-Cognitive Subscale, memory, language, executive function, and processing speed.	Health insurance, marital status, income, parental education and occupation, childhood class status and employment	Public health insurance was associated worse scores on general cognition, learning and memory, processing speed and executive function. Lower parental education and occupation complexity was associated with lower scores on global cognition learning and memory. Childhood employment was associated with lower scores on learning and executive function.

Table 3

Table 3: Example of Studies Examining the Association between Neighborhood Deprivation and Cognition/Neurobehavioral Outcomes in Pediatric and Adult						
Author, Year,	Type of Study	Population	Age Range	Cognitive/ Neurobehavioral Domains	Neighborhood Deprivation	Findings
Baxendale and Heaney, 2011, United Kingdom	Cross-sectional	Pharmaco-resistant epilepsy with hippocampal sclerosis (HCS)	22-43 years	General Cognitive Ability and List and Design Learning	English Indices of Deprivation	Greater neighborhood deprivation was associated with poorer IQ and verbal learning for those with a left-lateralized HS.
Hohmann et al., 2021, Germany	Cross-sectional	Pharmaco-resistant focal epilepsy	24-50 years	Psychomotor speed, verbal learning, and mental distress	Social Indices (SIs) of Berlin	Lower structural socioeconomic status, independent of individual social, demographic, or biological factors, was linked to poorer cognitive performance and increased mental distress.
Busch, et al., 2023, USA	Cross-sectional	Pharmaco-resistant focal epilepsy	28-48 years	General Cognitive Ability, Attention, Processing Speed, Language, Executive Function, Visuospatial Skills, Memory, Reasoning Ability	Area Deprivation Index	Greater neighborhood disadvantage was associated with poorer cognitive performance across all measures and more severe depression, anxiety, and cognitive dysfunction.
Reyes et al., 2023, USA	Cross-sectional	Focal temporal and frontal epilepsy	60-73 years	Global cognitive function, memory, language, executive function, and processing speed	Area Deprivation Index	Greater neighborhood disadvantage was associated with poorer performance on global cognitive measures, practical judgment, learning and memory, and executive function.
Schraegle et al., 2023, USA	Cross-sectional	Newly onset idiopathic childhood epilepsy	8-18 years	General cognition, academic achievement, language, verbal memory, executive function, and fine motor dexterity	Area Deprivation Index	Greater neighborhood disadvantage was associated with poorer global intellectual functioning, language, passive inattention, memory, and fine motor dexterity.
Schraegle et al., 2023, USA	Longitudinal	Newly onset idiopathic childhood epilepsy	8-18 years	General Ability (Intelligence)	Area Deprivation Index	Greater neighborhood disadvantage was linked to delayed cognitive development at the two-year follow-up.
Chiang et al., 2023, USA	Cross-sectional	Childhood epilepsy	8-16 years	Quality of Life in Childhood Epilepsy	Area Deprivation Index	Graeter neighborhood disadvantage was associated with poorer quality of life in children and adolescents with epilepsy.
Struck et al., 2025, USA	Cross-sectional	Juvenile myoclonic epilepsy	16-24 years	General abilities, speed/response inhibition, and verbal learning and memory	Area Deprivation Index	Greater neighborhood disadvantage was poorer performance across three cognitive factors assess in JME.

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