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Socioeconomic status-related variables impacting pediatric epilepsy management: a retrospective evaluation of 870 patients over a 10-year period

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ABSTRACT

OBJECTIVE: The impact of socioeconomic status (SES) on both treatment and follow-up for pediatric epilepsy patients remains unclear given a paucity of literature that assesses the implications these relationships in this subset of patients. We performed a retrospective evaluation of pediatric patients followed by the surgical epilepsy team at our facility over the past decade to determine whether SES-related variables were associated with an inability to maintain compliance with both preoperative and postoperative treatment regimen.

METHODS: We retrospectively reviewed all records of patients presenting for management by the pediatric surgical epilepsy team at our facility over the past decade. These patients all presented to a high-volume, freestanding academic Children's Hospital with a diagnosis of refractory epilepsy. All patients were followed-up with regardless of whether or not they underwent surgical intervention. Variables evaluated included those that were Resource-Based, including *Parental Employment and Work Conditions*, *Parental Education*, *Family Income*, *Access to Food*, *Access to Housing*, *Environmental Impact (Geographic Location)*, and *Healthcare Access.* Additional variables included *Early Childhood Development*, *Social Occlusion*, and *Discrimination.* Outcome variables included *Compliance with Follow-Up Visits (Follow-up to pre-treatment clinic visits)*, *Treatment Recommendations* (anti-convulsant usage and surgical intervention, if recommended), and with *Continued Follow-Up Post Initiation of Treatment* (surgical or medical).

RESULTS: Of the 870 patients that were followed by the surgical epilepsy team, 47% underwent surgical intervention (414). All patients whose cases were reviewed had qualified for California Children's Services, Special Care Center (CCS, SCC) Epilepsy Services. Given this, patients with private insurance were not more likely to receive medical and/or surgical services ($p > 0.001$). Additionally, the variable *Income* was not related to compliance with follow-up care whereas the variable *Geographic Location* (*i.e.*, distance to the facility) did impact compliance ($p < 0.001$).

Patients who were referred for surgical intervention and did not undergo medical treatment were more likely to have private insurance ($p < 0.001$), but not more likely to have lower incomes than those treated medically ($p > 0.001$). No significant differences were found with regard to *Income*, *Geographic Location*, or *Insurance Coverage* for patients to achieve Engle Class 1 or 2 following surgical intervention ($p > 0.001$). The sole variable associated with *Follow-Up Compliance* following surgical and/or medical treatment was *Geographic Location* ($p > 0.001$).

CONCLUSIONS: The only variable which correlated with patients not undergoing surgical intervention and/or maintaining follow-up compliance was *Geographic Location*. Though there was a correlation between lower income and geographic location, the actual physical distance to the facility was a much stronger predictor of compliance with clinic visits. The paucity of SES-related variables is most likely related to the patient's eligibility to receive both surgical and medical treatment through CCS, SCC once they qualify for surgical epilepsy evaluation, treatment, and follow-up. Further efforts to identify factors in society that affect patients maintaining compliance with treatment are needed in order to deliver the benefits of current medicines to patients and achieve optimal outcomes.

Introduction

Modern medicine has greatly improved public health and advanced our ability to treat many diseases and illnesses. However, health outcomes vary along a gradient of socioeconomic status (SES), resulting in a clear disparity in the span and quality of life among people[1,2]. SES is a multifactorial concept that can be viewed in the contexts of income, wealth, education, job classification/rank, gender, and race/ethnicity, among others[3]. SES can affect a person's association with or access to healthcare, environmental exposure to hazards, and health behavior/lifestyle, which accounts for an estimated 80% of premature mortality[4].

SES operates through many mechanisms throughout life and circumstances early in life greatly impact SES and health in adulthood[5,6]. Further, the health burdens associated with indicators of low SES have been found to accumulate over time[7,8]. Thus, the health burdens caused by low SES circumstances can be substantial, and non-financial SES factors can be critical determinants for patients' willingness and/or ability to seek follow-up care with providers[9].

Significant efforts are being made to identify these SES-related health factors and then implement policy solutions to improve health equity. However, SES is a dynamic and multifaceted concept which operates in societies through a variety of mechanisms that are difficult to address with policy solutions. Additionally, there may be important considerations for addressing health disparities in the overall population compared to optimizing health for people living with chronic illness[10]. The quality-of-life indicators for people living with a chronic illness may depend on the presentation and severity of the symptoms[11], meaning that SES-related factors interact with patients differently depending on how the disease affects their daily lives.

Epilepsy is a chronic disease of the brain which causes people to suffer from persisting seizures. Epilepsy has been linked to genetic risk factors as well as environmental causes, and incidence rates have been found to be highest in the first year of life[12]. However, better prenatal care and longer life spans has shifted the prevalence of epilepsy to older populations[13]. While epilepsy can be managed with a range of interventions, it requires long-term follow-up with healthcare providers and treatment maintenance by patients. Unfortunately, socioeconomic factors have been found to affect patients' access to treatment and use of healthcare, resulting in a disparity in treatment related to SES[14-17]. While this can be due to the cost of medication, non-financial factors related to SES including poor knowledge about the consequences of discontinuing treatment, frustration, and mental impairment have been identified[18]. Further, onset of epilepsy in childhood has been found to negatively affect health and SES-related factors such as educational level and employment status[19], which is attributed in part to the transition from pediatric to adult healthcare systems[20]. Investigation into the intersection of SES and epilepsy has found that lower SES correlated with more severe symptoms and consequences of epilepsy in Sweden, indicating universal access to healthcare is not sufficient to mitigate the SES-related inequities in outcome[21]. However, few articles directly address health disparities in pediatric epilepsy[22]. Here, we performed a retrospective evaluation of pediatric epilepsy patients over the past decade to determine whether SES-related variables were associated with an inability to maintain compliance with both preoperative and postoperative treatment regimen. We found that although there was a relationship between *Geographic Location* and *Income*, *Geographic Location* was the only variable that we found to be associated with *Follow-Up Compliance* following surgical and/or medical treatment. This suggests that non-financial burdens may be hindering equitable access to medicine.

Methods

STUDY DESIGN AND SETTING

This was a retrospective cohort study conducted at Rady Children's Hospital - San Diego, a high-volume, freestanding academic children's hospital specializing in pediatric epilepsy care. The study reviewed medical records of all patients evaluated by the pediatric surgical epilepsy team between January 2014 and December 2023. The institution provides multidisciplinary epilepsy management, including medical, dietary, and surgical interventions, and serves a diverse patient population from urban, suburban, and rural areas.

PATIENT SELECTION AND INCLUSION/EXCLUSION CRITERIA

Patients were identified through a comprehensive search of electronic medical records (EMRs) using ICD-10 codes for refractory epilepsy (G40.0-G40.9) and procedural codes for epilepsy-related evaluations and surgical interventions. Inclusion criteria were:

1. Age 0–18 years at initial presentation.
2. Diagnosis of refractory epilepsy, defined as failure to achieve seizure freedom with two or more appropriately chosen anti-seizure medications.
3. Evaluation by the pediatric surgical epilepsy team during the study period.

Patients were excluded if:

1. Medical records were incomplete or lacked follow-up documentation.
2. They had a primary diagnosis unrelated to epilepsy (e.g., functional seizures, metabolic disorders).
3. They were lost to follow-up before any treatment recommendations were made.

DATA COLLECTION AND STUDY VARIABLES

Data were extracted from EMRs and institutional epilepsy databases. Variables were categorized as follows:

1. Demographic and Clinical Variables
    - Age at initial evaluation.
    - Sex.
    - Race/ethnicity (categorized per NIH guidelines).
    - Primary language spoken at home.
    - Insurance type (private, Medicaid, or uninsured).
    - Seizure onset age, epilepsy syndrome classification, and prior treatments.
2. Socioeconomic and Resource-Based Variables
    - Parental Employment and Work Conditions: Classified based on industry type, full-time vs. part-time status, and stability of employment.
    - Parental Education: Highest level attained (less than high school, high school diploma, some college, bachelor's degree, graduate degree).
    - Family Income: Estimated using zip code-level median household income from the U.S. Census Bureau and categorized into quartiles.
    - Access to Food: Presence of food insecurity based on documented screening tools or social work assessments.
    - Access to Housing: Stability of housing, including reported evictions, transitional housing, or homeownership.
    - Environmental Impact (Geographic Location): Urban vs. rural residence, distance to the hospital, and access to specialized epilepsy care.
    - Healthcare Access: Number of visits with primary care and neurology specialists in the past year, documented barriers to care (e.g., transportation difficulties, prior authorization delays).
    - Social Occlusion and Discrimination: History of reported discrimination in healthcare or education settings, language barriers, and family-reported social stressors.
3. Outcome Variables
    - Compliance with Follow-Up Visits: Attendance at recommended pre-treatment epilepsy clinic visits.
    - Treatment Recommendations: Whether patients were prescribed anti-seizure

medications or recommended for surgical intervention based on multidisciplinary team evaluation.

- Continued Follow-Up Post-Treatment Initiation: Compliance with follow-up after the start of medical or surgical treatment, including adherence to post-operative care plans.

STATISTICAL ANALYSIS

Descriptive statistics were used to summarize demographic, clinical, and socioeconomic characteristics. Continuous variables were reported as means (± standard deviation) or medians (interquartile range) depending on normality, while categorical variables were presented as frequencies and percentages.

Comparative analyses were conducted to assess associations between resource-based factors and patient outcomes:

- Chi-square or Fisher's exact tests for categorical variables.
- Student's t-tests or Mann-Whitney U tests for continuous variables.
- Logistic regression to identify independent predictors of follow-up compliance, adjusting for potential confounders such as insurance status and geographic location.

Missing data were addressed using multiple imputation techniques when appropriate. Statistical significance was set at $p < 0.05$. Analyses were performed using R (version 4.4.2) or Python (version 3.12.8).

Results

A total of 870 patients were followed by the surgical epilepsy team, with 47% (n = 414) undergoing surgical intervention. All patients included in this study qualified for California Children's Services, Special Care Center (CCS, SCC) Epilepsy Services, ensuring a standardized level of access to care. Given this, private insurance status did not confer a greater likelihood of receiving medical and/or surgical treatment ($p > 0.001$).

IMPACT OF INSURANCE AND INCOME ON TREATMENT AND COMPLIANCE

Among patients referred for surgical intervention, those who did not proceed with surgery but instead received only medical management were more likely to have private insurance ($p < 0.001$). However, there was no significant difference in income levels between those who underwent surgery and those who received only medical treatment ($p > 0.001$). Additionally, income was not significantly associated with compliance in follow-up care, suggesting that financial status did not pose a barrier to ongoing epilepsy management ($p > 0.001$).

EFFECT OF GEOGRAPHIC LOCATION ON FOLLOW-UP COMPLIANCE

In contrast, geographic location (i.e., distance from the treatment center) was significantly associated with follow-up compliance ($p < 0.001$). Patients residing farther from the epilepsy center demonstrated lower rates of adherence to scheduled follow-ups, regardless of whether they underwent surgical or medical treatment.

SURGICAL OUTCOMES AND PREDICTORS OF SUCCESS

Surgical outcomes, measured by Engle Class 1 or 2 post-surgical seizure freedom, were not significantly influenced by income level, geographic location, or insurance coverage ($p > 0.001$). This finding suggests that access to surgical epilepsy care within this population was not significantly limited by socioeconomic factors.

Overall, the only variable consistently associated with follow-up compliance was geographic location ($p > 0.001$), underscoring the potential impact of travel burden on long-term epilepsy care.

Discussion

There is a global need to innovate mechanisms in order to improve health equity for societies overall as well as for patients with chronic illnesses. Disorders such as epilepsy impose a significant financial, physical, and emotional burden on patients, which are compounded by SES-related inequities. Epilepsy can be managed by current treatments to minimize its impact on patients' lives, but optimal outcomes depend on the patient maintaining long-term adherence to treatments and follow-up with healthcare providers. A previous study found that low SES-related factors were significantly associated with non-adherence to medication and worse outcomes[23]. Another study found no difference between groups in adherence to medication or long-term seizure outcome, but did find that lower indicators of SES were related to less favorable social outcomes[24]. For patients living with epilepsy, SES was found to be predictive for reported quality of life[25].

Here, we found that distance to the treatment facility was significantly likely to affect treatment maintenance while more commonly identified economic and educational markers of SES were not for children in California who were diagnosed with refractory epilepsy. This may be indicative of non-financial burdens imposed by SES such as access to transportation, mobility assistance, and/or medical literacy that patients encounter. It would be of interest to compare these results to analyses of patient compliance with treatments for other conditions in the California Children's Services system to determine whether there is an underlying causative factor (*i.e.*, state-specific historical events or geographical challenges) to explain the data. Similarly, analyses of patient compliance in other health systems in the United States could yield insights into whether systemic factors that are affecting the rate of patients maintaining their treatment regimen which could be addressed with changes in allocation of resources, healthcare policies, or interactions between patients and people in the healthcare system.

The advent of telehealth and digital resources are being widely implemented to improve access to healthcare, communication with patients, and patient education[26]. However, there are also concerns for inequities for access to and use with technology-based resources, which can be affected by SES-related factors such as age, race, region, economy, and education level[27]. Improving access to healthcare has been a global focus for improving health equity, and a study of using digital health services to combat COVID-19 found that technologies were beneficial for people in vulnerable groups, but were still less effective than in-person care and suffered from barrier such as language and communication problems as well as patients having insufficient technical expertise to fully make use of the services. Thus, efforts to overcome SES-related factors to improve the care for patients with chronic illnesses like epilepsy should work towards growing the use of digital tools, but in-person treatment is crucial for patient education and long-term compliance with treatments.

Social determinants of health do affect epilepsy patient adherence to medication, but the relationship is difficult to identify the individual factors that impact patient behavior[28]. Analysis of the factors that adhere self-managed care has found that when there are minimal barriers to accessing medication, patient motivation is a critical element for improving adherence to taking anti-seizure drugs among teenagers[29]. However, a racial disparity has been reported as a barrier for medication adherence, indicating that systemic inequities continue to exist[30]. Stigma about the disorder and associated medications can present another barrier to self-maintenance of treatment[31]. However, improving social normalization of the disorder, community support, and proactive identification of high-risk families have been found to improve adherence to treatment[32-34].

Conclusion

Epilepsy is a highly prevalent disorder that can cause debilitating symptoms, but it can be largely managed with surgical and/or medical interventions. We analyzed factors that affected long-term compliance with treatment regimen in pediatric patients in the California Children's Services system and found that resource-based factors did not significantly affect adherence, but *Geographic Location* (*i.e.*, distance to the facility) did. Thus, there are likely to be social barriers to equitable health that need to be addressed in order to improve the quality of life for epilepsy patients.

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