Factors Associated with Underutilization of Pediatric Epilepsy Surgery Among Underserved Populations in the United States

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Introduction

Epilepsy is one of the most common chronic pediatric neurologic conditions with an estimated 470,000 children affected in the United States in 2015 (CDC 2020; Fine & Wirrell 2020). In Washington State, an estimated 10,200 children aged 0-17 were diagnosed with epilepsy in 2015 (CDC 2020). Peak incidence appears to occur prior to the age of one with some experts specifying the first few months of life (Wilfong 2021). Rates of epilepsy also appear to be higher in males than females (Wilfong 2021).

Seizures are the essential feature of epilepsy and are defined as abnormal, excessive or synchronous neuronal discharges typically occurring in the cerebral cortex that may manifest clinically as mental status changes or physical symptoms including eye deviation and limb/body movements, among many other signs and symptoms (Wilfong 2021). An operational definition was developed by the International League Against Epilepsy (ILAE) which states that epilepsy can be diagnosed when any of the following parameters are met (Fisher et al. 2014): [1] At least two unprovoked (or reflex) seizures occurring >24 h apart or [2] one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years or [3] Diagnosis of an epilepsy syndrome. Despite the seriousness of this condition, prognosis is generally favorable and fortunately treatment in the form of anti-seizure medications are fairly effective.

In fact, studies have shown that nearly two-thirds of pediatric epilepsy patients are able to achieve seizure freedom for 3 to 5 years with medication and half are eventually able to wean off their seizure medications (Fine & Wirrell 2020). However, there are a subset of patients with epilepsy, about one-quarter, who are unable to achieve adequate seizure control in spite of being correctly treated with 2 or more anti-seizure medications. For these children, their risk of cognitive, behavioral, and psychiatric comorbidities, along with seizure-related injury and sudden unexpected death by epilepsy (SUDEP) are higher (Fine & Wirrell 2020).

For children who experience refractory (drug-resistant) epilepsy, non-pharmacologic treatment options in the form of resective surgeries can lead to improved seizure control as well as improved cognitive development, psychiatric and social functioning, enhanced quality of life, and reduced mortality (Madaan et al. 2021). These procedures can range from a lesionectomy, removal of a small portion of the brain or tumor identified as the epileptogenic zone, to a hemispherectomy which is the removal of one-half of the brain (Kiriakopoulos et al. n.d.). Rates of seizure freedom have been reported as 60%-70% (Glauser & Loddenkemper 2013). Potential surgical candidates require referral to a comprehensive pediatric epilepsy center as well as a multi-disciplinary team which will likely include a child neurologist, epileptologist, neuropsychologist, and neurosurgeon (Glauser & Loddenkemper 2013; Madaan et al. 2013; Fine & Wirrell 2020).

The number of pediatric epilepsy procedures performed continues to increase over time, but despite the known efficacy and safety of these surgeries, the amount of surgical evaluations for epilepsy are less than the estimated number of potential candidates that may benefit from surgery (Armour et al. 2021). Furthermore, health disparities and inequities exist with regards to access to epilepsy surgery. Health equity experts within the field of child neurology have identified certain racial/ethnic groups and socioeconomic factors which are more likely to have delayed surgery time or lower rates of receiving surgery.

Specifically, Black and Hispanic patients were less likely to undergo pediatric epilepsy surgery (Armour et al. 2021); one study found that African-Americans were 60% less likely to undergo surgery as compared to non-Hispanic whites even when controlling for age, education, sex, socioeconomic, and medical insurance coverage (Burneo et al. 2005). Patients with limited English language proficiency were also found to have longer wait times to surgery (Armour et al. 2021). Moreover, pediatric patients with private insurance are outpacing patients with public insurance in terms of receiving epilepsy surgery (Armour et al. 2021; Hauptman et al. 2013). Lastly, one study completed in Canada (comparable to the United States in terms of barriers to medical care) found that lower income families had significantly longer times to surgery despite their universal health care system, and suggested that several factors related to the social determinants of health such as lack of transportation and work restrictions with regards to taking time off, could potentially explain their findings (Rubinger et al. 2016).

The epidemiologic data has certainly demonstrated that inequities exist within epilepsy surgery care, but as researchers continue to study these differences, some have also theorized the underlying reasons behind these disparities. As such, the main objective of this literature review is to identify and elucidate the numerous factors driving the underutilization of epilepsy surgery among historically underserved pediatric populations in the United States.

Methods & Results

I conducted a literature search in PubMed which included four phrases: “pediatric epilepsy surgery inequities”; “pediatric epilepsy surgery inequalities”; “pediatric epilepsy surgery access underutilized”; “pediatric epilepsy surgery access”. Eighty-eight total articles were populated (sans duplicate articles). After screening through the eighty-eight articles by reading through the titles and abstracts, articles that mentioned factors and reasons behind the underuse of epilepsy surgery among children as well as those focused in the United States were included, which amounted to nine articles. The nine articles were then read in full and several themes emerged that explained the possible reasons behind the disparate utilization of epilepsy surgery amongst underserved populations, which are further reviewed in the discussion section below.

Discussion

*Provider Knowledge/Attitudes*

Gaps in provider knowledge and attitudes toward epilepsy surgery appears to be a factor in the underutilization of epilepsy in general, as well as, amongst underserved populations. Studies have shown that a small, but significant, number of physicians are unaware of the definition of drug-resistant epilepsy (failure of 2 tolerated and appropriately chosen anti-seizure medication) (Samanta & Ostendorf et al. 2021; Armour et al. 2021; Beatty et al. 2021; Samanta & Singh et al. 2021). For example, Armour et al. (2021) mention a study which found that only 14% of referring neurologist were aware that surgery should be considered after two failed trials of anti-seizure medications, while 19% of referring neurologists considered epilepsy to be “drug-resistant” after all anti-seizure medications were trialed. There are also studies which show that significant knowledge gaps exist among neurologists about which epilepsy syndromes are amenable to surgery, misunderstanding of surgical risks and benefits, and which indications and timing for referrals are actually appropriate (Samanta & Ostendorf et al. 2021; Armour et al. 2021; Beatty et al. 2021). These gaps in knowledge can in part be explained by differences in exposure to epilepsy surgery in their training years and beyond (Samanta & Ostendorf et al. 2021; Samanta & Singh et al. 2021).

*Provider Implicit Bias*

Another significantly understudied and insidious reason for the underrepresentation of pediatric patients of color in epilepsy surgery is implicit bias (Samanta & Singh et al. 2021; Armour et al. 2021). Samanta & Singh et al. (2021) note that data on the contribution of implicit bias to differences in epilepsy surgery utilization does not exist. However, increasing knowledge of implicit bias in medicine has found that communities of color are negatively affected and has been associated with worse communication between provider and patient and worse ratings of care (Armour et al. 2021). Taken together, implicit bias likely affects patient’s/family’s trust and understanding of epilepsy surgery and thus leads to less utilization. Samanta & Singh et al. (2021) ultimately advocate for more research in this topic as significant racial and ethnic differences exist in epilepsy surgery referrals and usage.

*Patient and Family Attitudes/Knowledge*

Two studies (Baca et al. 2015 and Samanta & Hoyt et al. 2021) examined parent attitudes toward epilepsy surgery. Baca et al. (2015) aptly described a parent’s time course from diagnosis to surgery for their child as “A journey around the world”. In their study, parents reported several barriers that would invariably affect underserved populations to a disproportionate degree, in particular folks with limited English proficiency and those with limited educational attainment. For example, navigating the complex US healthcare system, seeking additional or further information about epilepsy and epilepsy surgery through the internet and other information sources, and managing numerous anti-seizure medications (Baca et al. 2015).

Samanta & Hoyt et al. (2021) found similar barriers in their literature review of parental attitudes/knowledge of epilepsy surgery; patients were unsatisfied with the information provided by their physician which necessitated long searches for information. Also, the idea that surgery is a “last resort” despite the recommendation that surgery be considered after two failed trials of anti-seizure meds (Samanta & Hoyt et al. 2021). This goes along with common misperceptions of surgical risk outweighing benefits leading to families and parents believing that brain surgery is “scary or horrific”. However, these negative parental attitudes could be driven in part by inconsistent practice of guidelines and poor communication on the part of the provider (Samanta & Hoyt et al. 2021; Baca et al. 2015).

Armour et al. (2021) corroborate many of these family attitudes, and also examines cultural factors and historical trauma from the health care system leading to significant mistrust as a major factor for dissuading Black and Hispanic patients and their families from accepting treatment plans directed by a physician. Furthermore, Armour et al. (2021) mentions that a study among Chinese and Vietnamese adults found that participants believed epilepsy control could only be achieved through medication alone.

*Social Determinants of Health*

The Social Determinants of Health (SDOH) are defined by the Office of Disease Prevention and Health Promotion as “the conditions in the environments 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” (Healthy People 2023). Some examples of these social determinants include safety of neighborhoods, education, and access to healthcare.

Hauptman et al. (2013) conducted a study which found that children with Medicaid insurance experience longer times from seizure onset to epilepsy center referral and seizure onset to surgery as compared to children with private health insurance. They postulate that delays in care may be due to the children’s transition from uninsured to gaining Medicaid insurance (Hauptman et al. 2013). Similarly, Baca et al. (2015) reported that parents expressed frustration with insurance-related barriers such as certain policies requiring only certain physicians be seen and difficulties related to authorization of procedures or imaging which impacted their ability to receive timely care.

Financial and social support are important factors for families considering epilepsy surgery for their child. Armour et al. (2021) explain that time off from work and lost wages from staying in the hospital would negatively impact the financial stability of a family, and could potentially affect them seeking care in the first place. Moreover, it could affect post-surgical recovery through food insecurity or other parental stressors. Lack of transportation may also play a role as many office visits and imaging procedures are required for work-up (Armour et al. 2021). Ibrahaim et al. (2012) also state that, simply, the geographic location of a patient will affect their quality of care and potentially referral for epilepsy surgery. They use the tangible example of inconsistent MRI machine quality at different epilepsy centers, in which higher quality machines may be able to better detect epileptogenic lesions as compared to lower quality machines, thus leading providers to more likely recommend surgery.

Conclusion

Epilepsy surgery is a viable and effective treatment modality for pediatric patients with intractable epilepsy. However, health disparities exist within the utilization of epilepsy surgery among different ethnic/racial and socioeconomic groups that can likely be explained by various factors including provider knowledge of epilepsy surgery, providers’ implicit bias, family and patient knowledge/attitudes toward epilepsy surgery, and various social determinants of health. These barriers can likely be tackled with existing strategies for reducing health disparities as many of the overall themes contributing to these inequities in epilepsy surgery are similarly found in other chronic conditions such as diabetes or hypertension.

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