Inequities in access to pediatric epilepsy surgery: a bioethical framework

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Epilepsy is a common childhood condition associated with a considerable medical and psychosocial burden. Children in whom medical treatment fails to reduce seizure burden represent an especially vulnerable patient population because prolonged, uncontrolled seizures are associated with poor developmental and neurocognitive outcomes. Surgical treatment in the form of cortical resection, functional disconnection, or neuromodulation may alleviate or significantly reduce the disease burden for a subset of these patients. However, there remains a dichotomy between the perceived benefits of surgery and the implementation of surgical strategies in the management of medically intractable epilepsy. The current paper presents an analysis of the bioethical implications of existing inequities in access to pediatric epilepsy surgery that result from inconsistent referral practices and discrepant evaluation techniques. The authors provide a basic bioethical framework composed of 5 primary expectations to inform public, institutional, and personal policies toward the provision of epilepsy surgery to afflicted children.

Key Words • ethics • pediatric epilepsy • epilepsy surgery

INFANTS and children with prolonged, refractory epilepsy demonstrate worse cognitive outcomes, because seizures are thought to affect the developing brain adversely.14,24 Longer duration of uncontrolled epilepsy is associated with a lesser likelihood of future freedom from seizures and worse developmental and behavioral outcomes.17 It is well established that surgical treatment for resection of seizure foci, functional disconnection, or neuromodulation may bestow considerable benefit on afflicted children. Although a set of referral guidelines has been proposed for pediatric patients,6 many children continue to face barriers in access to surgical interventions. In an international survey of pediatric epilepsy surgery centers, the mean duration of the disorder before surgery was 5.7 years, with significantly longer mean times for older children.19 More importantly, this study also found that only a minority of children at greatest risk of epileptic encephalopathy received time-appropriate surgery. Particular patient populations at risk include children with refractory infant-onset epilepsies, in whom early surgical intervention has been shown to mitigate the detrimental effects of seizures on brain development.16

In the adult literature, a practice parameter established by the American Academy of Neurology in association with the American Epilepsy Society and the AANS recommended referral of adults with temporal lobe epilepsy to a surgical center after failure of first-line medication. In one study, the average adult referral time for presurgical evaluation from diagnosis was 18.6 years, with no statistically significant difference after the implementation of the practice guideline.9 Because the majority of these patients are young adults, it is expected that a sizable subgroup may have benefited from surgical evaluation as children, and they are therefore germane to the subsequent discussion.

At present, it remains unclear why a dichotomy exists between the mounting evidence for early referral for surgical evaluation and the discordant lack of momentum in the implementation of surgical strategies for the management of medically intractable epilepsy in children. We discuss the implication of existing inequities in access to pediatric epilepsy surgery—as a result of inadequate referral patterns and discrepancies in presurgical evaluations—through an applied bioethical framework. The purpose is to identify ethical implications of inequities in access to surgery, and to inform public, institutional, and personal policies toward the provision of surgical treatments for childhood epilepsy.
Ethical Frameworks

Ethical frameworks function as scaffolding for shaping public health, institutional, and personal policies toward existing problems. In the section of its influential 1983 report titled “An Ethical Framework for Access to Health Care,” the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research made the distinction between health care and other commodities, where the former was deemed essential for quality of life and longevity. The report identified ethical obligations for societies, institutions, and governments to facilitate equitable access to health-related resources. The distinction here between equality and equity in access to health care is paramount. The latter notion emphasizes the elimination of systemic disparities in access to health care between groups with different levels of underlying social advantages or disadvantages. Whereas inequality is a reflection of social diversity, equity is a normative ethical value grounded in the principle of distributive justice.

Several frameworks exist for considering inequities in access to health care and/or limited resources. Wynia and Schwab described an ethical framework for the provision of health care coverage by defining 5 central expectations: 1) transparency; 2) participation; 3) equity and consistency; 4) sensitivity to value; and 5) compassion. In their review, Giacomini and colleagues identified 17 themes that are common to a large number of policy-related ethical frameworks. To develop the current framework, we identified existing ethical challenges related to inequities in access to pediatric epilepsy surgery and classified them into 5 relevant expectations (Table 1).

Access. In the most basic sense, health care providers have an ethical obligation to facilitate access to epilepsy surgery for selected patient populations. This pertains to the physician’s fiduciary duty—the obligation to “do good” enshrined in the Hippocratic oath, and comprises the first expectation of the current framework. Intimately associated with this duty is the ability to identify children who would benefit from surgical intervention. In this sense, physicians have an obligation to appreciate the value of surgical intervention and to adhere to evidence-based guidelines. In fact, many conflicts between the roles of referring physicians as both patient advocates and gatekeepers of health care systems are mitigated by evidence-based outcomes and collaborative practice guidelines encouraging early referral patterns.

Protection of the Vulnerable. Another expectation of the current framework is the protection of the vulnerable. Among children who face barriers in access to epilepsy surgery, there are various disproportionately affected subgroups. One such population is composed of children with nonlocalization-related epilepsies who may benefit from palliative procedures that could improve their quality of life by reducing seizure frequency. The implementation of palliative surgical strategies is however highly discordant between centers. Another subgroup comprises children with severe developmental delay. Epilepsy surgery pioneers Falconer and Rasmussen initially considered developmental delay to be a contraindication to epilepsy surgery; however, current practice guidelines do not discriminate against children with developmental delay, because this does not predict seizure outcome. Additionally, we have previously described ethical justifications for the consideration of palliative procedures for children with epilepsy as well as the role of surgical intervention in severely developmentally delayed children. Other subgroups of children that have shown a lower rate of access to epilepsy surgery and antiepileptic medical therapy include African Americans, children whose parents have less education, older children, and those on polytherapy and with concurrent psychiatric diagnoses. The identification and protection of these vulnerable subgroups of children is important to maintain beneficence and avoid maleficence when addressing inequities in access to epilepsy surgery.

Transparency. Many centers use different strategies for preoperative evaluation of children referred for surgi-

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Inequities in access to pediatric epilepsy surgery

Inequities in access to pediatric epilepsy surgery are deep rooted and difficult to address, others, such as regional and urban-rural disparities in access to health care, can be overcome by simple measures such as the referral of complex cases to quaternary centers and centralization of specialized care.

Although the proposed bioethical framework is not intended to address global inequities in access, the inequity in access to pediatric epilepsy surgery in developing countries is also a significant consideration. Twenty percent of the global burden of epilepsy lies in the developing world, and a staggering majority of patients receive ineffective management of their disease. For afflicted children, the option of surgical intervention is often altogether unavailable. A thorough examination of the ethical challenges of epilepsy management in low-resource settings is beyond the scope of the current paper, but surgical strategies for the treatment of epilepsy in developing countries have been shown to be successful, sustainable, and ethically justifiable.

Societal Benefit. The final expectation of the current framework is sensitivity to cost effectiveness. It has been demonstrated, for instance, that the application of surgical strategies for the treatment of refractory epilepsy is more cost effective than continued medical management. In addressing inequities in access to pediatric epilepsy surgery, it is important to realize that these procedures may have an added societal benefit of reducing health care costs.

Conclusions

Children with medically intractable epilepsy comprise a vulnerable patient population facing numerous barriers in access to surgical interventions, which are imposed by inadequate referral patterns and discrepant evaluation techniques. We have identified the ethical implications of inaccessibility to surgical care and have proposed a bioethical framework for shaping public, institutional, and personal policies toward the provision of pediatric epilepsy surgery. We have identified 5 expectations to address existing inequities, as follows: 1) access sensitivity to the value of surgical intervention; 2) protection of vulnerable populations; 3) transparency; 4) equity despite inequality; and 5) societal benefit. It is hoped that enhanced knowledge of the considerations presented in this framework will improve our ability to care for afflicted children.

Disclosure

The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

Author contributions to the study and manuscript preparation include the following. Conception and design: Bernstein, Ibrahim, Barry, Fallah. Drafting the article: Ibrahim, Barry, Fallah. Critically revising the article: Bernstein, Ibrahim, Snead, Drake, Rutka. Study supervision: Bernstein, Snead, Drake, Rutka.

References


