Community-engaged research: a powerful tool to reduce health disparities and improve outcomes in pediatric neurosurgery

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Innovations in science, technology, and biomedical research have led to marked improvements in the health of the United States population overall. However, health disparities, defined as differences in health outcomes between groups of people based on social, economic, or environmental disadvantages, continue to exist and, in some cases, are widening.1 Social determinants of health—the conditions and environments in which individuals are born, live, and work—promote health disparities.2 Groups that experience health disparities generally have higher levels of exposure to adverse factors such as poverty, low education, environmental hazards, psychosocial stressors, and lack of access to healthcare.

Disparities in access to, delivery of, and outcomes of healthcare are shown to exist within neurosurgery based on factors such as health insurance, race, gender, and socioeconomic status.3–7 As a vulnerable population, pediatric neurosurgical patients are particularly susceptible to these disparities. Studies have demonstrated that patients with public insurance and patients from lower socioeconomic status have reduced access to treatment and greater rates of adverse outcomes.8 Moreover, health disparities experienced during childhood have the potential to affect a child throughout their lifetime.9,10 Therefore, there is a critical need for research focused on reducing disparities and improving health outcomes in pediatric neurosurgery.

Traditionally, research has been siloed within academia, with scientists and clinicians developing questions for inquiry with minimal involvement of patients and families, community stakeholders, or the public. Study results are shared with the academic world without intentional measures to ensure that the public is aware of and understands their findings. This traditional, investigator-driven research model is inadequate when considering the issues of health disparities. Research that does not address the concerns of the community experiencing health disparities does not lead to tangible improvements. In that logic, there are major opportunities for improvement in the use of time and resources devoted to research. More importantly, research dissonant from the needs of the target community may worsen the very problems it seeks to solve. To effectively address the complex health disparities in pediatric neurosurgical care, it is imperative for researchers to partner with the patients and communities experiencing such disparities. A partnership would ensure that the research is contextually appropriate, and its findings can eventually be translated into implementation initiatives. The goals would include practical, sustainable changes that promote health equity.

Community-engaged research is a framework that may be utilized to address health disparities and improve outcomes, in this context, for pediatric neurosurgical patients. Community-engaged research is “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the wellbeing of those people.”11 It follows the established academic research process, but with emphasis on involving the community—patients, health service systems, community organizations, and other stakeholders—in the various stages of the research process.12 The strength and intensity of this partnership and the degree of community involvement
may vary substantially, from serving in an advisory role to equally participating in all phases of the scientific process, from formulating the research question to study design, data collection, analysis, interpretation, and dissemination of results. Often, long-term partnership is preferred to allow for continuity of engagement and ensure sustainable application of the research findings.

There are many potential benefits to using a community-engaged approach to research. First, community-engaged research may strengthen the links between research and practice. When researchers develop questions about health issues of concern to the community, the results are more likely to be translatable to real-world settings. Second, community-engaged research builds crucial trust and fosters community understanding and support. Without trust, underrepresented and underserved populations have minimal incentive to participate in research. Enhanced ability to reach such populations leads to better participant recruitment, enrollment, and retention: this inclusivity is essential for understanding, treating, and representing the entire population that we care for in health systems. For instance, it is known that much of current research such as genetic research is disproportionately represented by White patients. Third, community-engaged research can help ensure that interventions are culturally and linguistically appropriate and may help improve the reliability of study measurement tools, procedures, and questions.

Community-engaged research spans a wide range of research methodologies and can be used in many research settings. Examples of previous projects include partnering with adolescents to develop a digital communication intervention to reduce adolescent obesity, the development and evaluation of preventative measures in pediatric type 2 diabetes, community-based participatory research to inform culturally specific preoperative interventions for Latino youth and their families, and community partnerships for a surgical clinical trial internationally. The principles of community-engaged research are suitable to pediatric neurosurgery as well.

There is precedent for utilizing principles of stakeholder inclusion in neurosurgery research. For instance, the Patient-Centered Outcomes Research Institute (PCORI) funds studies that can help patients and their caregivers make better-informed healthcare decisions. Stakeholder engagement is integral to such studies, including providing answers and defining outcomes that matter to patients and their families. In pediatric neurosurgery, that includes studies on Chiari surgery in collaboration with the Bobby Jones Chiari and Syringomyelia Foundation, ventriculoperitoneal shunt surgeries in collaboration with the Hydrocephalus Association, and medical treatment versus epilepsy surgery treatment for Lennox-Gastaut syndrome in collaboration with the Lennox-Gastaut Syndrome Foundation. Partnerships between PCORI pediatric neurosurgery investigators and patient advocacy organizations have led to research studies that have made tangible improvements in disease-specific patient populations. The principles of stakeholder inclusion used in these collaborations can be applied to community-engaged research in pediatric neurosurgical care. Using a framework of community-engaged research, pediatric neurosurgeons can partner with communities to specifically target health disparities and promote health equity.

Pediatric neurosurgeons are in a unique position to conduct meaningful research using a framework of community engagement. They often develop a long-standing relationship with patients and their caregivers due to recurring visits or surgeries over prolonged timeframes throughout childhood. This relationship often creates a special bond and deep trust with families, giving pediatric neurosurgeons an insight into the longitudinal and transition challenges their patients face. Mutual support of the neurosurgical community and patient populations is synergistic and valuable. Clinical care for pediatric neurosurgical patients is a team-based multidisciplinary endeavor. For example, children with spina bifida interact with urologists, orthopedic surgeons, physiatrists, and psychologists. The multidisciplinary nature of pediatric neurosurgical care creates additional opportunities for collaboration. Health disparities can be addressed from multiple disciplines as well as from multiple touchpoints in inpatient, outpatient, and emergency department encounters with the health system. Pediatric neurosurgeons should involve a variety of collaborators and partners—families, providers, health systems, patient advocacy organizations, community groups, and other stakeholders—in conducting community-engaged research to address health disparities. Community partners may represent communities defined by geography, socioeconomic characteristics, race, ethnicity, or primary language.

Promoting healthy equity and reducing disparities in pediatric neurosurgical care are imperative. With these goals in mind, community-engaged research is a much-needed framework to improve the health of all children with neurological disease. Patients’ and families’ voices need to be a defining part of the discourse on outcomes that matter in their brave journeys.

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**Disclosures**

The authors report no conflict of interest.

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