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Epilepsy Surgery in Childhood Versus Adulthood: What Are We Waiting for?

Long-Term Employment Outcomes After Epilepsy Surgery in Childhood

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Objective: To analyze long-term employment outcomes in a population-based cohort of adults who underwent epilepsy surgery in childhood or adolescence and to compare the results to general population reference data. Methods: Prospective data on epilepsy surgery procedures performed on patients <19 years of age between 1995 and 2012 were extracted from the Swedish National Epilepsy Surgery Register. Five-, 10-, 15- and 20-year follow-up data were analyzed. Patients aged ≥19 years at follow-up were eligible for inclusion. Educational attainment and employment status were analyzed in relation to seizure outcome. Education and employment outcomes of seizure-free patients with a preoperative IQ of ≥70 were compared to general population reference data. Results: A total of 203 patients were included. The mean age at surgery was 13.6 years and 66% had IQ ≥70. Of these, a majority had attained at least high school education 5 years after surgery. Employment rates were 44%, 69%, 71%, and 77% at the 5-, 10-, 15-, and 20-year follow-ups, respectively. Seizure-free patients were significantly more likely to work full-time. Educational attainment and rates of full-time employment of seizure-free patients were similar to the general population. A majority of patients with IQ <70 had attended special education and were reliant on social benefits. Conclusion: Long-term overall employment rates were higher compared to most previous studies on surgery in adults. Seizure-free patients with a preoperative IQ ≥70 showed rates of full-time employment similar to the general population. Further research is needed to determine whether this also applies for occupational complexity and wages.

Commentary

I once met a 4-year-old child with medically refractory focal epilepsy with recurrent status epilepticus due to neonatal stroke. The family previously had been advised not to consider surgery because it was elective and had risks. Therefore surgery should be postponed until the child was an adult and could be a part of the decision process. I disagreed with this recommendation. However, the advice of the other neurologist may have some merit. Epilepsy surgery often is considered elective and is certainly invasive. For children who are likely to have the cognitive ability to make their own health care decisions, should we wait? This was a good opportunity to review the literature. As a surrogate marker for long-term socioeconomic outcomes of epilepsy surgery, let us examine employment in patients with medically refractory epilepsy who undergo surgery in childhood versus adulthood.

The Swedish National Epilepsy Surgery Register (SNERS) provides prospective, longitudinal, population-based information on long-term outcomes after epilepsy surgery. In the cohort of adult patients, they found that 36% to 65% of seizure-free patients with 5- and 10-year follow-up worked full time up to age 54 years and only 24% to 27% worked full time after that age.[1] Only 23% of patients working part-time before surgery, and who became seizure free, worked full time 10 years after surgery. Similarly, 31% of patient who were unemployed before surgery worked full time 10 years afterward.[1] Multivariate analysis revealed preoperative employment, seizure freedom, and younger age were predictors of postoperative employment. However, of those who had full-time employment before surgery, 79% continued to work at 5 years and only 47% worked 15 years after surgery. Of those who were seizure free, 58% to 59% worked full time 5 to 10 years postoperatively. The authors concluded that "seizure freedom alone is not enough to retain full-time working capacity."[1]

Recently, the SNERS was reviewed to determine employment outcomes when surgery was done during childhood (age <19 years). In this cohort, approximately 1/3 had IQ <70 (vs approximately 5% in the adult cohort).[1,2] Therefore, the results were dichotomized, based on IQ. In seizure-free patients with IQ ≥70, 62% to 76% worked full time after age 25 years at the 10-, 15-, and 20-year follow-ups, consistent with full-time employment rates of the general population at the same time

points (66%-68%).[2] Seizure freedom was a positive predictor of employment.[2] These 2 studies suggest employment rates in adults who undergo epilepsy surgery remain lower than the general population, even in seizure-free patients who worked full time before surgery. By comparison, children with IQ $\geq$ 70 who undergo epilepsy surgery go on to have employment rates consistent with the general population.

How can we account for these differences? Perhaps more patients who undergo surgery as children are able to achieve seizure freedom. Seizure freedom rates of adults and children in this registry 5 and 10 years postoperatively have been previously reported. Overall, 62% of operated adults and 50% of operated children (of whom 34% had IQ <70) were seizure free.[3] In this cohort, seizure freedom in those with IQ >70 was 62% to 66% throughout follow-up.[2] Therefore, even though seizure freedom is a predictor of full-time employment, rates of seizure freedom do not explain the differences in employment.

Most likely, the authors were absolutely correct: that "seizure freedom alone is not enough to retain full-time working capacity."[1] Epilepsy as a disease is not just seizures. Therefore, how can we expect life to go back to "normal" in a patient dealing with the long-term consequences of epilepsy? Elliott et al examined quality of life in young adults who underwent epilepsy surgery during childhood. Those who were seizure free were found to have improved cognitive function and self-perception, compared to nonoperated patients or those with continued seizures.[4] This improved cognitive function and self-perception can certainly lend itself to improved employment. Likely, it's more than that.

Epilepsy carries with it a significant social burden that often prevents normal social development. Lendt et al noted difficulties in socioeconomic development after epilepsy onset in 64% of patients, and the vocational phase of development was most affected.[5] Like many milestones in childhood, social and independence milestones are meant to occur at a specific time and in a specific order. Epilepsy disrupts this.

Coleman reviewed the trajectory of social milestones in adults who underwent anterior temporal lobectomy for intractable epilepsy, the majority of whom had epilepsy onset during childhood.[6] A consistent sequence of social milestone achievement was identified, going through stages of independence and autonomy, following by confidence, then acceptance and stability. These stages, which are often normal parts of adolescence and early adulthood, occur 2 to 20 years after surgery—disrupting the typical developmental timelines.[6] Furthermore, there are additional disruptions at each step. For example, while they are increasing independence and autonomy, 54% reported changes in relationship dynamics, including conflicts and separations due to the postsurgical adjustment process.[6] Similarly, while 59% underwent gradual return to work within 24 months of surgery, 10% of seizure free and 50% with ongoing seizures subsequently stopped working. Finally, 27% did not go on to have children, including 50% with ongoing seizures; and first children occurred in most 6 to 15 years after surgery.[6] This study highlights the importance and consistency of patterns of social independence, but also shows how they are delayed in patients with epilepsy.

Imagine what the outcomes could be if surgery were done in childhood, during the age-appropriate periods of social milestone acquisition? I suspect this is a significant contributor of why children who undergo epilepsy surgery have improved employment compared to adults.

Given this information, what is our justification for waiting? Are we concerned that we might operate on someone whose epilepsy was not actually intractable? We know that focal epilepsy may not become intractable for many years after epilepsy onset, especially when onset of epilepsy is in childhood. In a prospective cohort of 7 surgical centers, up to 26% of patients have reported a prior remission before surgery, and 8.5% had a remission $\geq$ 5 years.[7] However, the reverse—patients with intractable epilepsy becoming seizure free on medication—is unlikely to happen. In the SNERS, none of the nonoperated children were seizure free at long-term follow-up.[3] Therefore, if we see a child with intractable focal epilepsy, why wouldn't we consider surgery? What are we waiting for?

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