Development of a Pediatric Epilepsy Program: Analysis of Early Multidimensional Outcomes

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Abstract

Background A Pediatric Epilepsy Program was instituted in Manitoba in 2016. This report seeks to describe changes in the management of pediatric epilepsy patients in Manitoba since the inception of this Program, to provide an early analysis of local outcomes, and to present a framework for further program development.

Methods Data was collected for patients treated both before and after inception of the Program. Caregivers completed questionnaires on quality of life and program satisfaction. An online database was created to capture demographic information, seizure and quality of life outcomes, and caregiver satisfaction ratings. Descriptive statistics were used to summarize the results.

Results Prior to commencement of the Program, 16 patients underwent vagal nerve stimulator (VNS) insertion. At last follow-up, 6.25% of patients achieved Engel class I outcome, 75% achieved class III outcome, and 18.75% were classified as class IV. Following inception of the Program, 11 patients underwent resective procedures and 3 underwent VNS insertions. At last follow-up, 78.6% of patients achieved Engel class I outcome, 14.3% achieved class III outcome, and 7.1% were classified as class IV. Since inception of the Program, the average Quality of Life in Childhood Epilepsy Questionnaire-55 score measuring patient quality of life was $(59.7 \pm 23.2)/100$. The average Care-Related Quality of Life-7D score measuring caregiver quality of life was $(78.3 \pm 18.6)/100$. Caregiver satisfaction had an average rating of $(9.4 \pm 0.8)/10$.

Conclusion Access to epilepsy surgery has significantly improved for children in Manitoba and has led to favorable, early multidimensional outcomes. Structural organization, funding, and multidisciplinary engagement are necessary for program sustainability and growth.

Keywords
- pediatric epilepsy
- program development
- quality improvement
- epilepsy surgery

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Background

Epilepsy is a neurological condition characterized by recurrent and persistent seizures. In North America, it is estimated that 1 in 26 people will develop epilepsy in their lifetime.[1–3] In the province of Manitoba, with a population of approximately 1.37 million, the prevalence of epilepsy is estimated to be upwards of 50,000 patients. Epilepsy is associated with accidental trauma, heightened morbidity and/or mortality, negative side effects from antiepileptic drugs (AEDs), and emotional, psychological, and social stressors. The cumulative effects of unimpeded seizures can disrupt cognitive and behavioral development, with significant health-related and socioeconomic costs at the personal, familial, and societal levels.[4–6]

Of newly diagnosed patients with epilepsy, nearly half (i.e., 47%) will attain seizure freedom with just one AED.[7] Another 13% of patients are estimated to achieve seizure freedom with the addition of a second medication. Beyond this, an effect of diminishing returns is established, with only 4% benefiting from the addition of a third agent. Thus, for patients with "medically refractory epilepsy," (i.e., approximately one-third of epilepsy patients), epilepsy surgery offers the only chance at improved seizure control and/or seizure freedom. This has led to recommendations by the International League Against Epilepsy (ILAE) supporting earlier referrals for epilepsy surgery.[8] Achieving seizure freedom earlier and at younger ages can have positive impacts on cognition, development, social integration, and mental health, leading to improved quality of life.[9–11]

In Canada, access to AEDs, tools for comprehensive work-up, and access to epilepsy surgery all remain inconsistent from province to province. Certain subgroups of children face disproportionately large barriers in access to epilepsy surgery,[12] and geographic location seems to impact a child's chances of surgical candidacy and seizure freedom, as there may be significant variability in practice patterns and available technologies.[13] In Manitoba, in an effort to discern the state of clinician knowledge toward the management of epilepsy, a qualitative survey was previously delivered to primary care and specialist physicians across a spectrum of disciplines.[14] Notably, only 33.3% of respondents had heard of the ILAE guidelines, with 56.5% unaware of invasive electroencephalogram (EEG) techniques to study the condition. Note that 78.7% of respondents understood a role for epilepsy surgery, but 11.1% were unaware of surgical therapies beyond vagal nerve stimulation.[14] These results highlighted a concerning gap in epilepsy knowledge and awareness toward the condition as well as the need for increased epilepsy-focused resources (including epilepsy surgery) in the province.

In this context, a coordinated effort led to the creation of a formalized Pediatric Epilepsy Program in 2016, bolstered by recruitment of dedicated epilepsy-focused specialists in neurosurgery and neurology, and dedicated participation from a neuropsychologist. On the back of private donations graciously received through the Children's Hospital Foundation, the Winnipeg Children's Hospital completed eventual construction of a two-bed Pediatric Epilepsy Monitoring Unit (PEMU) in late 2017. A bimonthly multidisciplinary Refractory Epilepsy Conference was instated, with participation from specialists in neurology, neurosurgery, neuroradiology, neuropsychology, nuclear medicine, and neuropathology. These developments have bolstered the organized referral, review, and treatment of pediatric patients with medically intractable epilepsy from Manitoba, Nunavut, and North-Western Ontario.

Here, we report an early quality-focused review characterizing the management of children undergoing evaluation for epilepsy in Manitoba, including quantifying surgical wait times from time of diagnosis, types of surgeries being offered, clinical outcomes of pediatric patients who have undergone epilepsy surgery, assessment of the quality of life of patients and their caregivers receiving care, and caregiver satisfaction with the Pediatric Epilepsy Program.

Methods

A retrospective chart review was undertaken of all pediatric patients who had previously undergone epilepsy surgery at the Children's Hospital in Winnipeg between 1997 and 2016, prior to the start of the formalized Pediatric Epilepsy Program in 2016. This patient cohort served as a historical control for seizure outcomes of pediatric epilepsy surgery patients, allowing for comparisons to be made with patients treated following inception of the new program in 2016. A secure electronic database was created using REDCap software (Vanderbilt University). This was used to prospectively capture and record the demographics and outcomes of new, incoming patients (between 3 and 20 years of age) assessed through the program and undergoing epilepsy surgery, with at least a 3-month follow-up period. Data fields collected in the REDCap database are shown in ►**Supplementary Appendix A** (available in the online version). Patients who underwent previous epilepsy surgery performed elsewhere (i.e., outside Manitoba) were excluded from this study. All patients and their families were consented in accordance with the study protocol, which was approved by the Bannatyne Campus Research Ethics Board at the University of Manitoba.

With respect to primary outcome measures, seizure frequency and number of AEDs were preoperatively recorded for each patient and at several postoperative intervals (3 months, 6 months, and at last follow-up). Surveys were conducted to document quality of life metrics and caregiver satisfaction using validated tools drawn from the literature, as described herein. Patient quality of life was assessed using the "Quality of Life in Childhood Epilepsy Questionnaire" (QOLCE-55) which assesses parent-reported health-related quality of life of children with epilepsy between 4 and 18 years of age (►**Supplementary Appendix B**, available in the online version).[15–17] This tool takes approximately 12 to 14 minutes to complete, and evaluates functioning in four domains: cognitive, emotional, social, and physical.

Impact of caregiving on caregiver quality of life was assessed using the "Care-Related Quality of Life" instrument (CarerQol-7D). This tool assesses the burden of care as per five established negative dimensions (i.e., relational challenges, mental health concerns, difficulties combining daily activities

with care tasks, financial problems, and physical limitations) and two positive dimensions (i.e., fulfillment from caregiving and social/family support) associated with providing care (►**Supplementary Appendix C**, available in the online version). Utility scores have been developed for each dimension; possible scores range from 0 to 100, with higher scores denoting reduced caregiver burden.[18] The CarerQol-7D tool also measures overall caregiver happiness on a scale of 0 to 10, with 10 being a state of complete happiness.[19]

Similarly, caregiver satisfaction was quantified at the onset of the newly developed Pediatric Epilepsy Program. Ygge and Arnetz[20] developed a parent version of an existing adult patient satisfaction questionnaire that measures satisfaction based on the following parameters: information about the illness, information about routines, accessibility, medical treatment, care processes, staff attitudes, participation, and staff work environment. Caregiver satisfaction was therefore assessed in our population using this instrument (►**Supplementary Appendix D**, available in the online version), which has been found to demonstrate satisfactory internal content and construct validity, as well as internal reliability.[20]

Where able, aggregated data was analyzed and presented using standard descriptive statistics. Demographic, clinical, and outcome-related numerical data were summarized using means, standard deviations, and ranges. Categorical variables were presented as frequencies and percentages.

Results

Demographics

Detailed demographics for two patient groups treated either prior to, or following, inception of the Pediatric Epilepsy Program are presented in ►**Table 1**. Prior to 2016, 16 children (9 females; 7 males) underwent epilepsy surgery in Manitoba. Etiologies of epilepsy for these patients were heterogeneous, ranging from metabolic to structural causes. Seizure frequency ranged from 60 seizures per day to clusters of seizures every 2 weeks. Eleven out of 16 patients (68.75%) experienced multiple seizures per day. The average number of AEDs per patient was 3 ± 1. With regards to type of procedure, all patients in this cohort underwent insertion of a vagal nerve stimulator (VNS) for medically refractory epilepsy. The mean age at surgery was 9.7 ± 3.5 years, and the mean time to surgery from seizure onset was 5.5 ± 2.9 years (range 2–11 years). There were no complications documented as related to the effects of surgical intervention.

Following inception of the Pediatric Epilepsy Program in 2016 and completion of a new PEMU in 2017, 14 children (6 females; 8 males) underwent work-up and referral for epilepsy surgery. The etiology of epilepsy in this cohort included low-grade epileptogenic tumors (5 patients, 35.71%), cortical dysplasia (2 patients, 14.29%), and a host of other diverse pathologies (summarized in ►**Table 1**). For this cohort of

Table 1 Demographic information for pediatric epilepsy patients treated prior to (pre-2016), and following inception of a Pediatric Epilepsy Program and Epilepsy Monitoring Unit in Manitoba (2017 onwards)

	Prior to 2016	After inception of a formalized Pediatric Epilepsy Program and EMU (2017 and onwards)
n (M:F)	16 (7:9)	14 (8:6)
# of AEDs at time of surgery	3 ± 1	2 ± 1
Mean age at surgery (y)	9.7 ± 3.5	11.2 ± 5.1
Mean time to surgery from seizure onset (y)	5.5 ± 2.9	5.5 ± 3.0
Etiology of epilepsy	Pachygyria (2) Gray matter heterotopia (1) Cortical dysplasia (1) Ceroid lipofuscinosis (1) Trauma (1) Lissencephaly (1) Perinatal stroke (1) Aicardi-Goutieres syndrome (1) Dravet syndrome (1) Mosaic trisomy 13 (1) Q10 deletion syndrome (1) Unknown (4)	Low grade tumor (5) Cortical dysplasia (2) Mesial temporal sclerosis (1) Cavernoma (1) Arachnoid cyst (1) Trauma (1) West syndrome (1) Unknown (2)
Surgery type	Vagal nerve stimulator insertion (16)	Anterior temporal lobectomy and amygdalohippocampectomy (5) Hemispherectomy (1) Frontal lobectomy (1) Nontemporal tumor resection (2) Cavernoma resection (1) Arachnoid cyst resection (1) Vagal nerve stimulator insertion (3)

Abbreviations: AED, antiepileptic drug; EMU, epilepsy monitoring unit.

patients, seizure frequency varied from greater than 100 per day to clusters of seizures every 2 months. Six out of 14 patients (42.86%) experienced multiple seizures per day. The average number of AEDs per patient was 2 ± 1. The types of epilepsy surgery performed in this cohort included: standard anterior temporal lobectomy and amygdalohippocampectomy (5 patients, 35.7.1%), hemispherectomy (1 patient, 7.14%), frontal lobectomy (1 patient, 7.14%), nontemporal tumor resection (2 patients, 14.29%), cavernoma resection (1 patient, 7.14%), arachnoid cyst fenestration/marsupialization (1 patient, 7.14%), and VNS insertion (3 patients, 21.43%). The mean age at surgery was 11.2 ± 5.1 years, and the mean time to surgery from seizure onset was 5.5 ± 3.0 years (range 4 months–10 years). A perioperative complication developed in 1 patient (7.14%), who experienced transient right-hand weakness following a left frontal lesionectomy; this deficit fully resolved within 1 month. The average length of hospital stay for these patients was 4.64 ± 3.30 days; all patients were discharged home.

Primary Outcomes

The comparative results of two patient cohorts undergoing epilepsy surgery prior to, and following, inception of the new Pediatric Epilepsy Program are shown in ►**Fig. 1**. Of the 16 patients who had surgery prior to 2016, follow-up ranged from 1 to 5 years. At last follow-up, 1 patient (6.25%) was seizure-free (Engel class I), 12 patients (75%) had a worthwhile improvement in seizures (Engel class III), and 3 patients (12.5%) experienced no worthwhile improvement in seizures (Engel class IV). All patients remained on AEDs at last follow-up. In the cohort of 14 patients undergoing epilepsy surgery through the new Pediatric Epilepsy Program and PEMU (2017 onwards), follow-up ranged from 3 to 12 months. At last follow-up, 11 patients (78.6%) were seizure-free (Engel class I), 2 patients (14.3%) had worthwhile improvement with at least a 50% reduction in seizure burden (Engel class III), and 1 patient (7.1%) had no worthwhile improvement (Engel class IV) following VNS placement. One patient (7.1%) was weaned off his AEDs by the last follow-up visit.

Patient Quality of Life Metrics

For the cohort of patients treated following inception of the new Pediatric Epilepsy Program and PEMU (2017 onwards), we sought to establish quality of life metrics, to serve as a historical control for future studies assessing quality initiatives of this program. Notably, 11 out of 14 patient caregivers (78.6%) completed the QOLCE-55 as a surrogate measure of patient quality of life. Two patients were excluded due to age, and one caregiver did not complete the questionnaire. The average composite QOLCE-55 score was $(59.69 \pm 23.22)/100$, with higher scores in emotional ($[69.38 \pm 16.69]/100$) and social functioning ($[66.56 \pm 29.83]/100$). The lowest score was related to cognitive functioning ($[51.05 \pm 32.42]/100$). Of interest, scores were higher in patients about to undergo resective/disconnective surgery (i.e., lobectomy, hemispherectomy, lesionectomy, etc.) ($[63.70 \pm 22.29]/100$), as compared

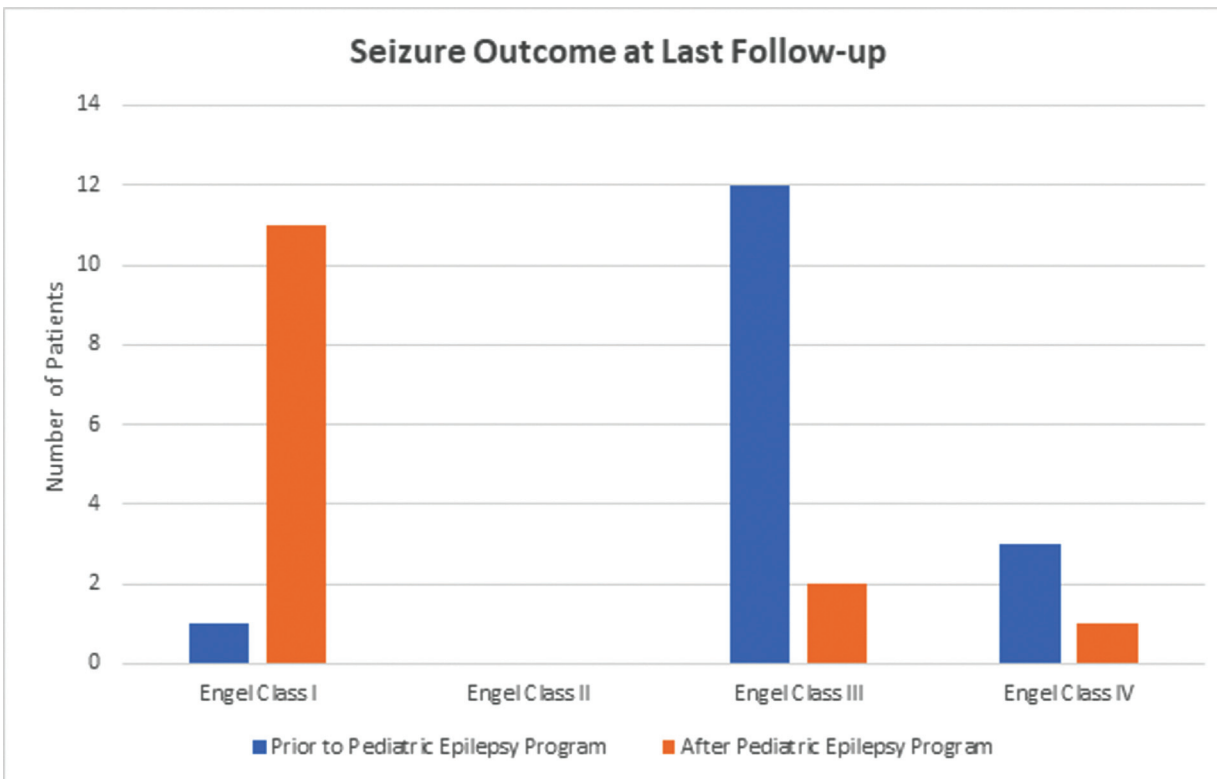

Fig. 1 Seizure outcome at last follow-up for pediatric patients treated with epilepsy surgery prior to (blue columns) and following (orange columns) inception of a Pediatric Epilepsy Program and Epilepsy Monitoring Unit. The introduction of a full complement of epilepsy surgical procedures led to a demonstrable improvement in seizure outcomes, with increased numbers of patients attaining seizure freedom (Engel class I outcomes).

with those scheduled for nonresective surgery (i.e., VNS insertion) ([49.00 ± 26.85]/100)—however, this result was not found to be statistically significant ($p = 0.5$).

Caregiver Quality of Life and Satisfaction Metrics

In the same cohort of pediatric patients treated since formation of the Pediatric Epilepsy Program, caregiver quality of life and satisfaction surveys were conducted to establish a historical control for future comparative studies assessing the efficacy of the program. Of note, 100% of caregivers completed the CarerQol-7D survey, used as a surrogate measure of caregiver quality of life. The average composite CarerQol-7D score was (78.31 ± 18.64)/100. Scores were similar between patients scheduled for resective/disconnective surgery ([78.21 ± 16.46]/100) and nonresective surgery (i.e., VNS insertion) ([78.73 ± 31.30]/100), with no significant differences noted. The average global happiness score for the caregiver cohort was (7.23 ± 1.68)/10. Additionally, 12 caregivers out of 14 (85.7%) completed the Parent Questionnaire, which was used as a marker of caregiver satisfaction. In the cohort of pediatric patients undergoing evaluation and treatment through the newly implemented Pediatric Epilepsy Program, caregiver satisfaction received an average score of (9.38 ± 0.77)/10, with the highest subcategory scores observed in staff attitudes ([96.18 ± 8.23]/100) and participation ([92.36 ± 10.93]/100). The lowest subcategory score was in staff work environment ([70.00 ± 23.20]/100). Intermediate subcategory scores were also captured as follows: Information – illness (mean [91.67 ± 13.30]/100); Information – routines (mean [86.81 ± 15.67]/100); Accessibility (mean [86.11 ± 17.81]/100); Medical treatment (mean [90.28 +/− 12.73]/100); and Caring process (mean [90.63 ± 11.11]/100).

Discussion

Epilepsy surgery can significantly decrease seizure burden in medically intractable patients, with seizure-free success rates reported as high as 70% or more in the literature.[21] Given that epilepsy impacts the health and quality of life of patients (and their caregivers), earlier referral for screening and consideration of epilepsy surgery is now recommended.[22,23] For patients in underserved regions, wait times for out-of-province referrals in Canada can be lengthy (measured in months to years), with concomitant personal, familial, and societal costs, in addition to the ever-looming risk of epilepsy-related morbidity and mortality (including "sudden unexplained death in epilepsy," or SUDEP[24,25]). In this context, following the establishment of a formal Pediatric Epilepsy Program at the Winnipeg Children's Hospital in 2016 and completion of a PEMU in late 2017, we sought to capture an early snapshot of the program's impact on patient care in Manitoba.

Based on the early experiences reported herein, the mean time to surgery from seizure onset for pediatric epilepsy patients in Manitoba remained relatively stable, from 5.5 ± 2.9 years (range 2–11 years) in the pre-Program era as compared with 5.5 ± 3.0 years (range 4 months–10 years) once the Program was underway. Apart from vagal nerve simulator insertion procedures, the Program introduced a full complement of epilepsy surgical procedures, affording patients and their families the opportunity to be treated locally within the province. The early impact of these procedures was assessed, such that at last follow-up, satisfactory seizure outcomes were achieved as evidenced by an increased number of patients attaining complete seizure freedom (78.6% vs. the earlier pre-Program cohort of patients, 6.25%, achieving Engel Class I outcomes). These dramatic improvements in seizure outcomes are consistent with reported surgical results published from higher volume centers in North America and Europe.[8,26–28]

Patient quality of life scores assessed at the onset of the Pediatric Epilepsy Program included an overall mean QOLCE-55 score of 57.69%, which is also consistent with other reported values in the literature, typically ranging from 30 to 60% preoperatively and 30 to 80% postoperatively.[19,29–31] Similarly, the mean CarerQol-7D score of 78.31 and mean global happiness score of 7.23 reported for our caregiver cohort, serving as a surrogate measure of caregiver quality of life, is concordant with other CarerQol-7D scores in the literature. The latter are seen to range from 70 to 80, with global happiness scores ranging from 6 to 8 among caregivers of epilepsy patients, as well as other (mixed) caregiver cohorts.[19,32] Overall, our preliminary results highlight the positive effects of introducing a formal pediatric epilepsy surgery program in Manitoba, setting an early cornerstone for subsequent data collection as the Program evolves.

Program Development—Lessons Learned and Future Directions

Importantly, in underdeveloped regions, there is a clinical and societal impetus to develop multidisciplinary programs, bolstered by requisite infrastructure and equipment, to introduce a defined standard of care for patients with epilepsy. This is particularly important for patient populations who lack access to such programs in Canada, and for whom out-of-province referrals are not feasible due to patient factors, cost, and/or geographic disparity, among other limitations. Experiences with epilepsy program development have rarely been published, aside from those in developing countries or severe low-resource settings, hence the value of our report herein. High complexity health care such as that required to deliver epilepsy surgery demands a dedicated multidisciplinary team that not only includes physicians and nurses, but also buy-in from hospital leadership and government. Innovative solutions are often required to overcome limitations in equipment and facilities, as has been reported elsewhere.[33] In this context, in terms of "lessons learned," we briefly review several fundamental tenets necessary for the continued growth and sustainability of the Pediatric Epilepsy Program in Manitoba, focusing on the themes of structural organization, funding, multidisciplinary engagement, and ancillary support.

First, structural organization is necessary from the onset, referring to the acquisition and retention of key human and physical resources. The Pediatric Epilepsy Program at the Winnipeg Children's Hospital was conceived out of targeted recruitment of an epilepsy-focused neurosurgeon and two

pediatric epileptologists, receiving support from leadership to make this a high priority in the region's health care agenda. The formation of the PEMU in late 2017 was the result of a collaborative, multidisciplinary planning effort encompassing numerous stakeholders across various medical specialities, nursing representatives, EEG technicians, site leads, hospital leadership, and government. It was imperative for these diverse components to come together toward pursuit of a common goal—to provide better care for pediatric patients with epilepsy in the province. A longitudinal database is also necessary to monitor each patient's progression through the system, and essential to allow multiple providers to monitor patient progress and long-term surgical outcomes.

Second, funding is a well-recognized component of program development that is essential to permit proper structural organization and continued growth. Local epilepsy success stories, academic credibility, research efforts, fundraising initiatives, and public education highlighting the importance of medical and surgical care for epilepsy, have all been helpful in attracting private donations and government funding, the latter being imperative to any further expansion of the Program.[13] In general, fiscal responsibility and management of these funds is paramount to the longitudinal health and sustainability of such complex programs, not just in the procurement of one-time capital costs, but in securing operating funds to run the program. It is imperative that this process receive coordinated oversight from hospital leadership, foundations, and committed government officials, alike.

Additionally, both multidisciplinary engagement and ancillary support are mandatory in the conception, formation, and establishment of an epilepsy surgery program. Competent nursing staff, EEG technicians, physician specialists, physical and occupational therapists, nutritionists, and social workers are just some examples of the diversity of staff and expertise required to deliver a sustainable and comprehensive epilepsy program. A regular bimonthly Epilepsy Conference has been effective in providing an avenue for interdisciplinary discussion, team building, and collaboration focusing on patient management and program development issues. Frequent interaction with site leads, hospital leadership, hospital foundations, and government further bolster the health of the program, allowing for strategic and consistent planning to expand on a provincial scale.

Of relevance, Kolb's adult learning cycle for experiential learning may be applied to the development of surgical education programs (►**Fig. 2**).[13] This cycle integrates four key components: experience, assessment, goals, and change. According to this framework, the multidisciplinary epilepsy program described herein experienced the initial stages of program development, as manifested through the early "experience" of treating a small cohort of pediatric epilepsy patients and reporting on their seizure outcomes. In addition to this preliminary experience, an early "assessment" of multidimensional clinical outcomes and patient/caregiver metrics was undertaken. Moving forward, in accordance with Kolb's cycle, the next step will be to set formal goals which include: (1) Increased patient and referring physician awareness about the program; (2) streamlining the path from early referral to epilepsy work-up and surgical management; (3) introduction of invasive EEG methods for treating complex epilepsy; and (4) bolstering financial support for the program, including securing operating costs for program sustainability. As per the last step of Kolb's cycle, changes may then be introduced on the basis of ongoing data capture and iterative evaluation, to improve overall performance and complete the cycle.

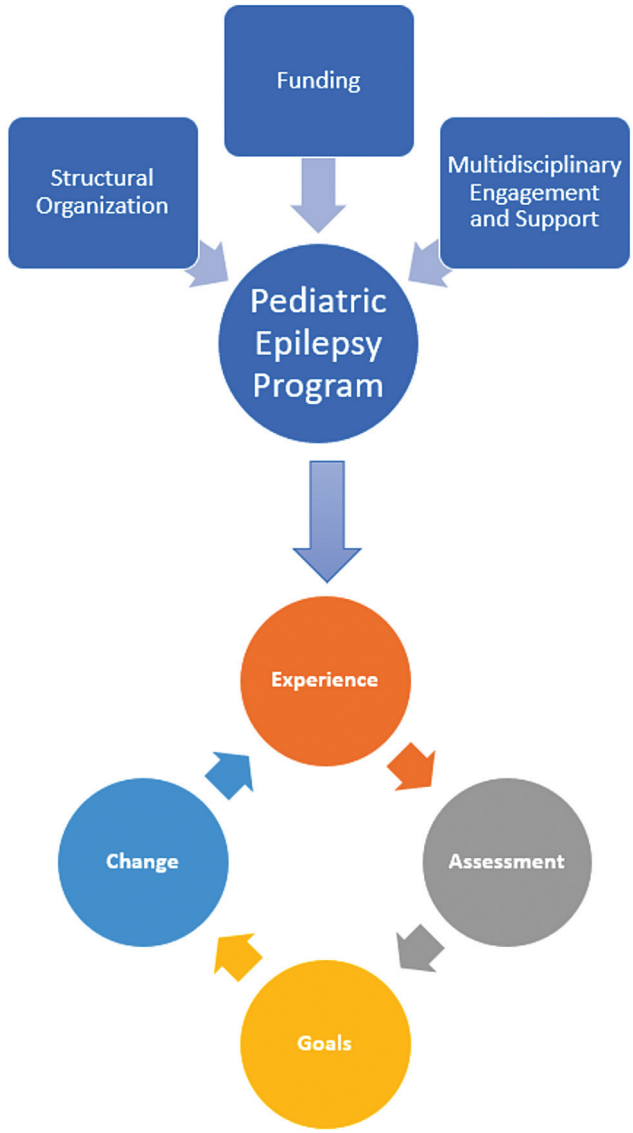

Fig. 2 Simplistic diagrammatic representation of the requisite elements necessary to develop and sustain a multidisciplinary epilepsy program. Please note Kolb's learning cycle (bottom), comprised of the fundamental elements required to drive educational program development, namely experience, assessment, goals, and change.

Limitations

Primary limitations to evaluating pediatric epilepsy surgery outcomes in this cohort relate to the small sample size and short duration of follow-up, the majority of which is accounted for by the very early stages of the Program which also coincided with the clinical upheaval incurred by the COVID-19 pandemic in early 2020. Moreover, although

evaluating outcome measures as early as 6 months postsurgery or later is ideal to capture lasting postsurgical outcomes, the data presented herein is important to begin collecting, serving as proof-of-concept for future studies examining the later downstream effects of the Program.

Despite offering a wider variety of surgical procedures since the implementation of the program and opening of the PEMU, the time from epilepsy diagnosis to surgery remained stable. This relatively long wait time (5.5 years) may be due to a variety of contributing factors, one of which likely relates to the infant stage of the program. Depending on the complexity of patient pathology, some patients require a lengthier preoperative work-up and/or a higher number of investigations prior to surgery. Certain preoperative investigations such as magnetoencephalography and invasive EEG monitoring are also unavailable in Manitoba; as such, patients requiring these investigations must rely on lengthy out-of-province referrals to other Canadian provinces (bordering on months to years). In addition, delayed referrals to the Program, perhaps owing to lack of clinician knowledge or awareness about epilepsy surgery or even the Program itself, as well as variable operative wait times, may also be contributing factors. Increased advocacy for epilepsy patients and enhanced exposure of the program among the general pediatric (and adult) community through presentations, medical conferences, local literature, and social media, among other sources, are anticipated to further improve awareness for the Program.

Finally, given the small sample sizes reported, it was not feasible to compute statistical analyses on factors that may influence seizure and quality of life outcomes. Nevertheless, by starting a database at the earliest stages of program inception, it is hoped that such analytical metrics shall be pursued in the future. This process will be conditional on increased data capture relying on increased volumes of patients and possibly multicenter collaborations.

Conclusion

Experiences with epilepsy program development are infrequently reported in the literature. With the formation of a formal Pediatric Epilepsy Program at the Winnipeg Children's Hospital in 2016, followed by construction of a PEMU in late 2017, access to epilepsy surgery has dramatically improved for children with refractory epilepsy in the province of Manitoba. The Program offers a wide variety of procedures not previously available, and has been underway for nearly 3 years, with satisfactory seizure outcomes and safe postoperative results. A formalized clinical database has been established to capture the early experience with the Program, and favorable multidimensional outcomes have been surveyed, including clinical outcomes, patient and caregiver quality of life metrics, and caregiver satisfaction. Although the Program is in its early stages (notably also coinciding with the COVID-19 pandemic in early 2020), these results are important to capture and serve as a historical control for future comparisons, as the Program continues to evolve. Ultimately, these early findings may also permit better informed counseling of patients and families with respect to epilepsy care in Manitoba.

Our experience has led to important lessons learned as they relate to multidisciplinary program development in underserved regions. Specifically, we highlight the need for structural organization, funding, multidisciplinary engagement, and ancillary support to secure program sustainability and expansion. A longitudinal research database is necessary for continuous quality assessment and iterative improvement. These steps will serve to bolster future program development and growth of the Pediatric Epilepsy Program, to provide improved clinical care for patients with medically refractory epilepsy in the region served.

Conflict of Interest
None declared.

References

1 Theodore WH, Spencer SS, Wiebe S, et al. Epilepsy in North America: a report prepared under the auspices of the global campaign against epilepsy, the International Bureau for Epilepsy, the International League Against Epilepsy, and the World Health Organization. Epilepsia 2006;47(10):1700–1722
2 America EFo. About Epilepsy: The Basics Maryland. 2020 Accessed January 29, 2022 at: https://www.epilepsy.com/learn/about-epilepsy-basics
3 Hesdorffer DC, Logroscino G, Benn EKT, Katri N, Cascino G, Hauser WA. Estimating risk for developing epilepsy: a population-based study in Rochester, Minnesota. Neurology 2011;76(01):23–27
4 Bowen JM, Snead OC, Chandra K, Blackhouse G, Goeree R. Epilepsy care in Ontario: an economic analysis of increasing access to epilepsy surgery. Ont Health Technol Assess Ser 2012;12(18):1–41
5 Langfitt J, Wiebe S. Cost-effectiveness of epilepsy therapy: how should treatment effects be measured? Epilepsia 2002;43 (Suppl 4):17–24
6 Picot MC, Jaussent A, Neveu D, et al. Cost-effectiveness analysis of epilepsy surgery in a controlled cohort of adult patients with intractable partial epilepsy: a 5-year follow-up study. Epilepsia 2016;57(10):1669–1679
7 Shah R, Botre A, Udani V. Trends in pediatric epilepsy surgery. Indian J Pediatr 2015;82(03):277–285
8 Ryvlin P, Cross JH, Rheims S. Epilepsy surgery in children and adults. Lancet Neurol 2014;13(11):1114–1126
9 Ueda R, Kaga Y, Kita Y, et al. Postoperative improvement of executive function and adaptive behavior in children with intractable epilepsy. Brain Dev 2021;43(02):280–287
10 Widjaja E, Jain P, Demoe L, Guttmann A, Tomlinson G, Sander B. Seizure outcome of pediatric epilepsy surgery: systematic review and meta-analyses. Neurology 2020;94(07):311–321
11 Helmstaedter C, Beeres K, Elger CE, Kuczaty S, Schramm J, Hoppe C. Cognitive outcome of pediatric epilepsy surgery across ages and different types of surgeries: a monocentric 1-year follow-up study in 306 patients of school age. Seizure 2020;77:86–92
12 Ibrahim GM, Barry BW, Fallah A, et al. Inequities in access to pediatric epilepsy surgery: a bioethical framework. Neurosurg Focus 2012;32(03):E2
13 Ahmed K, Ibrahim A, Anderson O, et al. Development of a surgical educational research program-fundamental principles and challenges. J Surg Res 2011;167(02):298–305
14 Avery E, MacDonald C, Ng M, Serletis D. Survey of epilepsy and seizure awareness in Manitoba: an evaluation. Epilepsy Behav 2019;92:195–199
15 Goodwin SW, Lambrinos AI, Ferro MA, Sabaz M, Speechley KN. Development and assessment of a shortened Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). Epilepsia 2015;56 (06):864–872

16 Ferro MA, Goodwin SW, Sabaz M, Speechley KN. Measurement equivalence of the newly developed Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). Epilepsia 2016;57(03): 427–435
17 Conway L, Widjaja E, Smith ML, Speechley KN, Ferro MA. Validating the shortened Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55) in a sample of children with drug-resistant epilepsy. Epilepsia 2017;58(04):646–656
18 Hoefman RJ, van Exel J, Brouwer WBF. Measuring Care-Related Quality of Life of Caregivers for use in economic evaluations: CarerQol Tariffs for Australia, Germany, Sweden, UK, and US. Pharmacoeconomics 2017;35(04):469–478
19 Jain P, Subendran J, Smith ML, Widjaja E, Team PSPEPSQOL Study Team. Care-related quality of life in caregivers of children with drug-resistant epilepsy. J Neurol 2018;265(10): 2221–2230
20 Ygge BM, Arnetz JE. Quality of paediatric care: application and validation of an instrument for measuring parent satisfaction with hospital care. Int J Qual Health Care 2001;13(01):33–43
21 Cross JH. Epilepsy surgery in childhood. Epilepsia 2002;43 (Suppl 3):65–70
22 Datta AN, Snyder TJ, Wheatley MB, et al. Intelligence quotient is not affected by epilepsy surgery in childhood. Pediatr Neurol 2011;44(02):117–121
23 Van Schooneveld MM, Braun KP. Cognitive outcome after epilepsy surgery in children. Brain Dev 2013;35(08):721–729
24 Verducci C, Hussain F, Donner E, et al. SUDEP in the North American SUDEP Registry: the full spectrum of epilepsies. Neurology 2019;93(03):e227–e236
25 Sveinsson O, Andersson T, Carlsson S, Tomson T. The incidence of SUDEP: a nationwide population-based cohort study. Neurology 2017;89(02):170–177
26 Wiebe S, Blume WT, Girvin JP, Eliasziw MEffectiveness and Efficiency of Surgery for Temporal Lobe Epilepsy Study Group. A randomized, controlled trial of surgery for temporal-lobe epilepsy. N Engl J Med 2001;345(05):311–318
27 Abarrategui B, Mai R, Sartori I, et al. Temporal lobe epilepsy: a never-ending story. Epilepsy Behav 2021;122:108122
28 UK Children's Epilepsy Surgery Collaboration. The UK experience of stereoelectroencephalography in children: an analysis of factors predicting the identification of a seizure-onset zone and subsequent seizure freedom. Epilepsia 2021;62(08):1883–1896
29 Adla N, Gade A, Puchchakayala G, et al. Assessment of health related quality of life in children with epilepsy using Quality of Life in Childhood Epilepsy Questionnaire (Qolce-55) in tertiary care hospital. J Basic Clin Pharm 2017;8:74–77
30 Titus JB, Lee A, Kasasbeh A, et al. Health-related quality of life before and after pediatric epilepsy surgery: the influence of seizure outcome on changes in physical functioning and social functioning. Epilepsy Behav 2013;27(03):477–483
31 Sabaz M, Lawson JA, Cairns DR, et al. The impact of epilepsy surgery on quality of life in children. Neurology 2006;66(04):557–561
32 Baji P, Golicki D, Prevolnik-Rupel V, et al. The burden of informal caregiving in Hungary, Poland and Slovenia: results from national representative surveys. Eur J Health Econ 2019;20(Suppl 1):5–16
33 Rocque BG, Davis MC, McClugage SG, et al. Surgical treatment of epilepsy in Vietnam: program development and international collaboration. Neurosurg Focus 2018;45(04):E3