JACQUELINE SAUNDERS

Challenges for Children with Epilepsy and the Need for Specialized Transition Programs

This literature review analyzes current research about children with epilepsy and the necessity for specialized transition care programs. It focuses on transition care programs in Canada, which assist individuals with chronic illnesses to switch from a pediatric healthcare model to an adult healthcare model. It explores challenges faced by children with epilepsy that make maintenance of the condition variable for every individual, and how these challenges contribute to the necessity for transition care programs. Despite multiple initiatives across Canada that advocate for the need for transition care programs due to the cognitive, psychological, and developmental challenges children with epilepsy experience, results demonstrate that transition programs are often temporary, and more programs need to be implemented to be available to families of children with epilepsy. Due to the complex nature of epilepsy, the age of transition with its increased risk of psychological and cognitive challenges, and often additional comorbidities, specialized transition programs are required to ensure optimal treatment is maintained. It is crucial that healthcare professionals be equipped with the skills for planning around special healthcare needs, follow evidence-based transition plans, and ensure access to services for individuals going through transition. Results also show transitioning youth are unprepared and parents are not informed about transition programs. Multiple resources found facets of a good transition program include a multidisciplinary team, collaboration between healthcare and families, a family-centred approach, educating families and patients on condition, and a unique plan for each individual. Future research should further explore and define the qualities of a successful transition care program.

Keywords: Epilepsy, childhood epilepsy, transition care programs, epilepsy healthcare, challenges in epilepsy, health-related quality of life, epilepsy outcomes

INTRODUCTION

Participants

Epilepsy is one of the most prevalent neurological disorders, affecting an estimated 50 million people worldwide who live with the condition. Onset often occurs before the age of 30 (Gilmour et al., 2016). Diagnosing epilepsy is complex; it is based on an assessment of symptoms, brain correlates, and cognitive outcomes. Treatment and control of the disorder requires a multidisciplinary team consisting of parents, physicians, and other healthcare providers to ensure optimal medical and developmental care. Epilepsy is a long-term condition and is more prevalent among children than adults (Kotsopoulos et al., 2002); seizures are the most common neurological emergency in the neonatal period (Pressler et al., 2021). Epilepsy affects children into adulthood and treatment can be complicated and life-long (Reger et al., 2018). People with epilepsy are at higher risk for emotional, behavioural (Davies et al., 2003), academic (Puka & Smith, 2016), and adaptive disorders (Papazoglou et al., 2010), which can affect their ability to manage their own care, i.e., the conceptual, social, and practical skills required to perform daily life tasks. Managing epilepsy requires ongoing monitoring because the clinical status of the condition can change throughout an individual's life and classification changes are common (Hanaoka et al., 2017). Childhood onset entails switching from a pediatric healthcare model to an adult healthcare model including changing physicians, increasing responsibility for treatment monitoring, and changing from family-centred to patient-responsible care. These programs aim to improve patient outcomes and are targeted for chronically ill patients who often experience unnecessary and poorly coordinated care, worsening health outcomes, poor mental health challenges, and additional family and friend burden when switching healthcare models (Weeks et al., 2020). Although there have been numerous initiatives advocating for implementation of transition care programs through organizations such as the Government of Canada, the Ministry of Health and Long-Term Care Ontario, and Critical Care Services Ontario, there is limited literature looking at effectiveness of transition programs. Programs are not easily accessible or abundant, and only 15% of families are having transition discussions (Baca et al., 2018).

The goal of this literature review is to determine if there is a need for specialized transition care programs for children diagnosed with epilepsy in Canada. Additional research questions explore the characteristics of effective transition care programs and identify gaps and future steps.

EPILEPSY LITERATURE REVIEW

Epilepsy Overview

Epilepsy is a disorder of the brain and was once defined as having two unprovoked seizures less than 24 hours apart. Presently, a seizure is defined as "a transient occurrence of signs and/or symptoms due to an abnormal excessive or synchronous

neuronal activity in the brain" (Fisher et al., 2016); in other words, there are excessive neurons firing in the brain which could result in observable or unobservable symptoms. Multiple factors affect the nature of seizures such as age, genetic predispositions, brain injuries, and medications (Fisher et al., 2016). The International League Against Epilepsy (ILAE) Classification of the Epilepsies provides current classification criteria for epilepsy and is the most widely used system worldwide in epilepsy research and provision of care (Fisher et al., 2014). According to the ILAE, a practical definition of epilepsy includes any of the following three criteria: at least two unprovoked seizures less than 24 hours apart, one unprovoked seizure and probability of further seizures occurring sometime over the next 10 years, and diagnosis of an epilepsy syndrome (Fisher et al., 2014). There are three levels of labelling epilepsy in the ILAE system. Level 1 identifies a seizure type determined by the area where the seizure happened in the brain (e.g., *Focal onset* means a seizure in one area, *generalized onset* means a seizure in both hemispheres, and *unknown onset* means it is unknown where seizure started). Level 2 determines the epilepsy type, which is based on seizure type. Level 3 determines a diagnosis of Epilepsy Syndrome once a characteristic group of features is identified (Fisher et al., 2016) based on ILAE guidelines. When there is not enough information available about an individual's condition, or when there is limited access to diagnostic methods such as neuroimaging, seizure type may be the only level of diagnosis (Scheffer et al., 2017).

Clinical diagnosis of epilepsy is multiaxial and based on seizure type(s), syndrome, etiology, and family history as determined by a neurologist with specialist training in epilepsy. Each epilepsy diagnosis is unique, and people may have more than one categorization depending on the complexity of the presentation.

Biological & Developmental Outcomes

Early onset epilepsy requires a child to navigate the challenges of typical development in addition to the challenges associated with an epilepsy diagnosis. Camfield et al. (2017) summarized findings from the 2016 Paris 2nd Symposium on Transition in Epilepsies that emphasizes four factors to consider during transition age: brain matter changes, endocrinological changes, sexual development, and psychological development. Endocrinological changes of puberty can have an effect on the incidence and expression of seizures, and the resulting stigma may affect formation of peer relationships.

Psychological & Neurological Outcomes

Executive Functions

Executive functions (EFs) are a set of higher-order mental processes responsible for goal-directed behaviour, decision making, abstract thinking, and cognitive flexibility. EFs play a key role in adaptive functioning (i.e., the ability to navigate the demands of daily life) (Sirois et al., 2016). Importantly, adaptive functioning affects Health-

Related Quality of Life (HRQOL) (Sherman et al., 2006), which is often reduced in children with epilepsy (Modi et al., 2011; Conway et al., 2018) and is possibly a result of EF deficits (Parrish et al., 2007; Sherman et al., 2006). Sherman et al. (2006) found several subsets of neuropsychological measures were predictors of HRQOL; lower HRQOL scores were associated with lower adaptive functioning. Reduced adaptive functioning can result from uncontrolled seizures (Papazoglou et al., 2010; Parrish et al., 2007). This is challenging because one third of people diagnosed with epilepsy live with uncontrolled seizures (Shafer & Sirven, 2013). Children with active epilepsy have higher rates of anti-epileptic drug (AED) use which can also affect HRQOL (Papazoglou et al., 2010). Modi et al. (2011) demonstrate improved HRQOL once complete seizure control was achieved and conclude that AED use and seizure control affect HRQOL. Different AEDs produce different deficits in EF, and different epilepsies produce different cognitive deficits (not always resulting in adaptive functioning issues) (Culhane-Shelburne et al., 2002).

Depression

Patients with epilepsy are at risk for depression, with different epilepsy conditions and seizure locations yielding different risk rates (Schraegle & Titus, 2017; Zhao et al., 2012). Children with epilepsy often have anxiety disorders and display suicidal ideation (Caplan et al., 2005). Psychopathology can present challenges to healthcare professionals (Reilly et al., 2013), making it prudent for physicians, clinicians, families, nurses, and other related healthcare professionals to collaborate to provide appropriate and comprehensive treatment for each individual case.

Social Outcomes

Impairment in neuropsychological functioning puts children with epilepsy at risk for social challenges (Drewel et al., 2009). Raud et al. (2015) evaluated the performance of attention, verbal executive, and fine motor tasks and describe EFs as significantly affected by type of epilepsy and age of onset. Moreover, the most significantly affected facet of EF was Theory of Mind, an abstract cognitive process that helps control social cognitive skills and may determine one's ability to perceive the beliefs of other people.

Health-Related Quality of Life in Epilepsy

Treatment

Epilepsy treatments vary depending on seizure type and epilepsy type. The most common treatment is AEDs, of which there are 35 different types. Surgery is the next common treatment, but additional therapies include neurostimulation (vagal nerve), diet therapy, and alternative therapies (Schachter et al., 2013). Approximately 30-40% of people have drug-resistant epilepsy (Kiriakopoulos & Shafer, 2018), so their options are to consider invasive techniques such as surgical or stimulation-based

treatments (e.g., responsive neurostimulation and deep brain stimulation) (Morris et al., 2013).

Seizure Control

Seizures can be controlled by AEDs and surgery for some individuals, and seizure control has been associated with increased HRQOL, although side effects from AEDs are negatively correlated with HRQOL (Modi et al., 2011). Some AEDs present a higher risk of cognitive and behavioural impairments (Burns et al., 2018). Factors that affect the quality of life in an individual with epilepsy are seizure frequency, control, and location; epilepsy type; and treatment methods. Monitoring treatment success (i.e., seizure control) is an integral part of managing the condition. Patients with active epilepsy had lower rates of academic achievement and higher rates of unemployment (Baca et al., 2018). Furthermore, active seizures are associated with depressive problems (Tavares et al., 2015), and frequency of failed medications can result in a "learned helplessness" mentality which affects HRQOL and highlights the importance of constant medical support throughout treatments (Sherman et al., 2006).

Healthcare Services

Healthcare quality has a major impact on epilepsy treatment and HRQOL. Having access to services, discussions with doctors about conditions and further treatment, medication compliance, and knowledge of the condition all affect quality of life (Baca et al., 2018; Chappell & Smithson, 1998; Gray et al., 2017). Sixty percent of patients with epilepsy were rarely or never satisfied with the amount of information provided by their doctor; 92% of patients with frequent seizures reported no changes in treatment (Chappell & Smithson, 1998). Coker et al. (2010) propose that there is a need for healthcare professionals to improve educating patients about their condition because patients did not have a full understanding of their condition or its treatments. Despite research showing that knowledge of a condition can have a significant effect on intellectual, social, and emotional aspects of quality of life, doctors are not providing enough information about epilepsy (Gray et al., 2017). The preferred choice for treating and maintaining epilepsy consists of a multidisciplinary team (Chappell & Smithson, 1998).

Transition Programs

Transition Period

Epilepsy treatment is often lifelong, with significant differences between pediatric and adult healthcare models. Pediatric healthcare is family-oriented, emphasizes parental involvement in decision making, provides easier access to resources (i.e., clinics and hospitals may offer services needed for children in one place), and offers a warmer environment. Adult healthcare emphasizes patient independence,

increased responsibility, and autonomy in accessing resources, such as choosing members of your healthcare team or finding specialized clinics (Castillo & Kitsos, 2017). However, individuals with epilepsy may be unable to take responsibility for the medication and treatment of their condition, may be unable to determine best fit for team members, or may not know where to access specialized healthcare.

The "transition period" for a child with epilepsy occurs when changing healthcare models at some time between the ages of 18 to 25 years, depending on the healthcare system. This age range is already developmentally, socially, and psychologically a challenging time for people without chronic health conditions. It can be especially challenging for individuals with epilepsy because of their increased risk of cognitive and neuropsychological challenges. Due to the variability in outcomes, comorbidity, and challenges with neuropsychological, developmental, and social functioning skills in children with epilepsy, physicians need to be informed and prepared for comorbidity and understand how these challenges may affect the ability of individuals to maintain their condition or treatment.

Healthcare programs must support the individual moving from pediatric to adult healthcare through a specialized transition program that emphasizes family-centred models and collaboration between families and healthcare providers. Key elements for ensuring a successful transition include guaranteeing that all young people with epilepsy have an identified healthcare professional equipped with the skills for planning around special healthcare needs, identifying knowledge and skills required to provide appropriate healthcare for patients with epilepsy, using evidence-based written transition plans, and ensuring access to services for individuals through childhood into adulthood (Castillo & Kitsos, 2017).

History and Prevalence

Canada acknowledged the importance of transition care programs on September 11, 2000, when the Government of Canada established the Primary Health Care Transition Fund (PHCTF) worth $800 million (Health Services, 2007). This initiative emphasized the importance of a multidisciplinary team and listed common objectives for the programs: improved access; emphasis on health promotion, disease and injury prevention; chronic disease management; 24/7 access to essential services; and coordination with other health services. The Canadian Collaborative Mental Health Care established in 2006 advocated for people with mental illnesses and the importance of a collaborative care team, but this program only lasted two years (Dudgeon, 2006). The Canadian Institutes of Health Research implemented a Transitions in Care initiative: a multi-pillar and trans-disciplinary initiative designed to optimize transition care outcomes through research on changing health status or care in key populations (CIHR, 2021). In 2011, the Ministry of Health and Long-Term Care in Ontario implemented a transition working group to design a framework guideline for transitioning healthcare that included a multidisciplinary team ranging

from physicians (pediatric and adult), epileptologists, psychologists/psychiatrists, neurologists, nurses, social workers, community representatives, specialists, parents of epilepsy, and patients of epilepsy (Andrade et al., 2017). The framework started at ages 12–15 and included seven detailed stages: financial aspects of transitioning, community and legal supports, readiness for transition, risk factors, diagnosis, possible obstacles, and discharge from healthcare (Andrade et al., 2017).

Critical Care Services Ontario (CCSO), comprised of a multidisciplinary team of senior clinical and administrative leaders, implemented an Ontario Critical Care Plan from 2018 to 2021 to address and identify priorities for improving patient and family care (Critical Care Services Ontario, 2018). While receiving support from the Epilepsy Implementation Task Force, the CCSO developed a Comprehensive Epilepsy Program to improve the quality of care in areas such as data-informed improvement, enhanced systems of care for optimal and contiguous progress, and clinicians' skills (Critical Care Services Ontario, 2018). The literature critically supports a collaborative approach for treating chronic conditions.

Transition Care Gap

Despite significant evidence for the need of transition programs (Baca et al., 2018; Camfield et al., 2017; Chappell & Smithson, 1998; Gray et al., 2017; McManus et al., 2013; Reger et al., 2018), programs are often only temporary (e.g., two years), and two of the three transition programs discovered during the course of this review are no longer running. For example, in response to the Ontario Epilepsy Strategy that attempted to make care centres accessible provincewide, the Hospital for Sick Children started a program called Good2Go which provided general information about transitioning and ensured that epileptologists, and paediatric and adult healthcare members, were all involved (Epilepsy Ontario, 2011); Health Quality Ontario started bestPATH, which aimed to improve health outcomes by establishing a smooth transition between areas of care with the main objective to minimize worsening of symptoms, to better coordinate care, and to improve quality of life (Health Quality Ontario, 2012). These are no longer running. BC Children's Hospital created ON TRAC for youth with chronic conditions or disabilities and provides clinical support, individualized transition care planning, and confirmation of transfer to adult care providers (2020). It was extremely difficult to find information about current transition care programs despite multiple initiatives for improved specialized healthcare (e.g., bestPath, Canada's Primary Health Care Transition Fund, a transition working group by the Ministry of Health and Long-Term Care in Ontario, and Critical Care Services Ontario - Ontario Critical Care Plan). Importantly, all parents should be aware of the changes in healthcare models and challenges that may affect a smooth transition, and there should be improved access to and awareness of transitioning care resources because parents are uninformed about the existence of these programs.

Knowledge of Condition

Critical components in a successful transition are knowledge of the condition and information resources about the condition. As reported by the National Survey of Children's Health, only 15% of youth received assistance from their healthcare professionals when transitioning from pediatric to adult healthcare (Crawford, 2018). Parents are not provided with knowledge of a transitioning process, and youth that are transitioning are unprepared. McManus et al. (2013) investigated aspects of transitioning in youth with special healthcare needs and concluded that only 44% of parents reported discussing transitioning with an adult care provider despite 59% who reported discussing other changing healthcare needs, and 78% of parents acknowledged the increased responsibility the youth now has in treatment maintenance. Gray et al. (2017) demonstrated that knowledge of the condition improved throughout the transition process for youth with a transition plan, but decreased for the parent/caregiver, and anxiety was lower in the group that experienced a transition plan. Moreover, while their study shows positive effects of transition programs on children's well-being, it also highlights that parents are not kept informed.

Cooley et al. (2011) provide a detailed clinical report about transitioning from adolescence to adulthood, which connects the necessity of an appropriate transition from pediatric healthcare to adult healthcare to physician education that emphasizes patient and family-centred models and guidelines of transition care. The report describes the need for uninterrupted and developmentally appropriate healthcare services during transition, which impacts transition policies, and includes reviewing the transition plan throughout development and implementing an adult care model (Cooley et al., 2011).

Six overarching themes discovered in this review for effective transition programs include: a collaborative approach that emphasizes a multidisciplinary team consisting of family members, physicians, nurses, and care coordinators; specialized healthcare providers; knowledge of the condition from the individual and family perspective; ongoing training of healthcare providers; individuals having access to resources such as services and information about transitioning; and having a comprehensive, individualized treatment plan that is monitored by the multidisciplinary healthcare team. All members of the multidisciplinary healthcare team, including parents, must be involved in the transition process. A pediatric transition package should accompany the transitioning patient to the new adult physician. Patient and family education is integral to the approach, as is the requirement of the medical professionals and family members to consider the risk factors and psychosocial factors that might affect successful transitioning. A Community of Practice (CoP) established by The Canadian Association of Paediatric Health Care Centres provided *A Guideline for Transition from Paediatric to Adult Health Care Needs: A National Approach* that included 19 recommendations to

facilitate a smooth transition through adolescence into adulthood (CAPHC, 2016). These emphasize personal choice, a family-centred approach, and ensuring inclusion of all facets of a youth's life in understanding transitioning while recommending individualized planning, education on the patient's condition, collaboration of healthcare teams, involvement in pediatric and primary providers, and comprehensive monitoring during transition. At the system level the recommendations include developing written policies, educating and accrediting organizations, and involving youth and families in the process.

The age for transitioning from pediatric to primary adult healthcare coincides with brain and behavioural developments required for independent functioning and the transition period is complex and stressful for the individual, family, and caregivers (CAPHC, 2016). Youth with special care needs are at higher risk for difficulties such as EF deficits, social functioning risks, depression, suicidal ideation, and engaging in risky behaviours requiring different adult care than an individual without special care needs. A transition program should be individualized specifically for the youth because every epilepsy diagnosis is unique, development rates vary, and every individual has different needs to prioritize. Adolescents without developmental disabilities will need a different plan than individuals with many or significant disabilities.

There is limited literature looking at the effectiveness of transition program outcomes (Camfield et al., 2019; Nabbout et al., 2019). Research showed transition programs help lower anxiety and improve self-esteem (Gray et al., 2017). However, awareness of transition programs is limited, parents do not know where to turn for resources, physicians are ineffective at coordinating and collaborating during transition, and transition programs can be costly. Despite literature supporting transition programs (Gray et al., 2017), only around 15% of families learn about them (Baca et al., 2018).

CONCLUSIONS

Epilepsy affects a significant number of people worldwide. Children with epilepsy are at higher risk for depression (Davies et al., 2003; Zhao et al., 2012), social challenges, and impaired EF (Parrish et al., 2007; Sherman et al., 2006). Emphasizing HRQOL is important when addressing challenges relating to transitioning with epilepsy such as AED use, surgery outcomes, treatment plans, and seizure control. Since epilepsy is often lifelong, unique, multi-faceted, and frequently associated with comorbidities, it is difficult for many youth to take responsibility for medication compliance and monitoring their condition. To date in Canada, there are few transition programs longer than two years, and parents are not being informed about them. Previous literature shows rates of epilepsy are highest in childhood (Kotsopoulos et al., 2002); knowledge and treatment methods have a profound effect on quality of life (Gray et al., 2017); children with epilepsy have increased risk for

developmental and psychological challenges; and despite support from literature for specialized transition programs, parents aren't informed about transition programs.

Future research needs to explore treatment outcomes for children with epilepsy to determine the best ways to implement transition programs and focus on EF and adaptive function as a predictor of HRQOL. More programs need to be implemented to ensure accessibility to all individuals, and physicians should engage families in transition discussions. More research about drug resistant epilepsy, alternative treatment methods, and seizure control is needed in addition to general research about epilepsy. Lastly, investigating social challenges and outcomes in children with epilepsy might help improve transition programs.

REFERENCES

American Psychological Association. (n.d.). *APA Dictionary of Psychology*. https://dictionary.apa.org

Charlesworth, T. E., & Banaji, M. R. (2019). [Website]. *Patterns of implicit and explicit attitudes II: Long-term change and stability, regardless of group membership*. http://www.people.fas.harvard.edu/~banaji/research/publications/articles/2021_Charlesworth_AP.pdf

Andrade, D. M., Bassett, A.S., Bercovici, E., Borlot, F., Bui, E., Camfield, P., Clozza, G.W., Cohen, W., Gofine, T., Graves, L., Greenaway, J., Guttman, B., Guttman-Slater, M., Hassan, A., Henze, M., Kaufman, M., Lawless, B., Lee, H., Lindzon, L., Loman, L.B…, Snead, C.O. (2017). Epilepsy: Transition from pediatric to adult care. Recommendations of the Ontario epilepsy implementation task force. *Epilepsia, 58*(9), 1502-1517. https://doi.org/10.1111/epi.13832

Baca, C. M., Barry, F., & Berg, A. T. (2018). The epilepsy transition care gap in young adults with childhood-onset epilepsy. *Epilepsy & Behavior, 87*, 146-151. https://doi.org/10.1016/j.yebeh.2018.06.052

BC Children's Hospital. (n.d.) *Transition to adult care*. Retrieved April 6, 2020, from http://www.bcchildrens.ca/our-services/support-services/transition-to-adult-care

Burns, T. G., Ludwig, N. N., Tajiri, T. N., & DeFilippis, N. (2018). Cognitive and behavioral outcomes among seizure-controlled children with partial epilepsy on antiepileptic drug monotherapy. *Applied Neuropsychology: Child, 7*(1), 52-60. https://doi.org/10.1080/21622965.2016.1241177

Camfield, P. R., Andrade, D., Camfield, C. S., Carrizosa-Moog, J., Appleton, R., Baulac, M., Brown, L., Menacehm, E. B., Cross, H., Desguerre, I., Grant, C., Hosny. H., Jurasek, L., Mula, M., Pfafflin, M., Rheims, S., ring, H., Shellhaas, R. A., Vinayan, K. P., Wirrell, E., & Nabbout, R. (2019). How can transition to adult care be best orchestrated for adolescents with epilepsy? *Epilepsy & Behavior, 93*, 138-147. https://doi.org/10.1016/j.yebeh.2018.12.015

Camfield, P., Camfield, C., Busiah, K., Cohen, D., Pack, A., & Nabbout, R. (2017). The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, and psychological issues. *Epilepsy & Behavior, 69*, 170-176. https://doi.org//10.1016/j.yebeh.2016.11.009

Canadian Association of Pediatric Health Centres (CAPHC). (2016). *A guideline for transition from paediatric to adult health care needs: A national approach*. https://ken.childrenshealthcarecanada.ca/xwiki/bin/download/Transitioning+from+Paediatric+to+Adult+Care/A+Guideline+for+Transition+from+Paediatric+to+Adult+Care/2017%2005%2010%20CAPHC%20Transition%20to%20Adult%20HC%20Guideline.pdf

Caplan, R., Siddarth, P., Gurbani, S., Hanson, R., Sankar, R., & Shields, W. D. (2005). Depression and anxiety disorders in pediatric epilepsy. *Epilepsia, 46*(5), 720-730. https://doi.org//10.1111/j.1528-1167.2005.43604.x

Castillo, C., & Kitsos, E. (2017). Transitions from pediatric to adult care. *Global Pediatric Health, 4*. https://doi.org/10.1177/2333794X17744946

Chappell, B., & Smithson, W. H. (1998). Patient views on primary care services for epilepsy and areas where additional professional knowledge would be welcome. *Seizure*, 7(6), 447-57. https://doi.org/10.1016/s1059-1311(98)80002-2

Canadian Institute of Health Research (CIHR). (2021). *Pre-announcement: Transitions in care – team grants phase 2*. Retrieved from https://cihr-irsc.gc.ca/e/52542.html

Coker, M., Bhargava, S., Fitzgerald, M., & Doherty, C. (2010). What do people with epilepsy know about their condition? Evaluation of a subspecialty clinic population. *Seizure, 20*(1), 55–59. https://doi.org/10.1016/j.seizure.2010.10.007

Conway, L., Widjaja, E., & Smith, M. L. (2018). Impact of resective epilepsy surgery on health-related quality of life in children with and without low intellectual ability. *Epilepsy & Behavior, 83*, 131-136. https://doi.org//10.1016/j.yebeh.2018.03.036

Cooley, W.C., Sagerman, P.J., & American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Journal of the American Academy of Pediatrics*, *128*, 182-202. https://doi.org/10.1542/peds.2011-0969

Crawford, C. (2018, October 31). *Guidance updated on transition of youth to adult care*. American Academy of Family Physicians. https://www.aafp.org/news/health-of-the-public/20181031caretransition.html

Critical Care Services Ontario (2018). *Ontario critical care plan 2018-2012*. Retrieved on 2020, April 8, from https://criticalcareontario.ca/wp-content/uploads/2020/10/CCSO-Strat-Plan-2018-2021-Feb-4-flat.pdf

Culhane-Shelburne, K., Chapieski, L., Hiscock, M., & Glaze, D. (2002). Executive functions in children with frontal and temporal lobe epilepsy. *Journal of the*

International Neuropsychological Society, 8(5), 623-632. https://doi.org/10.1017/S1355617702801308

Davies, S., Heyman, I., & Goodman, R. (2003). A population survey of mental health problems in children with epilepsy. *Developmental Medicine & Child Neurology, 45*(5), 292-295.

Drewel, E. H., Bell, D. J., & Austin, J. K. (2009). Peer difficulties in children with epilepsy: Association with seizure, neuropsychological, academic, and behavioral variables. *Child Neuropsychology, 15(*4), 305-320. https://doi.org/10.1080/09297040802537646

Dudgeon, S. (2006). From consortium to CCMHI. *Canadian Collaborative Mental Health Initiative (CCMHI)*. http://www.shared-care.ca/files/CCMHIataglance.pdf

Fisher, R.S., Acevedo, C., Arzimangolou, A., Bogacz, A., Cross, J. H., Elger, C. E., Engel, Jr. J., Forsgren, L., French, J. A., Glynn, M., Hesdorffer, D. C., Lee, B. I., Mathern, G. W., Moshe, S. L., Perucca, E., Scheffer, I.E., Tomson, T., Watanabe, M., & Weibe, S. (2014). ILAE official report; practical definition of epilepsy. *Epilepsia*, *55*(4), 475-482. https://doi.org/10.1111/epi.12550

Fisher, R. S., Shafer, P. O., & D'Souza, C. (2016) *2017 Revised classification of seizures.* Epilepsy.com. https://www.epilepsy.com/article/2016/12/2017-revised-classification-seizures

Gilmour, H., Ramage-Morin, P., & Wong, L. S. (2016). Epilepsy in Canada: Prevalence and impact. *Statistics Canada.* 82-003-X. https://www150.statcan.gc.ca/n1/pub/82-003-x/2016009/article/14654-eng.htm

Gray, V., Palmer, L., Whelby, K., Vinten, J., & Gait, L. (2017). Exploring the role of knowledge of condition and psycho-social profiles of young people with epilepsy during transition. *Epilepsy & Behavior*, *73*, 156–160. https://doi.org/10.1016/j.yebeh.2017.05.003

Hanaoka, Y., Yoshinaga, H., & Kobayashi, K. (2017). A ten-year follow-up cohort study of childhood epilepsy: Changes in epilepsy diagnosis with age. *Brain & Development, 39*(4), 312-320. https://doi.org/10.1016/j.braindev.2016.10.011

Health Services (2007, March 1). *Primary health care transition fund*. Canada.ca. Retrieved from https://www.canada.ca/en/health-canada/services/primary-health-care/primary-health-care-transition-fund.html

Health Quality Ontario. (2012, November). *Transitions of care*. Health Quality Ontario. https://www.hqontario.ca/Portals/0/documents/qi/health-links/bp-improve-package-transitions-en.pdf

Kotsopoulos, A. I., Merode, T. V., Kessels, F. G., De Krom, M. C., & Knotterus, J. A. (2002). Systematic review and meta-analysis of incidence studies of epilepsy and unprovoked seizures. *Epilepsia, 43*(11), 1409-1409. https://doi.org/10.1046/j.1528-1157.2002.t01-1-26901.x

Kiriakopoulos, E., & Shafer, P. O. (2018, October). The journey to epilepsy surgery: What you need to know. Epilepsy.com. https://www.epilepsy.com/learn/treating-seizures-and-epilepsy/surgery

McManus, M. A., Pollack, L. R., Cooley, W. C., McAllister, J. W., Lotstein, D., Strickland, B., & Mann, M. Y. (2013). Current status of transition preparation among youth with special needs in the United States. *Pediatrics*, *131*(6), 1090–1097. https://doi.org/10.1542/peds.2012-3050

Modi, A. C., Ingerski, L. M., Rausch, J. R., & Glauser, T. A. (2011). Treatment factors affecting longitudinal quality of life in new onset pediatric epilepsy. *Journal of Pediatric Psychology, 36*(4), 466-475. https://doi.org/10.1093/jpepsy/jsq114

Morris, G. L., 3rd, Gloss, D., Buchhalter, J., Mack, K. J., Nickels, K., & Harden, C. (2013). Evidence-based guideline update: Vagus nerve stimulation for the treatment of epilepsy: Report of the Guideline Development Subcommittee of the American Academy of Neurology. *Neurology*, *81*(16), 1453–1459. https://doi.org/10.1212/WNL.0b013e3182a393d1

Nabbout, R., Arzimanoglou, A., Chin, R. F. M., Grinspan, Z., Speechley, K., & Camfield, P. (2019). The evaluation and costs of transition programs for youth with epilepsy. *Epilepsy & Behavior, 93*, 133-137. https://doi.org/10.1016/j.yebeh.2018.12.014

Papazoglou, A., King, T. Z., & Burns, T. G. (2010). Active seizures are associated with reduced adaptive functioning in children with epilepsy. *Seizure, 19*(7), 409-413. https://doi.org/10.1016/j.seizure.2010.06.007

Parrish, J., Geary, E., Jones, J., Seth, R., Hermann, B., & Seidenberg, M. (2007). Executive functioning in childhood epilepsy: Parent-report and cognitive assessment. *Developmental Medicine & Child Neurology, 49*(6), 412-416. https://doi.org/10.1111/j.1469-8749.2007.00412.x

Pressler, R. M., Cilio, M. R., Mizrahi, E. M., Moshe, S. L., Nunes, M. L., Plouin, P., Vanhatalo, S., Yozawitz, E., de Vries, L. S., Vinayan, K. P., Triki, C. C., Wilmshurtst, J. M., Yamamoto, H., & Zuberi, S. M. (2021). The ILAE classification of seizures and the epilepsies: Modification for seizures in the neonate. Position paper by the ILAE Task Force on Neonatal Seizures. *Epilepsia (Copenhagen)*, *62*(3), 615–628. https://doi.org/10.1111/epi.16815

Puka, K., & Smith, M. L. (2016) Academic skills in the long term after epilepsy surgery in childhood. *Epilepsy & Behavior, 62, 97-103*. https://doi.org/10.1016/j.yebeh.2016.06.003

Raud, T., Kaldoja, M-L., & Kolk, A. (2015). Relationship between social competence and neurocognitive performance in children with epilepsy. *Epilepsy and Behavior, 52(*Part A), 93-101. https://doi.org/10.1016/j.yebeh.2015.08.028

Reilly, C., Kent, E., & Neville, B. G. R. (2013). Review: Psychopathology in childhood epilepsy. *Child and Adolescent Mental Health, 18*(2), 65-75. https://doi.org/10.1111/j.1475-3588.2012.00648.x

Reger, K. L., Hughes-Scalise, A., & O'Connor, M. A. (2018). Development of the transition-age program (TAP): Review of a pilot psychosocial multidisciplinary transition program in a level 4 epilepsy center. *Epilepsy & Behavior, 89*, 153-158. https://doi.org/10.1016/j.yebeh.2018.10.021

Schachter, S. C., Shafer, P. O., & Sirven, J. I. (2013, July). *Treating seizures and epilepsy*. Epilepsy.com. https://www.epilepsy.com/learn/treating-seizures-and-epilepsy

Scheffer, I. E., Berkovic, S., Capovilla, G., Connolly, B. M., French, J., Guilhoto, L., Hirsch, E., Jain, S., Mathern, w. G., Moshe, L. S., Nordli, R.D., Perucca, E., Tomson, T., Weibe, S., Zhang, Y-H., & Zuberi, M. S. (2017). ILAE classification of the epilepsies: Position paper of the IALE Commission for Classification and Terminology. *Epilepsia*, 58(4), 512-521. https://doi.org/10.1111/epi.13709

Schraegle, W. A., & Titus, J. B. (2017). The relationship of seizure focus with depression, anxiety, and health-related quality of life in children and adolescents with epilepsy. *Epilepsy & Behavior, 68, 115-122*. https://doi.org/10.1016/j.yebeh.2016.12.009

Shafer, P., & Sirven J. (2013) Facts about seizures and epilepsy. *Epilepsy Foundation*. https://www.epilepsy.com/learn/about-epilepsy-basics/facts-about-seizures-and-epilepsy

Sherman, E. M. S., Slick, D. J., & Eyrl, K. L. (2006). Executive dysfunction is a significant predictor of poor quality of life in children with epilepsy. *Epilepsia, 47*(11), 1936-1942. https://doi.org/10.1111/j.1528-1167.2006.00816.x

Sirois, P. A., Chernoff, M. C., Malee, K. M., Garvie, P. A., Harris, L. L., Williams, P. L., Woods, S. P., Nozyce, M. L., Kammerer, B. L., Yildirim, C., & Nichols, S. L. (2016). Associations of memory and executive functioning with academic and adaptive functioning among youth with perinatal HIV exposure and/or infection. *Journal of the Pediatric Infectious Diseases* Society, *5*(1), S24–S32. https://doi.org/10.1093/jpids/piw046

Tavares, T. P., Puka, K., & Smith, M. L. (2015). Emotional functioning: Long-term outcomes after pediatric epilepsy surgery. *Epilepsia, 56*(5). https://doi.org/10.1111/epi.12956

Weeks, L. E., Barber, B., MacDougall, E. S., Macdonald, M., Martin-Misener, R., & Warner, G. (2021). An exploration of Canadian transitional care programs for older adults. *Healthcare Management Forum*. *34*(3), 163-168. https://doi.org/10.1177/0840470420974040

Zhao, T., Sun, M., Yu, P., Zhu, G., Tang, X., Shi, Y., & Hong, Z. (2012). Evaluation of clinical aspects and quality of life as risk factors for depression in patients with epilepsy. *Seizure, 21*(5), 367-370. https://doi.org/10.1016/j.seizure.2012.03.006