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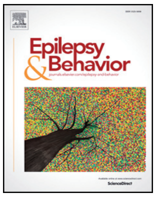

Conference Proceedings

How can transition to adult care be best orchestrated for adolescents with epilepsy?

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ABSTRACT

Objective evidence is limited for the value of transition programs for youth with chronic illness moving from pediatric to adult care; however, such programs intuitively "make sense". We describe the strengths and weaknesses of a variety of transition programs from around the world for adolescents with epilepsy. Consequences of poorly organized transition beyond suboptimal seizure control may include an increased risk of sudden unexpected death in epilepsy (SUDEP), poor psychological and social outcome, and inadequate management of comorbidities. The content of transition programs for those with normal intelligence differs from those with intellectual disability, but both groups may benefit from an emphasis on sporting activities. Concerns that may interfere with optimal transition include lack of nursing or social work services, limited numbers of adult neurologists/epileptologists confident in the treatment of complex pediatric epilepsy problems, institutional financial support, and time constraints for pediatric and adult physicians who treat epilepsy and the provision of multidisciplinary care. Successful programs eventually need to rely on a several adult physicians, nurses, and other key healthcare providers and use novel approaches to complex care. More research is needed to document the value and effectiveness of transition programs for youth with epilepsy to persuade institutions and healthcare professionals to support these ventures.

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1. Introduction

“Transition” is the purposeful, planned process that addresses the medical, psychosocial, and educational/vocational needs of adolescents and young adults with long-term conditions as they move from child-centered to adult-oriented healthcare systems. “Transfer” is the formal event when the healthcare of a young person moves from children's services to adults' services [1]. This paper summarizes the third, two-day symposium in France addressing transition to adult care for youth with epilepsy. The meeting took place in France in July 2018 and included 27 participants from France, Germany, UK, Italy, Canada, USA, Colombia, Egypt, and India. The previous meetings were summarized in a supplement to Epilepsia in 2014 [2], and three summary papers in a supplement to Epilepsy & Behavior in 2017 [3–5]. The current symposium focused on various models and realities for epilepsy transition as well as the costs and effectiveness of these programs. This paper summarizes the presentations and discussions along 5 themes — generic transition programs, transition programs for other disorders, existing epilepsy-specific transition programs, the results of inadequate transition in epilepsy, and special issues for transition for youth with intellectual disability (ID). A second paper based on this symposium will address costs and will propose methods of evaluation for the process of transition.

Youth with epilepsy live with uncertainty. A seizure may occur at any moment and leave them with postictal confusion and incontinence. Learning is often impaired and school success relatively unlikely. Their peers may be friendly but often secretly fear that epilepsy is a contagious, horrible disorder. An elusive goal of pediatric care is to overcome these difficulties. Antiepileptic drugs (AEDs) prescribed during childhood are often ineffective, and there is no reason to suspect that they will be more effective in adulthood. Employment seems a reasonable aim, but despite legal protections, many employers are not supportive. Marriage implies a caring partner who can also deal with uncertainty. Learning difficulties preclude many professions, and comorbid depression and anxiety frequently cloud daily life [6]. A transition program may provide a hopeful boost into adulthood, although there is very little objective data that demonstrate the value of transition programs for any chronic disease in childhood [7]. A systematic review in 2015 found 261 studies of interventions for transition, but there was limited overall evidence for effectiveness [8]. A Cochrane review in 2016 found only four valid studies with a total of 238 participants — too few to draw conclusions [9].

The goals for transition are rarely made explicit but three factors seem critical [10]. First, *provide youth with developmentally appropriate education about their epilepsy, clinical course, and treatment*. This leads to an expectation that the youth will learn to take personal responsibility and be able to do the things that successful adults with epilepsy need to do such as adhere to medication regimens, explain their disease to healthcare providers and peers, make appointments with appropriate healthcare providers, clearly articulate what is problematic for themselves, become independent in interacting with all aspects of adult medical care, and be able to assess when the healthcare system is letting them down and what to do about it. Second, *provide information about the potential lifestyle changes such as restrictions for driving, employment, and use of alcohol and other substances*. Third, *initiate and continue an ongoing relationship between the patient with epilepsy and his/her follow-up care providers to encourage lifelong engagement*. The details of these goals will vary with cognitive ability and may be very truncated when ID is significant. The parents or guardians of these youth will need to be “transitioned”.

How do we attain these deceptively simple goals? The ideal plan must encourage the patient to take charge of his/her life and see him/herself as a person with epilepsy rather than a dependent “epileptic”. Self-confidence and self-esteem need to foster from an early age, which can be enhanced in adolescents by having them take control of their daily life with epilepsy such as finding ways to avoid missed doses, learning who pays for medications and doctor visits, and how to negotiate the medical and insurance systems. How do they communicate their concerns to the doctor? What can they expect the doctor to do for them? What do they do if they do not understand what the doctor is telling them, and how shall they remember what the doctor suggested that they do? What additional sources of information should they use to decide if their adult doctor or other healthcare provider is skilled, and what do they do if they perceive their care as inadequate. Transition and transfer to the adult healthcare system should be as seamless as possible and include an excellent, succinct summary of the past history and treatment. There needs to be reassurance that the adult system understands the epilepsy syndrome, best treatment, and comorbidities. Keeping an initial appointment in the adult world is critical and should be verified.

There is no single way to achieve these goals, which must take into account the family's resources and location, the expectations of the patient and family, the capabilities of the young person with epilepsy, and the social milieu. As well, it is also important to consider the geographic distance between the patient's home and the pediatric and adult care providers, access to a case coordinator and/or an epilepsy nurse, and available community resources. There are a variety of programs that purport to help.

2. Generic transition programs

Generic transition programs have been developed in many centers. “Generic” means that they should apply to most chronic disorders in adolescence that are likely to persist into adulthood. Two generic programs were reviewed.

2.1. Ontario

An expert epilepsy transition task force in the Canadian province of Ontario suggested that such programs should be initiated at least 2 years before transfer to adult care and be the responsibility of the pediatric institution [11,12]. An adult primary care provider for the youth (not a pediatrician) needs to be identified along with medical specialists. The ability of the youth to make independent autonomous decisions must be clarified and developed. Readiness for transition should be assessed for the youth, family, pediatric healthcare providers, and appropriate community services [13]. A “mirror” service model should be developed that outlines the youth's current treatment needs and then matches these with potential adult providers. A formal program like “MyHealth Passport” transition tool may be very helpful. This tool provides a summary of the diagnosis, treatments, and concerns and is completed by the youth (along with help when needed) [14]. A year before transfer, medical and other appointments with adult providers are set up, along with solutions for logistic issues such as transportation. Following transfer, the case manager confirms directly with the youth and family that the first visit in adult care has taken place and offers help resolve of any issues related to adult care.

2.2. National Institute for Health and Care Excellence (NICE) guidelines

The National Institute for Health and Care Excellence (NICE) guidelines for transition suggest 9 key elements (see Table 1) [15]. A recent study has prospectively evaluated the importance of these key elements using a sample of 374 youth including 150 intellectually normal youth with type 1 diabetes, 106 with cerebral palsy, and 118 with autism spectrum disorder without an associated mental health problem [16]. Based on three annual interviews and standardized questionnaires only three of the NICE nine key elements were strongly associated with a good transition outcome — appropriate parental involvement, promotion of health self-efficacy, and meeting the adult team before transfer. Appropriate parental involvement “in their child's care, but with changing responsibilities” was assessed by asking parents and youth separately if

Table 1
Nice guidelines for generic transition programs [15].

- Age-banded clinic
- Meet adult team before transfer
- Promotion of health self-efficacy
- Written transition plan
- Appropriate parental involvement
- Key transition worker for each person
- Coordinated healthcare team
- Holistic life skills training
- Transition manager for clinical team

they thought that the level of involvement was appropriate. “Involvement” considered if the parent was present at a typical clinic visit and if the parent or youth did most of the talking. Promotion of health self-efficacy was assessed in part by asking the youth “Have you received enough help to increase your confidence in managing your condition?” Meeting the adult team before transfer could be in one of three settings: a joint clinic with both pediatric and adult healthcare professionals, an appointment in the pediatric center that included an adult physician, and an appointment in the adult clinic at which the youth was accompanied by a key worker from the pediatric clinic. The implication of this very important study is that all epilepsy transition programs should incorporate these three features.

3. Disease-specific transition programs for disorders other than epilepsy

Many transition programs have been developed for specific chronic disorders other than epilepsy, but few have been well-evaluated. Programs for renal transplant and type 1 diabetes stand out, because they have measurable objective outcomes (kidney rejection and Hemoglobin A1C (HbA1c) blood levels) that are not so evident in epilepsy. There are at least two studies that show the value of a transition program for youth with kidney transplants [17,18]. Both found that without a transition program about one-third of youth with a transplanted kidney lose their graft shortly after transfer to adult care, presumably as the result of poor adherence to immunosuppressive medications and/or the loss of medical follow-up. In both studies, the introduction of a transition program was associated with virtually no loss of grafts.

3.1. Transition programs for type 1 diabetes

These programs have been more frequently evaluated compared with those of other chronic conditions. A meta-analysis in 2017 identified a number of controlled trials involving 3382 youth with diabetes [19]. All of the studies showed maintenance or improvement in HbA1c levels in patients with a transition program, although this was not different than controls one year after transition. It seemed that pediatric care was reasonably effective, although transition programs were associated with reduced rates of ketoacidosis or severe hypoglycemia during young adulthood.

3.2. Transition programs for neurological disorders other than epilepsies

Some programs have been described, particularly for conditions for which advances in treatment has led to longevity in adulthood. The Spina Bifida Association has outlined the most critical stages in transition, although many American clinics lack comprehensive programs [20]. For example, they report that only 30% “communicate with the adult providers”. Duchenne dystrophy has been most frequently studied. At least 40% of boys with Duchenne muscular dystrophy are now alive at 40 years of age, and their care needs are increasingly complicated with extended life span [21]. In Japan, most adults with this disorder live in one of 27 specialized wards that provide comprehensive care for patients with Duchenne dystrophy [22]. This model of care would not likely be acceptable in countries where living at home or in a community setting is strongly valued. For the past 10 years, a network of specialists in Paris voluntarily, without remuneration, meets monthly (on a Saturday morning!) to work out transition needs of complex patients with neuromuscular conditions. Dedicated clinicians deemed it necessary as there is no established program to accomplish this important task during the work week, and there is often a significant physical distance between pediatric and adult care institutions. Advances in other neurological disorders are allowing children with formerly lethal disorders of childhood to live for unprecedented survival, and for which adult neurologists may not be prepared. Spinal muscular atrophy is an example of the new demands on adult neurology as genetic treatments create, in a sense, “prolonged palliative care”.

4. Transition programs specifically for epilepsy (Table 2)

Many centers use a generic transition program modified with epilepsy-specific modules starting between ages of 12 and 14 years. This is based on strong evidence that youth at this point have the ability to understand the principles of self-management and the developmental skills to self-advocate. This is also the age in the US for which initiation of transition is mandated in the educational system for children with special needs. The process is then completed in a transition/transfer clinic at age 16–21 years.

4.1. United Kingdom

4.1.1. Liverpool

The NICE Quality Standard Statements on young people with epilepsy emphasize that “Young people have an agreed transition period during which their continuing epilepsy care is reviewed jointly by pediatric and adult services” [23]. This statement was based on the examples of joint epilepsy transition clinics well-described first in Liverpool [24] and then replicated to some degree in Wales [25]. These clinics are staffed jointly by a pediatric and an adult epilepsy specialist and an adult epilepsy nurse. Patients are seen jointly for several visits until the transition team judged that the young person was ready to be cared for in the adult setting.

This format has some major strengths — epilepsy is the focus of the clinic, and care and management is expert. Most patients will have been cared for by the same pediatric neurologists that are part of the transition team, allowing continuity of care through the transition process. There is no fixed age for transfer to an adult service, and there is sufficient time for youth and their families to develop a rapport with the adult epilepsy team and environment. On the downside, this format does not readily address comorbidities such as ID or autistic spectrum disorder; although access to mental health and ID services should be available. There is the additional scheduling burden and cost associated with both pediatric and adult epileptologists seeing the patient at the same time, and the frequency of clinics is only monthly. This service has not been formally endorsed by the adult and pediatric Hospital “Trusts” (administrative entities in the UK). Convincing evidence of the value of such services is difficult to produce and ongoing commitment of key personal may be an issue.

In 2011, a UK-wide survey identified 15 centers that indicated that they had a form of transition program defined as “a clinic or service that provides joint pediatric and adult supervision of care from pediatric to adult services.” [26] Most centers were tertiary with no epilepsy transition programs at the secondary or primary care level. The programs varied between centers with six having no nursing support. Patients were transferred on to adult care after a single assessment in seven (47%) centers, at a fixed age of 18 years in four centers or in a flexible manner that was deemed patient-dependent in four.

Table 2
Summary of transition programs.

	Personnel and program	Comments/concerns
Edmonton, Alberta	Pediatric and adult epilepsy nurse specialists meet for several visits with patient and family	No generic transition program Little involvement of physicians Telemedicine overcomes some long distance travel problems
Hospital for Sick Children	There is a single visit with Pediatric and adult epilepsy nurse specialists Pediatric and adult social workers Adult Neurologist Adult Genetics Fellow	Strong generic program Little direct involvement of pediatric epileptologist except for case summary Relies on single adult epileptologist
Halifax, Nova Scotia	There are several visits with Adult nurse specialist Pediatric epileptologist Adult epileptologist	No generic program Discontinued when the two key pediatric epileptologists retired
Goteborg, Sweden	A conference with Adult epileptologist and pediatric neurologists is followed by continuing care with the adult epileptologist. Adult nurse specialist becomes involved after first visit with epileptologist	Good preparation before transition/transfer visit. Strong system of social supports
Great Ormond Street	12 goals for transition are reviewed one at a time in sequential visits (Table 2). There is a series of “teen talks” with epilepsy nurse specialist, There is a handoff clinic with pediatric and adult epileptologists (usually one visit)	Strong generic transition program Several subspecialty adult epilepsy clinics to receive patients with specific rare disorders
Liverpool UK	Adult nurse specialist, Pediatric and Adult epileptologists meet with patient/family for several visits	Functioning successfully for >20 years but no overall evaluation No generic program
Necker Hospital, Paris	There is a good generic program with support from a special unit “La Suite”. Transfer is to a hospital within the Rare and chronic Diseases Networks	Most transfers are to a single expert adult epileptologist at the Pitié-Salpêtrière Hospital
Pitié-Salpêtrière Hospital, Paris	Adult hospital “Jump” program provides a one-day, multidisciplinary assessment to decide further care needs	A unique program with high level of family satisfaction
The MOSES Program, Bethel, Germany	A comprehensive program with multiple teaching modules delivered by trained instructors in 14 one-hour lessons longitudinally or in 2-day workshop	Randomized clinic trial has established its effectiveness. Physicians are not directly involved.
School of Medicine of the University of Antioquia, Medellin, Colombia	One-week course on transition given to medical students	
India and Egypt	Transition programs not yet developed.	Epilepsy care may be throughout life by an adult neurologist. Psychiatrists play a significant role in adult and pediatric and epilepsy care

4.1.2. Great Ormond Street, London

There is considerable emphasis at Great Ormond Street Hospital on a transition program that begins in early adolescence and is based on the Ready Steady Go process and generic guidelines from NICE [15,27]. Transfer to adult services occurs by the age of 17 years. In addition, starting at the age of 12 years for those with normal intelligence, a series of “teenage talks” begin with the nurse clinician to cover a series of specific, epilepsy-related issues. There are 12 overarching goals for transition readiness ranging from “Remember to take your medications as prescribed” to “Make your own medical appointments including GP and Neurologist”. At each clinic visit, one or more goals are selected to be achieved by the next clinic. For patients with ID, the list of goals is modified but with the emphasis on as much independence as possible.

Most patients are eventually transferred to the existing adolescent clinic at the National Hospital for Neurology and Neurosurgery (NHNN) at Queen's Square. There are several specific adult clinics that accept transfers from the pediatric service including youth with Dravet Syndrome, metabolic disorders, epilepsy surgery, vagus nerve stimulator, and tuberous sclerosis. There are major problems to find adult services for youth continuing treatment with the ketogenic diet. Disorders such as the Sturge–Weber syndrome and Rasmussen syndrome also do not have a designated clinic to transfer to but remain in the complex epilepsy service.

At the time of transfer there is a one visit “hand off clinic” with joint attendance of a pediatric specialist and the adult epilepsy team. A decision is then made as to whether continuing transition should be through a more local service, transfer made to a specialist clinic, or care continued for a short time through the transition clinic itself.

4.2. Canada

4.2.1. Edmonton, Alberta

A nurse-led program in Edmonton, Alberta has been well-described [28]. Once a decision is made to transfer a young person with epilepsy to the adult epilepsy service, the pediatric and adult epilepsy nurses meet with the youth and family to discuss a series of topics that are individualized and in part determined by a transition readiness questionnaire. These sessions may be delivered via telehealth because of the enormous distances in the catchment area. Topics covered include seizure type, first aid for seizures, status epilepticus, medications and their side effects, seizure triggers, work/school/finances, driving, women and epilepsy, alcohol and drugs, home safety, nutrition/exercise, bone health, and community resources. The nature of the adult service (including differences from the pediatric model) is discussed with the eventual goal of the adolescent becoming as independent as possible in managing his/her own healthcare with ongoing nursing support as needed in the adult program, a goal that may take a long time to achieve.

For patients with ID, topics also include guardianship, trusteeship, income support, day programming, independent living, group homes, and in-home care.

Throughout the program, there is an emphasis on independence for the young person and support for the family. To date, 662 young people have benefitted from the program. Families seem to be very satisfied with the program, and because youth with epilepsy are now so much better prepared, the adult epilepsy program has made this transition program mandatory before transfer — a striking endorsement.

4.2.2. Halifax, Nova Scotia

A joint pediatric–adult transition clinic was developed with two pediatric neurologists, one adult epileptologist, and an adult epilepsy nurse [29]. This clinic was described in a publication that included details of a comprehensive medical summary prepared by the pediatric neurologists and a comprehensive social summary completed by the patient with help from the family [29]. Patients were seen in the adult setting. For the initial visit the history was reviewed with the pediatric neurologist, adult neurologist, adult epilepsy nurse, and the patient and family. The adult neurologist and nurse then met for an hour with the patient alone if he/she was cognitively normal; the family was included if there was associated ID. Then the pediatric neurologist rejoined the group for a discussion of future plans. One or two follow-up visits were scheduled with the pediatric and adult neurologist and epilepsy nurse. Thereafter, the adult service took over completely. The clinic seemed to function well, although there was inadequate work space for the pediatric neurologist when the patient was being seen by the adult service. Punctuality was a problem. About 50 patients were transitioned, but then the two pediatric neurologists retired from clinical practice, and the remaining pediatric neurologists at this center chose not to continue the clinic based mainly on concerns that the process was too time consuming.

4.2.3. The Hospital for Sick Children (HSC), Toronto and the Toronto Western Hospital

The Hospital for Sick Children (HSC)–Toronto Western Hospital transition program began in 2007. Patients with epilepsy are prepared for transition with the generic Good2Go program, a personalized “health passport” and a Transition Readiness Questionnaire that is prompted by the electronic health record at clinic visits before 18 years of age [14,30]. A medical summary is usually prepared by the pediatric service. The actual clinic consists of a single visit at HSC attended by the pediatric epilepsy nurse and the adult epileptologist along with a volunteer from the Epilepsy Toronto Adolescent Group. Four new patients are seen at each clinic [31]. Since 2014, the visits have also been staffed by both adult and pediatric social workers, the adult nurse practitioner and an adult epilepsy genetics fellow. All further visits are in the adult setting with the adult epilepsy physician.

Several one-page handouts related to finances, social interactions, education, housing, respite support, employment, and health insurance are prompted by the electronic medical record. They are given to patients and families during the pediatric epilepsy care visits. An adult ketogenic diet clinic was established to care for patients who continued to benefit from the ketogenic diet. A concern for this clinic is that it currently only involves a single, dedicated adult epileptologist. Expanding the pool of adult epileptologists/neurologists who are comfortable with pediatric onset epilepsy is a priority.

4.3. Sweden (Goteborg)

Patients with epilepsy in Sweden have access to a wealth of support services including social, habilitation therapies, and income. Many of the difficult issues in other countries seem to be managed relatively easily in Sweden, such as income support or housing for youth with ID. In addition, there is a well-functioning universal comprehensive electronic medical record. The exact nature of transition programs vary with location; however, there is a systematic attempt to be sure that by the midteenage years youth with chronic disease understand both their disorder and the adult healthcare system that will eventually care for them. In Goteborg, there is a biannual meeting between pediatric and adult neurologists who care for children with epilepsy to discuss the best care setting for each patient who is approaching transfer. Care for comorbidities is also arranged. Some patients have adult follow-up with family physicians only, if for example they are seizure-free. For those moving to adult epilepsy services, the first visit with the adult neurologist lasts 1 h and includes an introduction to the epilepsy nurse. Within a month there is a second visit with the nurse at which time there is introduction to the social worker and psychologist. A major dilemma for the patient with well-controlled epilepsy is making the decision about continuing AED treatment. The adolescent must decide at this point; practical issues such as retaining a driver's license are often more important than the risk of relapse after AED discontinuation. The presenter for this section suggested several key questions that adult epileptologists should ask of their newly transferred patients. These included: What do you know about epilepsy? Do you know anyone else who has epilepsy? Do you know what your seizures look like? Who knows that you have epilepsy? Do you tell other people about your disorder? What would your friends do if you had a seizure? Do you think you have side effects? Everyone forgets to take their meds… Do you? Discussions about alcohol, sex and contraception, driver's license, and choice of career are considered very important, and discussed candidly.

4.4. France

4.4.1. Necker Hospital, Paris

In France, under the rare diseases program, there are eight reference centers for epilepsy and 20 additional centers considered to have special competence in epilepsy care. The reference center at Necker Hospital in Paris has a transition program beginning at the age of 14 years with emphasis on parent and patient education. This focuses on seizures, cognition and learning, psychiatric and behavior disorders, motor abilities, sleep problems, nutritional disorders, therapies (efficacy and side effects), and social competence [32]. A list of the adolescent's services is then mirrored for transfer to the adult services. For adult epilepsy care, most transfers are to la Pitié-Salpêtrière reference center, where a single, dedicated epileptologist works within the rare disease network. A very high proportion of transferred patients have comorbid ID.

To assist the young person through the transition/transfer process, there is a unit in Necker called “La Suite”. This is an area for patients only; parents are not allowed. “La Suite” team includes social workers, a sport coach, educators, makeup specialists, hair dressers, and special medical clinics that include dermatology, primary care physicians, gynecology, endocrinology, occupational and physiotherapy, and nutrition. Patients can attend special classes of sports, meet others with chronic diseases, and have an appointment with any member of the suite team.

4.4.2. Pitié-Salpêtrière Hospital

In the Pitié-Salpêtrière Hospital, there has been a bold attempt to replicate the multidisciplinary nature of pediatric care. The “Jump Program” is a unit within the hospital for young adults with complex disorders [33]. Carefully screened patients are admitted for a single day with multiple disciplines scheduled to assess the patient. At the end of the day, a tailored program for follow-up is implemented, including subspecialists and allied health professionals. An evaluation of 133 consecutive patients (average age of 19.7 years, range: 15–36) showed high levels of patient/family satisfaction with this program [33].

4.5. Germany, the MOSES program, Bethel

The Modular Service Package Epilepsy (MOSES) program is an interactive educational program for late adolescents or adults with epilepsy and is applicable to all people with epilepsy regardless of epilepsy syndrome, severity, or duration of epilepsy [34]. The program is delivered by trained instructors in 14 lessons that each last about 1 h. Major themes are as follows: improving knowledge about epilepsy and its psychosocial consequences, coping with epilepsy and associated emotions, seizure management and seizure triggers, self-management, self-responsibility (active role within treatment), improving communication skills, and living with as few limitations as possible.

The MOSES program can be used gradually in clinical care or as an intensive two day workshop in groups of 6–14 participants. Although not specifically designed as a transition tool, it has been subjected to a randomized clinical trial with the treatment group enrolled immediately in a two-day course and compared with the control group randomized to a waiting list for six months before receiving the MOSES program [35]. The study involved 242 randomized patients at 22 German speaking centers. Patients had a wide variety of epilepsy syndromes, seizure severity, and comorbidities. Six months after the intervention, seizure control, knowledge about epilepsy, and a measure that assessed "coping with epilepsy" were significantly better in the treatment group. The latter is particularly relevant for transition. The MOSES program has been translated into Japanese, Czech, Lithuanian, and English and is continuing to be updated and modified. For example, recently a module on sudden unexpected death in epilepsy (SUDEP) has been included. In addition, there is a separate program to certify instructors in MOSES.

The MOSES program would seem to be a very valuable program to boost the knowledge and transition readiness of late adolescents with epilepsy. There is another similar, evaluated program ("FAMOSES") for younger children with epilepsy ages 8–12 years and their parents [36]. Parents significantly improved in their epilepsy-specific knowledge, coping, epilepsy-related fears, and in speaking about epilepsy with their child compared with the control group. All of these factors are relevant for transition.

4.6. Transition in less advantaged countries

4.6.1. Colombia

In Colombia, a national law was enacted in 2010 that appears to guarantee access to care for all people with epilepsy; however, this has not lead to direct improvements in care. Only one of the 56 medical schools includes transition as topic for teaching. In 2017, The School of Medicine of the University of Antioquia in Medellin introduced a one-week teaching course about transition that includes theory and practice for a variety of chronic illnesses in children, including epilepsy. It has been difficult to persuade insurance companies to pay for "healthy medical appointments" for adolescents with chronic disease.

4.6.2. India

Healthcare varies a great deal across India, an enormous country with a population of 1.35 billion. Primary care remains the biggest focus in the public healthcare system along with maternal–child health and immunization services. A mixture of corporate, private, and charity institutions provide some secondary and tertiary services especially to those who are financially advantaged. The 50,000 pediatricians throughout the country act as primary care or epilepsy consultants, but there are very few trained pediatric neurologists. This means that most of the epilepsy care for children and adolescents is delivered by family physicians, adult neurologists or psychiatrists. For those followed by adult neurology, there is no gap in physician care in later adolescence; however, there are no programs to help a young person with epilepsy to become more independent within a system where the neurologist does not change. Moreover, adult neurology services are not equipped to provide comprehensive care for patients with ID. As pediatric neurology develops as a specialty in India, there is a real opportunity to develop transition programs that have no historical constraints.

4.6.3. Egypt

In Egypt, a country of nearly 100 millions, there are only two academic medical centers. Throughout the country, services for children with epilepsy are sparse with few epileptologists. Most expert epilepsy care is by pediatric and adult neurologists, neurosurgeons, and psychiatrists. Comprehensive care for childhood epilepsy is limited, and there is concern about accuracy of diagnosis. Transition to adult care appears not to be an important priority at this point.

5. Other activities that may improve transition/transfer success

Many activities for youth that are not specifically centered on transition may have beneficial effects on maturity, socialization, and independence; although, these programs/activities have not been rigorously established to be of benefit. One of these is participation in sports.

5.1. Sports and transition

Basic research in animal models has shown that physical activity can prevent epileptogenesis and reduce seizure frequency, duration, and intensity in established epilepsy [37]. The proposed mechanisms are wide and include the following: a) release of beta-endorphins from the opioid system, b) release of steroids, c) increase in melatonin concentrations, d) increase of antiepileptogenic and cytoprotective parvo albumin, e) reduction in hyperreactivity of CA1 cells and generation of structural changes within the hippocampus, f) enhancement of the inhibitory effect of noradrenaline and GABA released during exercise, g) increased antioxidative mechanisms that decrease epileptogenesis, h) increased density of new blood vessels as a mechanism to decrease excitotoxicity, and i) release of neuroprotective trophic factors and expression of neuronal growth factors.

Despite these benefits, data from Finland, Canada, several sites in Midwestern USA, Norway, Brazil, Thailand, and Korea all show that physical activity is decreased in people with epilepsy compared with that of the controls [38]. Medical advice to participate in sports was offered less frequently to those with epilepsy and sometimes even discouraged by teachers, instructors, and physicians. Avoiding exercise was based in part on recommendations from relatives, friends, and physicians with the additional factors of fear and embarrassment of having a seizure in public, lack of time or motivation, fatigue, absence of sporting companions, and concern that exercise might precipitate seizures [36]. The 2010 National Health Survey in the United States reported that in the preceding week, only 39% of people with epilepsy had walked for ≥10 min per day, compared with 50% of the general population [39]. Not surprisingly, another study indicated that compared with siblings, adolescents with epilepsy were less likely to be involved in sport groups or engaged in physical activity, and more likely to be overweight and obese [40]. On the positive side, people with epilepsy in Arizona who had regular physical activities had fewer activity limited days [41]. Physical activity has been demonstrated to have an incredible range of beneficial effects including improvements in cardiovascular fitness, musculoskeletal wellbeing, posture, osteoporosis, depression and anxiety, self-image, vitality, neurocognitive function (attention, psychomotor speed, impulse control, inhibition/disinhibition, problem-solving skills), social competence, and overall quality of life. In terms of epilepsy, there is some suggestion that regular exercise is associated with better seizure control, fewer electroencephalographic (EEG) epileptiform discharges, and a decrease in the risk of SUDEP [36]. Based on this mass of data, it seems likely that encouraging sports and exercise is a very worthwhile aspect of transitional care for youth with epilepsy [42].

6. What happens if transition for epilepsy is poorly managed?

6.1. SUDEP (sudden unexpected death in epilepsy)

As noted above there are few evaluations of transition programs for any chronic disease. To date, we are unaware of evaluations of epilepsy transition programs that address such critical issues as seizure control, episodes of status epilepticus, SUDEP, management of comorbidities, or impact on family life. The major risk factors for SUDEP are drug-resistance, presence of generalized tonic–clonic seizures, and most importantly, a high frequency of generalized tonic–clonic seizures [43].

Much of the literature to date has suggested that the rate of SUDEP in childhood is lower in children than in adults [44], although a long-term follow-up study of a Finnish cohort suggests that the rate of SUDEP rises as epilepsy persists from childhood into adulthood [45]. In 2018, a study from the Province of Ontario, Canada identified 16 cases of definite or probable SUDEP in children over a one-year period [46]. Based on an estimate of the prevalence of epilepsy in the Province, the authors suggested that the risk of SUDEP was 1.11 per 1000 pediatric epilepsy person years with a wide confidence interval (0.63–1.79). This risk is close to the usual risk quoted for adult epilepsy. Of course, this is the risk for prevalent cases of epilepsy — the risk for incident cases is much lower in population-based studies [0.33/1000 patient years (range 0.13–0.53)] [43]. In addition, a large study from Sweden of 57,775 people with epilepsy found the incidence of SUDEP (again in prevalent cases) to be similar across the ages [47]. From the perspective of transition, it would seem prudent to consider SUDEP as an important topic to emphasize as the youth takes responsibility for factors in their control to concentrate on the importance of good seizure control.

6.2. Comorbidities

Comorbidities associated with epilepsy at any age may be more problematic than the seizures. Management of attention-deficit hyperactivity disorder (ADHD), anxiety disorder, and depression through the transition ages seem particularly important for a good quality of life in adulthood. From the perspective of transition, we reviewed other comorbidities such as sexual dysfunction and bone mineral health during the 2016 Paris transition conference [5]. In addition to biological factors, psychiatric comorbidities in people with epilepsy have been related to the chronic nature of epilepsy, low educational level of youth with epilepsy, high rates of unemployment or underemployment, difficulties in adjustment to consequences, fear of seizures and their unpredictable nature, social stigma, overprotection by families, legal limitations (especially driving regulations), and low self-esteem [48]. It has been estimated from a prevalence cohort study of children and adolescents with active epilepsy aged 5–15 years that 40% have ID, 33% have ADHD, and 21% have autistic spectrum disorder [49]. Attention-deficit hyperactivity disorder, if undiagnosed and untreated, is associated with an increased risk of developing a major psychiatric disorder in adulthood. Further, ADHD seems to have some special features when it is associated with epilepsy. The male/female ratio is close to one, and there is an increased chance of inattentive presentations. Still, it is well-established that outside of epilepsy, about 50% of adults with depression had an anxiety disorder in childhood. Based on all of these concerns, it is important to screen for and initiate treatment for psychiatric disorders around the time of transfer to adult care for youth with epilepsy.

Finally, suicidal thoughts and attempts should be screened for in adolescents with epilepsy, especially for those with special risk factors including depression, depression in relatives, polytherapy, refractory epilepsy, substance abuse, or epilepsy surgery [50].

6.3. Impact on family function and social outcome

Family function will be affected by failure to deal with many transition issues. Social outcome of childhood-onset epilepsy with normal intelligence has been well-studied. Approximately 70% of children followed >20 years have ≥1 serious adverse social outcome: incomplete education, unemployment, a formal psychiatric diagnosis other than ADHD, extreme isolation with no friends, no romantic relationships, living alone, and inadvertent pregnancy [6]. These studies were carried out before formal transition programs had been developed. It is likely that multiple factors contribute to these problems including poor seizure control, onset at a very young age, cognitive problems, low socioeconomic status, low parental education, poor family function, poor intervention services, low self-esteem, and lack of role models in family, school, or society.

Each one of these adverse social outcomes will obviously affect the social network supporting each young adult. Poor education leads to low rates of employment and prolonged dependency. Social isolation potentially means that the family continues to be over-involved in every aspect of the youth's life, and inadvertent pregnancy may lead to even greater dependency.

7. Managing epilepsy during late adolescence (16–21 years)

As emphasized throughout the transition literature, the process of transition ideally begins around the age of 12 years and continues until transfer to adult care, which is usually between the ages of 16 and 21 years. Special issues arise in the last few years of the transition process, with major differences for those with normal intelligence and those with ID.

7.1. Managing epilepsy during late adolescence with normal intelligence

Most teens with epilepsy and normal intelligence in the process of transition to adult epilepsy care have genetic generalized epilepsy or focal epilepsy from a discrete lesion or an unknown cause. Prior to transfer, the pediatric neurologist should reevaluate the diagnosis and treatment, ensuring up-to-date investigations (genetic, imaging, and autoimmune) and best current treatment (optimal AEDs, minimal polytherapy, potential surgery). The goals of transition are fairly straight forward.

Education over the later part of the transition period should take into account the stage of cognitive development. Early teens are more concrete thinkers and are still exploring their sense of identity [51]. They may have greater challenges with denial of illness and comprehending cause and effect, such as the consequences of poor compliance. By midlate adolescence, teens are refining their established sense of identity, and are capable of more abstract thinking [51].

When available, epilepsy nurses can capably provide much of the education. Checklists can ensure the content is complete and mastered by the adolescent. In addition to basic information about epilepsy, late teens should be encouraged to raise concerns regarding AED side effects and discuss strategies to improve compliance. They need to understand potential seizure triggers, risk of seizures including SUDEP, their emergency plan, and who and when to call if their clinical state deteriorates. Given the high risk of unplanned pregnancy in adolescents [52], females should be aware of the pregnancy and hormonal concerns of AEDs and the need for folate supplementation. Long-acting, reversible contraceptive methods including injections, intrauterine devices, or subdermal implants are very effective and well-tolerated. Interactions between oral contraceptives and AEDs need to be well understood. Adolescents have longer endogenous and delayed circadian rhythms, which are exacerbated by excessive screen time before bed — anticipatory guidance to maximize sleep hygiene seems worthwhile although changing these “addictions” may be difficult. Adolescence is a high risk period for the presentation or exacerbation of many psychiatric disorders, which significantly impact quality of life, including ADHD, depression, and anxiety. These often coexist, and are very treatable if recognized [53–55]. Adolescents must understand the local regulations regarding driving. Antiepileptic drug weaning in seizure-free teens with possible self-limited epilepsies should ideally take place prior to the legal driving age. Social issues to be addressed include access to medical insurance, occupational and higher education plans, and identification of social supports.

Experimentation with alcohol, cannabis, and other substances is common at this age and should be discussed.

While there is increased focus on the teen during this period, parents need to understand the goals and process of transition as well as normal adolescent cognitive development. They should be encouraged to address their concerns about the increasing independence of their teen with epilepsy.

7.2. Managing epilepsy during late adolescence with ID

The special issues that complicate the lives of patients with epilepsy and ID depend on the exact age of transfer and the jurisdiction. It is best to conclude formal arrangements about decision-making (legal guardianship) before the youth with ID moves to adult care; however, it is mandatory once the youth reaches the "age of majority" for their jurisdiction. If the age of majority comes after the age of transfer to adult care, then there is a temptation to leave the definition of who makes decisions to the adult healthcare system. The process to establish capacity for decision-making is a legal one, and physicians who provide expert advice about a patient's capacity may find that they are required to complete extensive paperwork or appear at a legal proceeding. This can be a time consuming and unwanted activity.

There are a multitude of other social issues that need to be addressed for the late adolescent with epilepsy and ID. Social support services often change at the end of childhood. When school ends there may be little or no organized activities outside the house and no respite care for parents [56]. In some countries, a several year gap in services is not unusual between the end of childhood (~age 18 years) and the beginning of adulthood ~age 21 years. These problems may lead to a major mismatch between parent and physician priorities. We are of the opinion that the among the highest parental concerns are often behavior management, long-term placement in a facility such as a group home, legal processes to obtain guardianship and power of attorney, respite care, management of menstrual cycles, and regulation of sleep. Physician priorities are more likely to include seizure control (often very challenging in this group), etiology, identifying an adult healthcare provider, behavior management, general health maintenance, and avoiding excessive extra work. Dealing with these challenges beyond control of seizures presents dilemmas. It is clear that leaving all of the social issues to be resolved by the pediatric or adult epileptologist is unlikely to be successful; physicians lack the time and often the knowledge to deal with these problems. A multidisciplinary approach that includes social work, nursing, and/or a transition coordinator is needed. Admittedly, it may be difficult to convince healthcare administrators of the need for such an expensive undertaking that does not match the usual, simple model of doctor–patient relationships. It is difficult to demonstrate that these extra efforts that seem so valuable are actually cost-effective, particularly in a medical care environment such as the United States where profit motives are so prominent. Cost-effectiveness issues for transition are dealt with in the subsequent paper from this symposium. Parent advocacy groups and political pressure may be required to improve the adult life of patients with epilepsy and ID. Observational studies suggest that adult life for patients with epilepsy and ID is often quite unsatisfactory for both the parent and family [57].

In addition, young adults with epilepsy and ID often had diagnostic evaluations prior to the current revolutions of genetic testing and more advanced neuroimaging. Before transfer to the adult healthcare system, we suggest that the pediatric providers review any completed evaluations and consider additional tests to define the etiology for those whose epilepsy has not clear cause. In many cases, the pediatric healthcare system has specific resources for completing such testing with developmentally appropriate supports (e.g., child life services) or access to pediatric anesthesia.

8. The outcome in adulthood of adolescents with epilepsy and intellectual disability?

There is very little specific information about the adult life of patients with epilepsy and ID. One study identified 183 adults with epilepsy and ID (average age of 40 years, range 16–72) from a single county in the UK [58]. Most had childhood-onset epilepsy. Epilepsy care was provided by a hospital-based neurology service in 37%, by the general practitioner in 67% (sometimes in combination with the hospital-based neurology service), and by the Community Intellectual Disability Team (CIDT) in 91%. The CIDT teams do not include a neurologist but may include a psychiatrist with expertise in epilepsy and/or a nurse with special training in epilepsy. Overall, a neurologist was involved in epilepsy care in only 54%.

In a second UK-based cross-sectional study of 90 adult patients of ages ≥ 18 years with epilepsy and ID living in the community, compared patient characteristics and outcomes between hospital-based neurology services and community ID services [59]. Most of the patients had intractable epilepsy, yet epilepsy variables did not predict which clinical service managed their epilepsy. Patients with neurological comorbidities were more likely to receive hospital-based services and those with psychiatric comorbidities were more likely to receive CIDT services for epilepsy control. Living at home predicted hospital-based services. For 18%, there was confusion about who was leading the epilepsy care, yet quality of life did not differ among the groups.

The implication of these two studies for transition is that it may not be clear who will be providing adult epilepsy care. Preparing the family for this ambiguity might be helpful. We suspect that similar unevenness in epilepsy care for adults with ID exists in many countries. There are likely many patients with ID who receive less than expert epilepsy care.

9. Conclusions

There are a variety of programs for transition from pediatric to adult care for young people with epilepsy. Although all of these models "make sense", none have been proven to be of value, in part, because there are no available metrics that determine success. All of these programs acknowledge the intense and rapid changes that occur during adolescent cognitive development that can impact epilepsy management including poor understanding or motivation to alter lifestyle to deal with factors such as sleep deprivation, alcohol, drugs, or treatment compliance. Models address the fact that teenagers with epilepsy are at increased risk of unwanted pregnancy, driving difficulties, unhealthy life styles, depression, and anxiety. Leaving the pediatric system also means moving from the "family-oriented" care offered at pediatric centers to the "patient-oriented care" offered in the adult healthcare system. Learning how to be a successful patient in the adult system is central to many models. Ideally, epilepsy transition teams should have expertise in meeting the psychosocial needs of young adults with chronic epilepsy. Dedicated epilepsy nurses can improve communication with patients and families. A variety of strategies appear to solidify the patient's knowledge about his/her own condition and include tools such as "My Health Passport" [14]. Epilepsy agencies and family support groups may also offer social events to improve social or job finding skills.

Patients with epilepsy plus ID are at increased risk of unsuccessful transition. The reasons are complex and include confusion among multiple heath care providers and rare epilepsy syndromes not familiar to many neurologists. Patients with ID may have difficulty cooperating for investigations such as blood work, EEG, and magnetic resonance imaging (MRI) that may lead to better epilepsy control. Adult hospital staff may not be well-equipped to work with patients who cannot behave as expected for their chronological age or who need sedation for studies [12,60]. Finally, compared with the pediatric system, the adult healthcare system may offer less supportive care beyond the treating specialist. There is an important role in adult care for a very engaged primary care physician who can provide a "medical home." Ideally, this physician will be very familiar with the patient, understand epilepsy and ID and is able to coordinate care [61]. Organized multidisciplinary care approaches in adult medicine are uncommon, but programs like "Jump" are helpful models [33]. Epilepsy community agencies and family support groups may assist with financial, social, and legal support [12].

Despite these barriers, many centers have developed transition plans that at least attempt to ensure that all patients with epilepsy leave the pediatric system with a diagnostic reevaluation, an updated treatment plan, a current emergency plan and a careful documentation of comorbidities [61].

Nearly all participants in this symposium agreed that it remains challenging to find adult neurologists who are comfortable with the increasing number of unusual pediatric epilepsies treated with novel drugs, neurostimulation, or special diets. Many large transition programs depend on the expertise of a single adult neurologist, a vulnerable arrangement. Including transition services in epilepsy and neurology training programs will be increasingly important.

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Conflict of interest

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