

Models for transition clinics

*Jaime Carrizosa, †Isabelle An, ‡Richard Appleton, §Peter Camfield, and ¶Arpad Von Moers

Epilepsia, 55(Suppl.3):46–51, 2014

doi: 10.1111/epi.12716



Jaime Carrizosa is a Child Neurologist, University of Antioquia, Medellin, Colombia.

SUMMARY

Transition is a purposeful, planned process that addresses the medical, psychosocial, educational, and vocational needs of adolescents and young adults with chronic medical conditions, as they advance from a pediatric and family-centered to an adult, individual focused health care provider. This article describes some of the models for transition clinics or services for epilepsy in five countries (Canada, France, Colombia, Germany, and the United Kingdom). These models include joint adult and pediatric clinics, algorithm-driven service, and a check list system in the context of pediatric care. Evaluation of these models is limited, and it is not possible to choose an optimal program. The attitude and motivation of health care providers may be the most important elements.

KEY WORDS: Transition, Transfer, Models, Education, Adolescence.

This article offers a description of some transition clinic models from Canada, France, Colombia, Germany, and the United Kingdom. It is not comprehensive review and makes few judgments about the quality of these services that vary a great deal from country to country. A brief summary of these programs is presented in Table 1.

TRANSITION IN CANADA

Most pediatric neurologists and all pediatric epileptologists in Canada work in the 16 academic centers scattered across the country. We suspect that they care for the majority of children with epilepsy, especially those who are pharmaco-resistant. There are very few formal transition/transfer programs for children moving to adult epilepsy care. Canada has a universal health care system, even though it varies somewhat between the 10 provinces and there is essentially no private practice outside

of the national health care system. Therefore, in principle, all patients have equal access to all modalities of care. However, enormous distances with many small communities means that organized transition programs are focused in the major urban areas.

All provinces have a physician reimbursement system that requires a consultation request from a family physician, emergency room physician, or another specialist for a child to be seen by a neurologist or epileptologist. Patients themselves cannot make an initial appointment with a specialist, but usually can book a follow-up visit. Reimbursement to the neurologist for a follow-up visit without a new consultation is usually less than if there is a new consultation. Therefore, the family physician plays a key role in determining the cadence of follow-up care.

Transition as a process has been endorsed by all of the pediatric speciality hospitals across the country, but the meaning of transition and the resources allocated varies. BC Children's Hospital in Vancouver has a transition program to prepare all children with chronic illness for adult health care¹; however, to the best of our knowledge, there is no formal transition/transfer process specifically designed for children with epilepsy. Although youth with epilepsy are carefully prepared for transition, transfer consists of a referral note to an adult epilepsy specialist. Another pediatric hospital in Canada has an extensive epilepsy outpatient

Accepted June 2, 2014.

*University of Antioquia, Medellin, Colombia; †Pitié-Salpêtrière Hospital, Paris, France; ‡The Roald Dahl EEG Unit, Paediatric Neurosciences Foundation, Alder Hey Children's Hospital, Liverpool, United Kingdom; §IWK Health Centre and Dalhousie University, Halifax, Nova Scotia, Canada; and ¶DRK Kliniken Berlin Westend, Berlin, Germany

Address correspondence to Jaime Carrizosa, Calle 18B Sur No 38-51 Apto 404 Medellin, Colombia. E-mail: carrizosa@une.net.co

Wiley Periodicals, Inc.

© 2014 International League Against Epilepsy

KEY POINTS

- Interesting models for transition clinics and services vary across countries.
- No model has been extensively evaluated for effectiveness.
- A “best” model does not exist and will vary with the setting.

clinic. An adult epilepsy specialist attends this clinic once per month and sees patients ready for transition/transfer. For most patients, the adult neurologist receives a chart summary prepared by a resident but does not meet directly with the pediatric attending child neurologist; however, the pediatric epilepsy nurse usually attends the single visit transition clinic. Subsequent visits take place in the adult epileptologist's office in the adult hospital.

In Halifax, Nova Scotia, a transition clinic was developed that took place in the adult hospital. It was attended by the patient's child neurologist and an adult epileptologist plus the adult epilepsy nurse clinician. Before the first visit, the pediatric neurologist prepared a detailed written summary of the medical epilepsy issues and the family prepared a written summary of psychosocial issues. The details of these forms are published and available to everyone.² At the first transition clinic visit, these documents were reviewed with the adult team. Then the patient (usually with the parents) sees the adult epileptologist on their own. The pediatric neurologist joins the family and adult epileptologist at the end of the visit for a summary and review of further follow-up plans. Subsequently there was at least one follow-up visit with both pediatric and adult neurologists together. The clinic was viewed as effective, but there has been no formal assessment. When two of the key physicians retired from clinical practice, the structure of this clinic did not persist.

In Edmonton, Alberta, there is a unique epilepsy transition program that is run by epilepsy nurse clinicians.³ The pediatric epileptologist provides a referral letter to the adult epileptologist. The family and patient then meet with the adult and pediatric epilepsy nurse clinicians (without the physicians) and review a number of key transition/transfer themes at one or more visits. Subsequently the patient (\pm parents) meets the adult epileptologist for ongoing care. A questionnaire assessment suggested that families strongly endorsed this process.³

Elsewhere in Canada, most transition/transfer consists only of a referral letter written by the pediatric neurologist to an adult epileptologist. The patient is then seen in the adult setting without further communication. The adult epileptologist communicates with the family physician and may, out of courtesy, send a copy of this note to the pediatric neurologist. Further follow-up by the adult epileptologist/neurologist often depends on the patient being referred back by the family physician. This traditional transfer system has

Table 1. Comparison of models discussed in this article

	Canada joint pediatric-adult	Canada adult neurologist in pediatric hospital	Canada nurse specialist	France referral center for rare epilepsies	Colombia proposed checklist	Germany Modus program	United Kingdom joint pediatric-adult
Manpower	Child neurologist Adult neurologist Adult nurse coordinator	Adult neurologist Pediatric nurse coordinator	Pediatric epilepsy nurse Adult epilepsy nurse	Adult neurologist	Pediatric neurologist	Patient and neurologist learning modules	Child neurologist Adult neurologist Adult epilepsy nurse coordinator Adult epilepsy clinic
Setting	Adult epilepsy clinic	Pediatric hospital	Adult hospital	Adult neurology office	Pediatric neurology office	Home and pediatric neurology office	Adult epilepsy clinic
Usual number of visits	2 or 3	1	2 or 3	Continuing care	Completion of checklist over several years		2-4
Who provides further care?	Adult neurologist who works in the transition clinic	Adult neurologist in adult office setting	Adult epilepsy program including the adult nurse involved in transition	Adult neurologist who works in the transition clinic	Adult neurologist	Adult neurologist in large specialty hospital center	Adult epilepsy clinic or other neurology setting
Formal evaluation	No	No	Yes ³	Yes ⁴	No	Yes ⁶	No
Possible problems	Manpower	Single adult neurologist may become overwhelmed		Single adult neurologist may become overwhelmed	Depends on vigilance of pediatric neurologist over years	Unclear if applicable to small center	Ongoing funding

shortcomings. The family physician may not be knowledgeable about epilepsy or new treatments. So prior to transfer, the patient and family need to understand clearly when a reassessment is warranted—for example unsatisfactory seizure control, perceived side effects, or planned/actual pregnancy.

There are some Canadian data about the adult outcome of children with epilepsy. These data indicate that major social difficulties are common and not easily addressed in the adult health care system. In addition, children with intellectual disabilities and epilepsy are unlikely to be seen or followed by an adult neurologist. Patients who outgrow their epilepsy in childhood also have important social issues in adulthood, but almost never see an adult neurologist. There is much room for improvement!

TRANSITION IN FRANCE

A referral center for rare epilepsies in Paris established a transition program in 2005. Improving and organizing the transition was one of the objectives of the center. The model involved a single, dedicated adult neurologist who was assigned to take over the follow-up as young people with severe epilepsy grew into adults. Most of the patients have severe epilepsy coupled with significant intellectual disability. Issues that have been complicated to address include sexual maturation in young adults with cognitive disabilities, psychogenic seizures during stressful developmental stages in adolescence and young adulthood, and care of specific epilepsy syndromes that last into adulthood. Transfer included a transfer summary from the pediatric epilepsy service plus complete access to all of the pediatric medical records. There is a sense that transfer should occur in early adolescence without waiting for complete or nearly complete seizure control. A long delay may make families less willing to accept the transfer to an adult service. There is an attempt to create an adult multidisciplinary team for persons with multiple disabilities. For example, youth with cerebral palsy may have severe epilepsy but will benefit from the coordinated care of other specialties such as physical medicine, physiotherapy, and occupational therapy.

This center has published the results of a family survey on transition for patients with Dravet syndrome.⁴ After the implementation of the transition program, families of patients with Dravet syndrome, a highly intractable and disabling epilepsy syndrome, considered that they did not experience any gap between the pediatric and adult care systems.⁴ However, they stated that both adult and pediatric caregivers failed to help patients achieve a level of autonomy appropriate for their potential.

TRANSITION IN COLOMBIA

A survey about transition was carried out during the VI Latin America Epilepsy Congress in Cartagena in 2010. It

concluded that formal transition/transfer services are nearly absent in this continental subregion. A third of the respondents indicated that their institution had some form of transition program, but most were a personal and informal enterprise and only 10% involved patients with epilepsy. All the transition programs in epilepsy were held in private clinics. Lack of guidelines and protocols was evident in 98% of all the programs.

The small number of transitional programs is probably accounted for by overcrowded pediatric and adult neurology services, an unclear separation between child and adult neurologists, heterogeneous health care systems, networks and insurance policies, and a lack of time for multidisciplinary teamwork. The respondents offered as possible solutions the need for public education about the transition process, the construction of guidelines about transition/transfer, greater communication and meetings between pediatric and adult services, and the creation of multidisciplinary teams. Thus education, communication, planning, and limited human and economic resources hinder the development of transition/transfer programs in Latin America.

The ideal transition program would be the planned work of a multidisciplinary team that receives continuous feedback from adult and pediatric services. This option could be developed in several parts in Latin America, but is not currently achievable in the majority of settings.

Solutions to this gap in service are not simple. Of considerable value might be a checklist that covered basic, common, and fundamental items of transition. These items could be reviewed during medical consultations during the years before transfer. Such a systematic approach might be sufficient for most patients and families. This model is patient based, does not consume much time, and the professional and economic burden is not necessarily high (Table 2).

Another option is a group-oriented model where a coach goes through several main topics with a group of adolescents with epilepsy. Confidence, privacy, shame, and personal needs could be barriers to achieving a purposeful transition in this setting, but openness, solidarity, and sense of inclusion could help build the fundamentals of a successful transition. Transition of patients with special needs would still require coordination of multiple health care professionals.

TRANSITION IN GERMANY

In 1997 an expert statement for the Ministry of Health emphasized the problematic health care situation of adolescents with chronic diseases when moving toward adulthood. However, this report had no further political consequences. During the past several decades, numerous transition projects were started, mostly initiated by pediatricians. These projects targeted the continuation of specialized medical care for adolescents with chronic diseases as they moved

Table 2. Proposed transition checklist

Transition items – date	Key notes	Observations
Name:		
Age:		
Diagnosis:		
Treating physician:		
Receiving physician:		
Complete medical history	Diagnosis and comorbidity; medication schedule(s) adherence, AED efficacy, drug interactions, adverse effects, AED withdrawal trials, plasma concentrations, seizure follow-up diaries; neuroimaging, electrophysiologic, neuropsychological studies; liver function, blood tests	
Education information	Building up awareness and consciousness about his/her disease, drug treatment, triggering factors; stigma; legal rights	
Family dynamics	Quality of parent adolescent relationship, overprotection, dependence, shame, cultural and religious background, resilience	
Individual health supervision issues	Nutritional status: weight/height/BMI; vaccinations, body image	
Sexuality, pregnancy and reproductive issues	Anticonception, irregular menses, sexual performance and desire, sexually transmitted diseases, pregnancy risks, sexual abuse, teratogenesis, pregnancy termination, breastfeeding	
Smoking, alcohol, drugs	Seizure risks, antiepileptic drug interaction, dependence, addiction, peer pressure	
Education and career choices	Vocational, technical, professional orientation; overnight duties	
Physical activity	Extreme sports, seizure control, SUDEP prevention	
Driver's license	Legislation, seizure control, autonomy	
Comorbidity	Physical and psychiatric comorbidity, drug treatment and interactions, quality of life	
Mortality	Higher risk of mortality, SUDEP, depression, suicide, accidents	
Insurance	Social security, family dependence, work insurance, treatment and follow-up guarantee	
Final notes:		
Date of transfer:		
BMI, body mass index; SUDEP, sudden unexpected death in epilepsy.		

into adulthood. Most projects were established at large hospitals, especially university hospitals, where specialized expertise was available for adolescents and adults. The projects were organized locally, each of them referring to one disease or one group of diseases. There was no special reimbursement for these efforts, and they remained focused on specific patients by specific physicians. With changing personnel these projects usually terminated. In 2008, a concept for a diagnosis-independent transition program⁵ was designed and involved health insurance agencies at an early stage. Essential structural features are case management, structured information transfer (electronic file), variable levels of support including education options, independence from local infrastructure, and reimbursement of transition-specific efforts. The criteria for the structured medical report were elaborated by experts in specific fields. In 2009 another expert report to the Ministry of Health stressed the importance of a successful transition process. To prove and refine the concept, the program started with patients with epilepsy or type 1 diabetes in the region Berlin/Brandenburg and three health insurance agencies. Three groups were differentiated, according to the degree of support. The first period was completed successfully in 2012. During the second period, the program was extended to additional disease groups and additional federal states. The medical societies of pediatrics, internal medicine, and neurology have agreed on this program as the basis of a transition program and support its use in regular health care. In 2013, the program

became a partner of the modular education system ModuS, which is offered to adolescents with chronic diseases and their parents.⁶ Transition is one important part in this educational program.

TRANSITION IN THE UNITED KINGDOM

The move of young people with epilepsy from pediatric to adult care is challenging for patients, their families, and health care professionals. It occurs at a critical time of development, and the success (or failure) of optimal management of epilepsy at this time may have a potentially irreversible impact on the patient's future. In the United Kingdom, there are four options for the continuing management of a young person at this stage. First, to be discharged back to their general practitioner; second, to remain under the care of the pediatrician or pediatric neurologist; third, to be referred to an adult physician or neurologist (neither of whom may have expertise in epilepsy care); and fourth, to be seen in a dedicated epilepsy-transition service. The benefit of this final option is that this operates separately from a pediatric or adult clinic and can provide continuity of specialist epilepsy care that is not only adolescent-specific, but is able to address specific evolving adult issues. This approach is endorsed by the National Institute for Health and Clinical Excellence,⁷ the Scottish Intercollegiate Guideline Network (SIGN 2005) epilepsy guideline, and

the National Service Framework.⁸ This document, “Transition: getting it right for young people” included the following: “These young people with neurological disorders and disabilities [defined as difficult or intractable epilepsy syndromes that differ from those seen in adult neurological practice] are the least well served as there is often no service available to take over their care when they leave paediatrics.”

The first reported transition service for young people with epilepsy in the United Kingdom was established in Liverpool in 1991.⁹ The service is held monthly in the adult neurosciences center and is supervised jointly by one of two adult neurologists and one pediatric neurologist. Between four and six new patients and seven and nine follow-up young people are seen in each clinic. The catchment area population is >4 million. All young people with epilepsy are seen in the clinic, irrespective of whether they have any comorbid difficulties (e.g., learning difficulties, autism spectrum disorder, cerebral palsy) and the severity of these difficulties. The minimum age at which a new patient is seen in the clinic is 16 years and the maximum is 22 years (mean 17.8 years). The clinic is supported by a nurse specialist in adult epilepsy, and there is access to a career and employment representative in the waiting area. There is no fixed time at which the young person leaves the transition clinic and is promoted to the adult epilepsy service, although most are promoted before the age of 23 years. The annual unexplained nonattendance rate is low at <10–12%. Once the young person is “promoted” into the adult epilepsy clinic, continuity of their care is provided by the two adult neurologists with specific interest in epilepsy who had seen them during their attendance in the transition clinic. This policy appears to be appreciated by the young people and their families. The Liverpool transition service has served as a model for many other transition epilepsy clinics in the United Kingdom.

In the 16 years since this initial publication, a national survey has indicated that there is still a limited transition service despite a clear professional consensus that this represents best clinical practice.¹⁰ This survey identified 15 “transition clinics” in the United Kingdom, all led by a pediatric neurologist who specialized in epilepsy, with or without an adult neurologist in the transition clinic. No two centers provided the same service.

It is currently difficult, even impossible, in areas of the United Kingdom to develop a transition service for young people with epilepsy. In part this relates to the increasingly rigid framework, health-economic and cost-effective pressures within the National Health Service, but it also probably reflects some reluctance to consider transition as a priority area of health care. Predictably, there are many issues that may militate against the development of new transition clinics. These include the philosophies and personalities of the medical staff; debate and disagreement over where a transition clinic should be based; and financial

issues relating to consultant and epilepsy nurse sessions dictated by the Hospital Trust or the newly established Clinical Commissioning Groups (CCGs), or both. The crucial issue that will determine an improvement in transition services is the attitude and motivation of the health care professionals supported by the medical Royal Colleges (Paediatrics and Child Health, Physicians and Psychiatrists) and directives issued by the Department of Health and National Institute for Health and Care and Excellence (NICE). Unfortunately this momentum to improve transition services may be impeded by opposition from individual Hospital Trusts and local CCGs, the groups that now determine the priority areas for all local health care in the National Health Service.

IS THERE AN OPTIMAL MODEL FOR TRANSITION/TRANSFER?

There has been little comprehensive evaluation of any of the programs outlined earlier. Therefore, it is impossible to choose the best based on any objective criteria. The problem of evaluation of transition programs is not unique to epilepsy and has been identified as a significant issue with all chronic diseases in children.¹¹ As noted previously, the United Kingdom and Canadian models for epilepsy transition that rely on joint visits with pediatric and adult specialists are clearly expensive, implying that funding in a private practice, insurance-based health care system may be difficult. The Canadian model is not likely to serve the needs of remote rural communities several thousand kilometers from specialized epilepsy care. The United Kingdom experience has been long, and the model appears to work well. The French model for severe epilepsies also seems to work well, but is very dependent on a single epileptologist in a regional center. The proposed check list for the Colombian system does not directly involve an adult neurology service, but it is clearly an excellent step. The German system began in tertiary care settings and we will wait to see how well it applies to less specialized settings.

It appears that there is a need for much more evaluation of existing transition models for epilepsy care, a theme that is seen in the literature for many chronic diseases in childhood.^{12,13}

DISCLOSURE

The authors declare no conflicts of interest. We confirm that we have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

REFERENCES

1. Ontrac: Transitioning Responsibly to Adult Care. Available at: ontracbc.ca/. Accessed August 7, 2014.
2. Camfield P, Camfield C, Pohlmann-Eden B. Transition from pediatric to adult epilepsy care: a difficult process marked by medical and social crisis. *Epilepsy Curr* 2012;12(4 Suppl.):13–21.

3. Jurasek L, Ray L, Quigley D. Development and implementation of an adolescent epilepsy transition clinic. *J Neurosci Nurs* 2010;42:181–189.
4. Kuchenbuch M, Chemaly N, Chiron C, et al. Transition and transfer from pediatric to adult health care in epilepsy: a families' survey on Dravet syndrome. *Epilepsy Behav* 2013;29:161–165.
5. Berliner TransitionsProgramm. Available at: <http://www.drk-kliniken-berlin.de/westend/krankenhaus-westend/berliner-transitionsprogramm/>. Accessed August 7, 2014.
6. Patientenschulung-kompas.de. Available at: http://www.patientenschulung-kompas.de/t_main.php. Accessed August 7, 2014.
7. National Institute of Clinical Excellence (NICE). *The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care*. Clinical Guideline 137. 6. NICE; 2012. Available at: www.nice.org.uk. Accessed November 25, 2013.
8. National Service Framework. *Improving the transition of young people with long term conditions from children's to adult health services. 'Transition: getting it right for young people' (best practice guideline)*. Department of Health March; 2006. Available at: <https://www.bspar.org.uk/DocStore/FileLibrary/PDFs/Transition%20getting%20it%20right%20for%20young%20people%20-%2023rd%20March%202006.pdf>. Accessed November 25, 2013.
9. Appleton RE, Chadwick D, Sweeney A. Managing the teenager with epilepsy: paediatric to adult care. *Seizure* 1997;6:27–30.
10. Iyer A, Appleton R. Transitional services for adolescents with epilepsy in the UK: a survey. *Seizure* 2013;22:433–437.
11. Sharma N, O'Hare K, Antonelli RC, et al. Transition care: future directions in education, health policy, and outcomes research. *Acad Pediatr* 2014;14:120–127.
12. Transition of care provided for adolescents with special health care needs. American Academy of Pediatrics Committee on Children with Disabilities and Committee on Adolescence. *Pediatrics* 1996; 98:1203–1206.
13. Rosen DS, Blum RW, Britto M, et al. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health* 2003;33:309–311.