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The evaluation and costs of transition programs for youth with epilepsy

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ABSTRACT

There is limited information about the effectiveness of transition programs for youth moving from pediatric to adult care with any chronic disease. Two Delphi studies and National Institute for Health and Care Excellence (NICE) guidelines about transition for epilepsy have suggested few critical outcome measures for transition. A single large prospective study found that the most important transition program elements were appropriate parent involvement, promotion of health self-efficacy, and meeting the adult team before transfer. Two Cochrane reviews of the value of transition for epilepsy found insufficient evidence to establish or refute the value of various programs, although evaluation of a few programs suggested a great deal of family/patient satisfaction. The cost of transition programs and their cost effectiveness have also not been established except for renal transplantation where transition programs were associated with fewer losses of the transplanted kidneys, a cost-effective outcome. Published data on the overall cost of care for children and adults with epilepsy may be helpful to establish a business plan for a transition program, and are briefly reviewed. Establishing cost effectiveness of transition programs for epilepsy would promote their establishment and viability. However, a number of studies will be needed based on the nature of the program, the healthcare system where it is carried out, and the type of epilepsy. In fee-for-service health systems, the reevaluation of patients with epilepsy prior to transfer may be sufficient to cover the costs of the transition program, whereas in single payer systems, there may be positive downstream health or societal benefits that justify the costs. A theoretical framework for comprehensive evaluation of epilepsy transition programs is needed. The Triple Aim Framework seems applicable with focus on population health, patient experiences, and cost and has the potential to assess transition interventions in the context of system-wide improvements in healthcare. Transition programs in general have not been well evaluated, and very little evaluation data exist regarding transition programs for epilepsy. We recommend more evaluative research using rigorous methodology to comprehensively assess these programs.

1. Introduction

There is increasing evidence of the potential value of transition programs for adolescents with epilepsy to allow a smooth transfer to adult care and an improved adult life; however, for the most part, this "evidence" is descriptive and not based on rigorous methodology. A closed seminar about transition to adult care for youth with epilepsy took place near Paris, France in July 2018. This symposium followed two previous ones, the first aiming to take transition out of the shadows in the context of different epilepsy syndromes [1] and the second to outline biologic, social, treatment, and outcome issues [2–4]. An accompanying paper from the current symposium outlines how transition for epilepsy might be best orchestrated based on the programs and experience in many countries [5]. The current paper summarizes the discussion about the evaluation of epilepsy transition programs and their cost.

2. Evaluation of epilepsy transition programs

To evaluate the utility of epilepsy transition programs, the goals of the programs need to be clear. As seen in Table 1, there are relatively few common elements across a variety of recommendations for transition programs.

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Table 1
Suggested key elements for transition programs.

	NICE guidelines	Delphi 2015	Delphi 2016	Ontario guidelines
Age-banded clinic	x			
Meeting with adult team before transfer	x			
Promotion of health self-efficacy	x	x	x	
Written transition program including transfer summary	x	x		x
Appropriate parental involvement	x	x		
Key transition worker	x	x		
Coordinated healthcare team	x			
Holistic life skills training	x		x	
Transition manager	x	x		
Start transition program at early age		x		
Seeing patient alone		x		
Identifying adult provider		x		
Ensuring that first appointment takes place		x		
Informing primary healthcare providers		x		
Assessing risk behaviors		x		x
Understanding characteristics of conditions and complications			x	
Adhering to medications and/or other treatment			x	
Attending most medical appointments			x	
Having a medical (health) home			x	
Avoiding unnecessary hospitalizations			x	
Understanding health insurance options and community supports			x	x
Having a social network of friends			x	
Rethink diagnosis and reinvestigate if appropriate, prior to transfer				x
Identify obstacles for patients with drug-resistant epilepsy				x

A Delphi study was carried out by an international group of experts to try to identify critical features for most transition programs regardless of the disease. Thirty-seven panelists included 24 physicians, 8 nurses, 2 psychologists, 2 transition program managers, and 1 research director. The process started with 34 key elements and 32 indicators [6]. After three rounds of the Delphi process, only 4 key elements were nominated as essential by ≥70% of the experts. These were the following: 1) starting transition planning at an early age, 2) discussing with the patient and family about self-management, including the young person's views and preferences for transition planning, 3) seeing the adolescent alone at least for part of the transition (if developmentally appropriate), and 4) identifying an adult professional willing to take on the young person.

Ten additional factors were rated as "essential or very important" by ≥70% of the "experts" with eight of the ten rated as essential or very important by >85% of experts. These were the following: tailoring the transition plan to the needs of the patient and family; identifying someone within the team to play the role of transition manager or coordinator; providing a written health and biopsychosocial profile summary to the patient and adult care provider before transfer; having a written transition protocol/plan that is available to patients, parents, and providers; making sure that at least one appointment with adult provider after transfer is scheduled and confirmed; verifying that the pediatric and adult clinics in question have sufficient knowledge and skills in adolescent health, including parents/legal representatives in the process of transition; informing primary care providers (pediatrician, GP, family doctor, nurse practitioner/advanced practice nurse) of the transition process; putting in place mechanisms/resources to contact patients lost to follow-up; discussing with patient and family the differences between pediatric and adult care; and finally, discussing with the patient risk behaviors and their influence on health. It is perhaps surprising that all of these suggestions are related to health outcomes and none to psychosocial development given the more global goal of a successful adult life. A potential explanation may be that there were no patient or parental representatives on the expert panel.

Many of the final ten elements listed above are similar to a comprehensive set of nine transition program principles outlined by the United Kingdom's National Institute for Health and Care Excellence (NICE) guidelines of 2016 on transition including: age-banded clinic, meeting with the 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, and a transition manager for the clinical team [7]. A careful study of these NICE program features followed 374 youth with diabetes, autism, and cerebral palsy annually for four years after transfer to adult care [8]. Based on four outcomes measures: Warwick Edinburgh Mental Wellbeing Scale, Mind the Gap Scale (a scale to measure satisfaction with services), Rotterdam Transition Profile (Participation), and Autonomy in Appointments, the authors found that of the nine elements, only three were associated with good outcome — appropriate parent involvement, promotion of health self-efficacy, and meeting the adult team before transfer. This is an important study because it not only points to the elements of a good transition program, but it also gives some focus to what should be assessed in establishing the potential value of a transition program for children with epilepsy.

A Cochrane meta-analysis in 2016 entitled: "Transition of care for adolescents from paediatric services to adult health services" only identified four randomized controlled trials that assessed transition programs [9]. These were small studies including a total of 238 patients, and the authors concluded that "There was evidence of improvement in patients' knowledge of their condition in one study, and improvements in self-efficacy and confidence in another, but since few studies were eligible for this review, and the overall certainty of the body of this evidence is low, no firm conclusions can be drawn about the effectiveness of the evaluated interventions. Further research is very likely to have an important impact on our confidence in the intervention effect and likely could change our conclusions. There is considerable scope for the rigorous evaluation of other models of transitional care, reporting on clinical outcomes with longer term follow-up."

Another systematic study examined outcome measurements in publications about transition [10]. The authors found only 26 publications that examined outcome after transfer and noted that the interventions were complex with multiple outcomes, major problems with blinding, and small sample sizes. Only a few studies were randomized, and there were problems of "recruitment and external validity, blinding, measurement validity, and standardized assessment". The net effect was that it was impossible to compare various trials or to come to any conclusions about best practice.

3. What outcomes should be evaluated?

3.1. Outcomes categories

There are few publications that attempt to evaluate transition programs for epilepsy. Outcomes that might be considered fall into four categories. First, it is important to assess what happens to the seizures. This could involve counting seizures directly, using other clinical outcomes (episodes of status epilepticus, death from Sudden Unexpected Death in Epilepsy (SUDEP)) or health services outcomes such as attendance at follow-up clinics, hospitalizations, emergency room visits, or treatment adherence. Second, mental health and psychosocial issues are important and include assessments for both mood disorders and suicide attempts as well as more general measures of psychosocial function such as marriage or divorce. Third, there are issues of finances and legal supports such as employment for those with normal intelligence or guardianship for those with intellectual disability (ID). The cost of care is also relevant. Fourth, assessments of patient/parent satisfaction and quality of life are important.

We are not aware of any study that has assessed such a broad array of outcomes in epilepsy around the time of transition/transfer. Several epilepsy cohort studies have assessed transition/transfer experiences for youth with epilepsy, although each study has used restricted outcome measures.

3.2. Programs that assessed transition and transfer experiences

3.2.1. Colorado Children's Hospital, Aurora, Colorado, USA

One such study from Colorado studied youth with refractory epilepsy who were of an age when transfer to adult care would be appropriate [11]. The authors developed several interventions and chose the time from referral to the time of visit with the adult service as the primary outcome measure. Also assessed was the effect of an education program on self-management. As well, they counted referrals to social work, whether there was any change in self-care, and considered the satisfaction level of the pediatric epilepsy service providers. Over time, there was a decrease in the time of referral to being seen in adult services and an increase in the counted referrals to social work. However, there were no significant changes in the outcome measures. The study had no data about seizure control or other changes once the transfer had been completed.

3.2.2. Necker Enfants Malades Hospital, Paris, France

A study from Paris of 31 patients with Dravet syndrome, who had already been transferred to adult care, used a series of Likert-type scale questions completed by parents to assess their experiences of transition [12]. Questions were divided into three groups: the pediatric experience, the time of transfer, and the first two years in adult care. Nearly all patients reported a great deal of satisfaction with both their pediatric and adult neurology care, although "92% of the families felt that the adult neurologist did not give them enough autonomy to make decisions." Sixty percent of families reported that their preparation for transfer was satisfactory, but 40% reported their preparation as "inadequate". Five factors strongly predicted satisfaction with transfer preparation: quality of transition preparation, longer duration of follow-up in pediatrics with the same child neurologist, good availability of pediatric staff, age > 18 years at the time of transfer, and "good health condition" at the time of transfer.

3.2.3. Children's Hospital, Edmonton, Alberta, Canada

A nurse-led transition clinic in Edmonton is described in the accompanying paper [5,13]. A series of Likert-type questions was completed by 144 patients (or parents if the child had ID) two months after the first adult epilepsy clinic assessment. Nearly all respondents indicated that the nurse-led transition program was appropriate, decreased their fears, and made them aware of the differences to expect between pediatric and adult care. This transition program involved both the pediatric and adult epilepsy nurse practitioners, and all respondents indicated that it was particularly helpful to have met the adult nurse prior to their first adult epilepsy clinic visit.

Therefore, it is clear that comprehensive, empirical evidence is scarce for the outcomes of transition programs for youth with any chronic disease and nearly nonexistent for epilepsy. A theoretical framework could assist further research. One example of such a framework is the Triple Aim Framework that considers three major categories of outcome [14]. First is outcomes related to population health, such as adherence to guidelines, disease specific outcomes like seizure control or mortality, and patient-reported outcomes such as quality of life and self-care skills. Second is patient care experiences, such as satisfaction with care, and identification of facilitators and barriers to accessing care. Third is outcomes related to cost, which includes gaps in care, costs of "no shows" for follow-up care, costs per patient, service use (both short-term and long-term), and location of care (i.e., outpatient vs. emergency vs. inpatient care). Although few studies have considered all three groups of outcomes, the Triple Aim framework is of great value because it aligns transition interventions with system-wide improvements in healthcare.

Few studies of transition have used the Triple Aim Framework. A meta-analysis considered studies that described an intervention for transition for pediatric to adult care including patients with and without a chronic condition [14]. Included were studies that compared experiences pre- and postintervention or compared an intervention with a comparison group. Thirty-three studies met the inclusion criteria. Twenty-seven studies used "population health" measures, mainly disease-specific. Fifteen studies assessed the cost, mainly service utilization. Eight studies addressed "experience of care", mainly satisfaction. There were only three studies that examined all three overall domains of the Triple Aim Framework, and these were all studies of Type 1 Diabetes [15–17]. These studies suggested that in the short run, the control of diabetes was not altered to a significant degree but attendance at follow-up was considerably better with transition programs.

4. Treatment needs of the epilepsies

There are no ideal "rules" about when to transfer a young person with epilepsy to adult care. In some jurisdictions, it is simply the age of patient that is considered. However, it is worthwhile to consider some of the issues that are better dealt with in pediatrics and others that might be better managed in the adult setting. These considerations will impact the cost of transition.

4.1. Self-limited epilepsies

These are mainly patients with Rolandic epilepsy. Seizures have resolved by mid adolescence, but there may be some residual learning issues; however, the long-term social outcome is typically normal [18]. A family physician or general internist in a community setting would seem more than adequate for ongoing care. Transition for these patients could be the same as for any healthy adolescent, and there would be no extra costs.

4.2. Idiopathic generalized epilepsies that persist

Juvenile myoclonic epilepsy (JME) is most important in this category. Here, the diagnosis should be well established during adolescence, and the patient needs to prepare for a lifetime of Anti Epileptic Drugs (AED) treatment even though some patients with JME will eventually have complete remission and no longer require medication [19,20]. Seizures are typically well controlled with medication. Of importance, the epidemiology of JME suggests that most but a majority of these patients are female, and thus, issues of contraception and pregnancy are very important. These latter concerns are often more familiar to adult neurologists/epileptologists, and earlier transfer during adolescence may be appropriate rather than waiting for young adulthood. Transition teaching during the pediatric years should likely focus on compliance and introduce issues of sexuality, restrictions, life style, and eventual employment, which need to be continued in adult care. These themes span both pediatric and adult care and will likely be associated with some incremental costs such as social work or employment counseling.

4.3. Epileptic and developmental encephalopathies

Here, the child neurologist/epileptologist is likely best informed about the nature of the epilepsy, its causes, comorbidities, natural history, and treatment. Adult epileptologists may be unfamiliar with the epilepsy syndromes, etiologies, and complex treatments with special AEDs or diets. The management of ID and difficult behavior problems may be very challenging in late adolescence. It is ironic that many of these children end up as adults in institutional care where their very complex epilepsy may be managed by family physicians or psychiatrists with or without occasional consultations with adult epileptologists. Transition/transfer costs may be substantial because of the important role for social workers, nurses, psychologists, and institutional caregivers. An ideal arrangement might be co-care with both pediatric and adult epileptologists.

4.4. Drug-resistant focal epilepsy

Until recent times, adult epilepsy care has been more focused on epilepsy surgery compared with pediatric care [21]. Arguably, earlier transfer to adult care for youth with drug-resistant focal epilepsy is appropriate to identify those with surgical options especially if the pediatric team does not have this expertise. The cost of transition/transfer may then include a major epilepsy surgery workup that is expensive but potentially cost effective if seizures are "cured" earlier in life by surgery leading to the possibility of more years of productive employment.

Clearly, the timing of transfer to adult care and choice of adult epilepsy provider are best seen as an individualized decision, based on the type of the epilepsy and on the local facilities and care programs.

5. Costs & financing of transition programs

Creating a successful transition program requires financing to develop, implement, and sustain the operations of the program. The source and justification for funding will depend strongly on the national healthcare policy environment. In some countries, healthcare is supported extensively by the state. All the necessary resources represent costs and must be offset with improved clinical outcomes (i.e., fewer seizures, improved quality of life), reduced downstream uses of healthcare resources such as emergency rooms, or improved social and employment outcomes. Alternatively, in a fee-for-service environment, such as that occurring in much of the United States healthcare system, some of these resources can be reframed as revenue, or as a means to improve patient satisfaction and reputation of the institution.

When deciding to implement a transition program, a medical center will need to balance the scope of a program with the degree of funding available. A minimal program might focus only on drafting a transfer note. Greater costs will be incurred by increasingly comprehensive transition programs, which might include a reevaluation of etiology or a dual clinic with the pediatric and adult team. A nephrology program in Vancouver was able to demonstrate the cost effectiveness of a kidney transplant transition program, facilitated by the use of a clearly defined clinical outcome — loss of the transplanted kidney [22]. Prior to the transition program, a simple transfer system was used to pass youth along to adult nephrology care. There was a high rate of kidney rejection presumably related to poor compliance with the net effect that several youth had to return to dialysis, a costly treatment. Following the introduction of an extensive transition program, loss of the transplanted kidney dropped to zero. The cost of the transition program was much less than the previous costs for dialysis, hence, the program was deemed highly cost effective. To the best of our knowledge, this is the only transition plan that has been assessed for cost effectiveness. Such straightforward outcome measures are difficult to establish in epilepsy transition programs.

A Delphi approach included 93 participants (including physicians, healthcare experts, and parents of children with chronic illness) to recommend the most desirable outcomes for transition [23]. At the end of three cycles, it was concluded that the following in descending order were the most important outcomes: achieving optimal quality of life, patient self-managing the patient's own condition, understanding characteristics of conditions and complications, knowing the names and purpose of medications, adhering to medications and/or other treatment, attending most medical appointments, having a medical (health) home, avoiding unnecessary hospitalizations, understanding health insurance options, and having a social network of friends. Many of these outcomes would be difficult to assess in a cost effectiveness analysis.

5.1. Estimation of costs for transition programs

In an attempt to estimate the costs of a transition program in epilepsy, we considered the seven recommendations of the Ontario Task Force on transition for people with epilepsy — introduce the concept of transition, explore available financial, community, and legal supports, determine transition readiness, screen for risk factors for poor transition, rethink diagnosis and reinvestigate if appropriate, identify obstacles for patients with drug-resistant epilepsy, and prepare pediatric discharge package [24]. To accommodate these recommendations within a new transition program, there would be startup costs. Each of the seven recommendations has an associated cost including personnel (physician, nursing, social worker, and other professionals), modifications to the electronic medical record, and clinic space. Possibly the most expensive would be reinvestigating the etiology of the epilepsy that might be justified in perhaps a third of patients. These investigations could involve admission to an epilepsy monitoring unit, an Magnetic resonance imaging (MRI) with sedation and extensive genetic testing. In a fee-for-service healthcare system, the revenue from the reinvestigation may outweigh the other transition clinic expenses making the transition program "cost effective". In a single payer government run system, it will be more complicated to establish cost effectiveness because it will be necessary to evaluate costs after the transition process has been completed using factors such as number of emergency room visits, impact on family income, and generation of income taxes.

5.2. Estimation of financial benefits from transition programs

There are some published data to help estimate the financial benefits of transition programs. For programs that promise reductions in unnecessary hospital use, a public accountable care organization in the United States found that for a child with epilepsy, a typical emergency department visit costs USD $640, and an unscheduled inpatient admission of USD $18,066 [25]. Of importance, the distribution of inpatient costs have a long tail — an admission for child with refractory status epilepticus regularly costs USD $150,000–$300,000, and in extreme cases, costs may exceed USD $1 million [26]. For programs that promise improvements in seizure control, several reports show that the cost of care for individuals with uncontrolled epilepsy is significantly higher than for controlled epilepsy. A recent review found that in the US, epilepsy-attributable direct costs ranged from $1022–$9327 per patient per year for individuals with controlled epilepsy, compared to $8592–$19,749 for individuals with uncontrolled epilepsy [27]. Similar estimates for other countries, both in the developed and developing world, have been recently reviewed [28]. For programs that promise an increase in epilepsy surgery, economic analyses have shown improvements in survival and quality-adjusted life expectancy [29] and overall reduced costs over 9–10 years [30]. And finally, some programs may promise reductions in indirect costs, e.g., the costs from unemployment, underemployment, and missed work for people with epilepsy and their caregivers [31]. A Spanish study estimated that indirect costs were *higher* than the direct costs, €1055 direct vs €1528 indirect over 6 months in their cohort of 171 adults with epilepsy [27].

6. Conclusions

We conclude that transition programs in general have not been well evaluated, and that evaluation data about epilepsy programs are particularly lacking. In the absence of such data showing the benefits of these programs and enabling the cost effectiveness evaluation, epilepsy transition programs may be expensive and difficult to implement. We urge that more efforts be made to prove the value of these programs.

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Conflict of interest statement

None of the authors declare conflict of interest.

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