A 10-step-algorithm for transitioning pediatric epilepsy patients to an adult service

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Background
When children with epilepsy reach late adolescence, transition to an appropriate service for adults is often problematic. Frequently transfer is abrupt or there is inappropriate retention in pediatrics. A significant number become disconnected (“lost”) from health care all together (Steinbeck et al. 2008) due to various barriers (Table 1). The conceptual differentiation between transfer and transition is crucial. Transfer is an event, transition is a process (Table 2).

Current evidence suggests that Transition Clinics improve quality of health care in chronic diseases starting in childhood, prevent comorbidity and long-term costs and reduce Disability-Adjusted-Life-Years. On an individual level the ultimate goals are to arrive at the maximum level of independence, self-sufficiency and self-worth, develop compliance, and more important to avoid self-stigmatisation, social isolation and failure in occupational issues.

Method
2 pediatric, 1 adult epileptologist and an adult epilepsy nurse developed a transition clinic for youth with epilepsy. The ultimate goal on an individual level was to gradually empower the individual child to become knowledgeable about epilepsy, self-sufficient and independent. With this approach, it was hoped to prevent stigmatisation, social isolation and failure in occupational issues. A Shared Management Approach (Table 3) served as a model (Kieckhefer and White 2006) to gradually hand over responsibilities from the health care provider and family members to the patient. Based on the first 36 patients (Table 4), we developed a 10-step-algorithm and a systematic process to see these patients (Figure 1, Table 5).

The 10 step algorithm
(1) Identification of patients ready for transition
(2) Preparation of patient and family for transition by the pediatric team
(3) Completion of a structured medical synopsis form including details of the epilepsy and treatment, proposed cause and investigations and associated problems
(4a) Documentation of “social” information using a structured format completed by the care-taker of a handicapped individual including: comorbid physical, cognitive and behavioural difficulties; custody and financial support; names and locations of health, educational and social services involved; medications, vitamins and alternative therapies, social network and recreation; and nutritional status
(4b) If the individual was normally intelligent, a detailed form was completed by the patient which includes: an outline of education and employment, driving status, medications, vitamins and alternative therapies, marital status, and extracurricular activities
(5) 3 and 4 forwarded from the pediatric to adult service
(6) Joint appointment at the adult hospital including patient, family, pediatric neurologists, adult epileptologist and epilepsy nurse to introduce the adult service
(7) Review of history and examination by the adult team
(8) Formulation of short and long-term plans with special focus on health care providers (epileptologist, neurologist, family physician, medical support services)
(9) Review with the entire group including patient and family to agree on diagnostic and therapeutic steps (medical and social) and follow up visits
(10) Summary letter to family physician and adult hospital health record

Conclusions
Our algorithm for transitioning pediatric patients with epilepsy to adult health care services provides a schema for the complex process of coordination, collaboration, and communication amongst youth, families, health care providers and services. Further research is needed to objectively document its value and to find the individually ideal health care provider (see cartoon).

References:
Allen, R.: Society of Adolescent Medicine
Kieckhefer and White 2006

Table 1: Frequent barriers for transitioning from pediatric to adult services

Table 2: Definitions of transfer and transition

Table 3: Shared Management Model

Table 4: Cohort characteristics

Table 5: 10-step algorithm

Figure 1: Process of transitioning including individualized follow-up visits

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