Global Issues in the Transition of Adolescents with Epilepsy – A Child Neurologist’s Perspective

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Disclosure

Nothing to disclose
Learning Objectives

• To view transition as an integral part of health care service

• Need to built up transition programs for adolescents with epilepsy, ideally as an interdisciplinary approach.
TRANSITION IN LATIN AMERICA

Transition programs are almost missing in Latin America (Cartagena Survey, 2010)

Important gap of pediatric neurologists:
Neurologists: 1/ 82 000
Neuropediatricians: 1/ 228 000
TRANSITION IN LATIN AMERICA

• Most of the aims purposed on a transition program (team work) in the US have to be assumed by the treating physician in Latin America.

• Social, cultural and economic characteristics are heterogenous in LA.
GOALS OF A TRANSITION PROGRAM

• To educate on specific and individual issues on epilepsy and related medical conditions.

• To promote communication, decision making, self care and self advocacy skills.

• To optimize the quality of life, life expectancy and future productivity.

BMJ 2006; 332: 25
Pediatrics 2002;110:1322
Timing of Transition

Early and mid adolescence

Ideally in a transition clinic

In absence of a transition clinic, treating physicians, either child or adult neurologists should discuss hallmark points with the patients or family.
It is possible that the quality of the parent – adolescent relationship, and not the disease severity, holds the key to successful transition, with a perceived parental acceptance having a more positive effect on adolescent psychological well being.
EPILEPSY - FAMILY DYNAMICS

• Impact of a chronic illness.
• Medical monitoring, medication adjustments, hospitalizations and absences from school can affect self image and self esteem, “feeling different”.
• Cultural and family perception on the diagnosis and treatment of epilepsy.
• Higher risk of internalizing (anxiety, depression), externalizing (aggression, hyperactivity) behaviour problems.

Epilepsia 2002, 43(Suppl): 26-30
EPILEPSY - FAMILY DYNAMICS

• Overprotection and dependency on parents.

• Fear of forming close relationships because of shame and not having the “self control” over the unpredictable seizure.

• Perceived and directed stigma.

• Higher risk of learning disorders and neuropsychological problems.

• Whether or not to disclose their epilepsy.

Epilepsy & Behavior 3 (2002) 368–375;
Epilepsy & Behavior 6 (2005) 556–562
HEALTH SUPERVISION ISSUES

Role of primary care physician/team - child neurologist:

• Accessible, comprehensive medical record with pertinent information

• Written transition plan that includes adult care destination.
HEALTH SUPERVISION ISSUES

- **Periodic evaluation of:** medication adherence, drug interactions, seizure control, adverse effects, plasma concentration, liver function, blood tests, EEG.

- **Health-social maintenance needs:** weight/height/BMI, nutritional counseling, vaccinations, contraception and sexuality issues, assessment of tobacco, alcohol and drug use, emotional status, academic achievement, sleep requirements, sports, social activity.
ANTICIPATORY GUIDANCE – GENETIC COUNSELING

• As the adolescent approaches the reproductive years, the cause of the epilepsy and inheritance patterns may be addressed according to his maturity status.

• These approaches can potentially define the risk to the adolescent/adult’s offspring.

• Targeted family history and tree construction; genetic evaluation to define a syndromic versus a non syndromic disorder.

EPILEPSIA 2000; 41: 447–452
ANTICIPATORY GUIDANCE – SEXUALITY, PREGNANCY AND REPRODUCTIVE ISSUES

• Types of contraception

• Drug interaction between oral contraceptives and AED.
Pregnancy:

- Higher risk of anemia, pregnancy induced hypertension, preterm births and low birth weight infants.

- Additional maternal and fetal risk posed by seizures.

- Risk of teratogenesis.

- Risk of STD exposure.

- Access to care, health coverage and ambivalence about informing her pregnancy.
Pregnancy:

- Pregnancy termination, emotional impact.

- Continue pregnancy: pregnancy and delivery plan, focus on seizure control, medication schedule and monitoring, teratogenesis prevention/ammelioration

- Keeping the baby or placing the baby into adoptive services.

EPILEPSIA 2008;49: 1446–1450;
EPILEPSIA 1996; 37:: S34–S44;
EPILEPSIA 2009; 50: 1237–1246
ANTICIPATORY GUIDANCE – EDUCATION AND CAREER CHOICES

Neuropsychological and psychiatric disorders must be taken into account, because they may impact adolescent’s ability to learn and assume responsibility for their health care.

Education and employment are crucial to financial security and psychological wellbeing and therefore represent another important concern for these adolescents.

The risk for unemployment for adults with epilepsy can be expected and may be related to misunderstanding, lack of knowledge and stigma on epilepsy by employers.

Epilepsia 2009; 50 (5): 1030–1039
Epilepsia 2010;50 (5): 1030–1039
Challenges for PWE entering the workforce: discrimination, changes in functional physical and mental capacity, unpredictability of seizures, medication side effects.

The adolescent should know the legal rights protecting him at workplace.
EDUCATION AND CAREER CHOICES

Patients and parents should be educated about any possible restriction that might affect ability to work (overnight work, military service or career, pilot, bus driver, construction employee etc).


PHYSICAL ACTIVITY - SPORTS

Physical activity should be encouraged

There is some experimental and clinical evidence that physical and active alertness reduces seizure frequency and stabilizes mood.

Experimental studies have shown that physical activity reduces the risk of SUDEP.

Epilepsy Behav 2010; 17: 432–435;
Epilepsy Behav 2003; 4: 507-510;
Epilepsy Behav 2008; 13: 307-315
PHYSICAL ACTIVITY - SPORTS

Safe types or low risk exercise and recreational activities should be recommended.

Measure the risk of injury according to seizure control, type of activity and protection elements (scuba diving, horse riding, motorcycling, rappelling, swimming etc.)

Epilepsia 1997; 38: 1054–1056
Epilepsia 2007; 48: 851–858.
DRIVER’S LICENCE

Legislation on driver’s licence for PWE is widespread, ranging from no explicit legal to almost a total restriction to drive.

Seizure control for one or more years is “generally” accepted to get a driver’s licence.

Epilepsy Behav 2007; 10: 55-62;
Epilepsia 1993; 34: 852–858;
Mortality rates for PWE are higher than for the general population caused by suicide, SUDEP, drowning and other accidents.

Psychiatric symptoms of depression/anxiety, suicidal ideation and other behavioural problems should be checked routinely and effectively treated.

A good treatment adherence, physical activity and omega 3 supplementation have demonstrated SUDEP reduction rates in experimental models.

Epilepsy Behav 2010; 18: 137-138
Epilepsia 2011;52: 1150–1159
Some countries have a coverage for children and adolescents with epilepsy (National Epilepsy Programs); most do not have a coverage at all and it depends on the family income.

Poverty and the presence of a disability influence negatively healthcare coverage of young adults.

Adolescents and young adults are living the “wonder immortal years” and do not necessarily measure de risks of a chronic disease; so they should be advised on health or life insurance.
Healthcare providers should address the issue of insurability before patients with epilepsy leave their parent’s policy or lose their eligibility for children’s services.

Getting a job is another opportunity to have a health insurance in many parts of the world.

Epilepsy Behav 2004; 5: 884-893;
Epilepsy Behav 2011; 22: 483-489
TRANSFER

• Transfer of care from the pediatric to adult healthcare system occurs at the successful completion of a thoughtful transition process.

• Transition and transfer occur on a predictable manner.

• Transition and transfer should be considered as a rule or as a natural process that everyone goes through.

• Flexibility has to be considered according psychosocial and developmental characteristics of the individual patient.
TRANSFER

Coordination between pediatric and adult services or health care professionals.

Transfer Checklist:
1. Complete medical history
2. Family dynamics
3. Individual health supervision issues
4. Genetic counseling
5. Sexuality, pregnancy and reproductive issues
6. Education and career choices
7. Physical activity
8. Driver’s licence
9. Comorbidity
10. Mortality
11. Insurance
ILAE PEDIATRIC COMMISSION

• Transition and transfer is an important topic to work on
• Literature overview
• No guidelines at the moment
• Global survey ongoing
• Construction of an evidence based guideline
FIGURE 1: TRANSITION PROGRAM

- EVALUATION FEEDBACK
- TRANSFER
- PEDIATRIC SERVICE
  - SEXUALITY, EDUCATION, CAREER, DRIVING, SPORTS, COMORBIDITY, INSURANCE
- ADULT SERVICE
  - AUTONOMY, SELF CARE, SELF ADVOCACY, COMMUNICATION SKILLS
TRANSITION PROGRAM

• Transition and transfer should be built up inside a multidisciplinary team, giving adequate orientation to individual needs.

• But in case of inexisting transition programs, those needs may be discussed by the treating physician.