Professionals in Epilepsy Care
Current Issues in Clinical Practice: Transitioning from Adolescent to Adult Epilepsy Care

December 1, 2012

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American Epilepsy Society | Annual Meeting
Disclosure

Nothing to disclose
Learning Objectives

• To discuss challenges for transitioning youth with epilepsy to the adult care.
• To present current theoretical models and practical clinical approaches to the transition of care.
• To highlight specific needs of adolescents with intellectual disability and epilepsy during transition to the adult providers.
• To recognize the diversity of practical strategies and understand specific roles of pediatric neurologist, nurses, social workers, and allied professionals in the transition to the adult care.
Agenda

• Peter Camfield, MD
  How Can Transition Best be Orchestrated? Models and Personal Experience

• Jaime Carriroza, MD
  Global Issues in the Transition of Adolescents with Epilepsy–A Child Neurologist’s Perspective

• Rebecca Schultz, PhD, RN, CPNP
  Challenges in Transitioning Youth with Intellectual Disabilities and Epilepsy

• Laura Jurasek, NP, MN
  Adolescent Epilepsy Transition and the Role of Nursing

• Janelle Wagner, PhD
  Conclusions!
How Can Transition Best be Orchestrated?

Dec 1, 2012

Peter Camfield MD

Dalhousie University and the IWK Health Centre
Disclosures

NONE
Learning Objectives

1. What are key issues that need to be solved for transition/transfer?
2. What are models for a transition/transfer process?
Very little good data
A lot of opinion, maybe
not even very expert
What happens if transition/transfer is badly managed?

- **Epilepsy** – no data about seizure control or QOL
- **Kidney transplant** – *(Harden BMJ. 2012)*
  - Prior to transition program 2000-2006 transfers to adult care 6/9 lost their graft.
  - After transition program 2006-2010, transfers to adult care 0/12 lost their graft.
- **Diabetes** *(Kipps Diabetic Medicine 2002)*
  - Attendance at follow-up clinic appointments dropped from 94% to 57%, when youth with type 1 diabetes were transferred to adult care.
What are the problems?

Cultural issues:

– **Pediatric care is family centered**
  • When you go to the physician your mother drives you and accompanies you into the office
  • The visit is as much about her as it is about you

– **Adult care is individually centered**
  • When you go to the physician your mother simply does not come
  • The physician is not interested in your mother
  • This is all about you
Slide Unavailable
What are the problems?

• Family
  – Fear of the unknown
  – Fear of letting go of control
  – Comfortable with status quo; attached to pediatric service (we are delightful and attentive)
  – Personal experiences with adult health care
  – With intellectual handicap or intractable epilepsy normal independence is precluded (he or she remains a “child”)
  – Adolescents typically less anxious than parents

(van Staa Child Care Health Dev. 2011)
What are the problems?

• Pediatric Service
  – Long-term attachment
    (we really enjoy working with these families)
  – View adult service, as possibly not competent
    particularly for psychosocial care and management of
    co-morbidities
  – Institutional support, time, reimbursement
  – Nagging feeling of not having done everything
    possible – in principle all childhood onset epilepsy
    should be cured in the pediatric years.
  – ? Problems facing our own mortality
What needs to happen?

A simple handoff is not going to be enough

*Transfer* – the formal handing over of care from pediatric to adult health.

*Transition* – a process to prepare youth with chronic illness and families for “adult’ health care.
Whatever model, there needs to be a transfer/summary note

(Camfield, Camfield, Pohlmann-Eden Epilepsy Currents 2012;12:13-21)

• **Physician** - Medical Transfer History – copy for the patient.

• **Family and normally intelligent patient** - Social and Medical Problems Besides Epilepsy Now or in the Past

• **Family when patient has mental handicap** - Social and Medical Problems Besides Epilepsy Now or in the Past
Models

• No transfer
• Abandonment to family physician
• Rehabilitation Program
• Adult Neurology/Epilepsy Clinic
• Transition Clinic
No transfer

Continued follow-up in a pediatric setting.

- The pediatric specialist ages with the patient – no transfer until the specialist retires or dies - unless the institution is committed to a “life to death” program.
- Fosters dependency - everyone deserves to grow up, adolescents feel out of place surrounded by babies
- Logistical problems - If you need your gall bladder out at age 30 in an adult hospital and have seizures post op, who knows about your epilepsy? Pregnancy? – Pediatricians know it happens but not much more.
- Lack of knowledge about adult diseases – hypertension, type 2 diabetes, COPD
Abandonment to family physician
(fend for yourself)

• The family physician takes full responsibility – a physician who has had little/no role during the pediatric years. The youth and family are not attached and doubtful of this physician’s competence.

• Few family physicians are experts at epilepsy. Newer treatments are less likely – just keep the prescriptions coming and be sure to do blood levels monthly (completely unnecessary).

(Camfield Semin Pediatr Neurol. 2006)
Rehabilitation Program

• Typically these are oriented towards consultation and short-term intervention and long-term follow up is unusual.

But

• Care is multidisciplinary co-morbidities are likely to receive attention

(Kent, J Neurol Neurosurg Psych 2004)
Adult Neurology/Epilepsy Clinic

• May be a consultation model with follow up visits only if re-referred from family physician.
• Few adult neurologists show interest in long term care for developmental brain disorders.
• Most adult neurologists are uncomfortable with mental handicap.
• Difficult behaviour in the office is not tolerated.
• The space is inadequate.
• There is nothing developmentally appropriate in the office.

(Gillam, Epi Behav 2009)
Transition Clinic

*We think this is the best model – little objective data*

- Attended jointly by adult and child neurologists in the adult setting.
- Families like this idea.
- There is a dialogue between pediatric and adult neurologists over several visits.
- Adolescent can try out and learn skills needed to cope with adult medicine – for example - answer “What is your problem”.
What do adolescents and families think?

(Rutishauser et al Eur J Pediatr. 2011)

• 283 adolescents with chronic disorders, ages 14-25 yrs (median age 16), not yet transferred to adult health care + their 318 parents from two university children's hospitals.

• The majority of adolescents (64%) and parents (70%) indicated ≥ age 18-19 years as the best time to transfer to adult health care.

• 53% of adolescents and 69% of parents preferred a joint transfer meeting with the pediatric and adult specialist
Managing the teenager with epilepsy: paediatric to adult care.
(Appleton Seizure 1997;6:27)

- 120 “transitioned” patients
- Clinic staff – pediatric neurologist, adult neurologist, nurse practitioner
- 37% had mental handicap and 45% had JME
- Most seen for 2 visits
- 10% did not have epilepsy, 22% had a change in medication
A teenager epilepsy clinic: observational study

*(Smith Eur J Neurol. 2002;9:373)*

- 207 patients - none with mental retardation. Seen with parents and then separately.
- Idiopathic Generalized Epilepsy 37%, Focal Epilepsy 34%, not epilepsy 30 (14%).
- 20% major change in AEDs; 12 (6%) referred for surgery
- “All patients received appropriate advice on driving, contraception, and alcohol”
- “Of the 86 females on antiepileptic medication at the time of consultation, only 12 were already taking folate”.
- “The clinic had an important role in confirming diagnosis, ensuring appropriate management, information provision and aiding seamless transition to adult epilepsy care.” No evidence but it seems right!
A nurse specialist program will be described by Laura Jurasek, PNP, M.N.
What needs to be done?

• **Transition:** Build skills that last for children and for parents. They should know enough about their epilepsy, its treatment and co-morbidities to know when to seek medical care and if the medical care is adequate.

Beware:
The natural history of many epilepsy disorders is not well understood – what do you prepare for?
When are adolescents ready to transfer?

(van Staa J Adolesc Health. 2011)

• 954/3,648 (26%) adolescents with chronic health problems for ≥ 3 years at one Dutch university hospital – web based questionnaire.

• “Adolescents' attitude to transition and their level of self-efficacy in managing self-care seem to be the keystones to transfer readiness. Strengthening adolescents' independence and self-management competencies, combined with early preparation and repeated discussions on transition, seem to be useful strategies to increase adolescents' readiness for transfer to adult care.”
What needs to be done?

• Start a transition program – aim for end of high school
• Learn the realities/practice style of adult neurology and pediatric neurology – spend a few afternoons in each others’ office/clinic. (It takes 2 to tango)
• Talk with patients and families often about long-term health issues. Emphasize education, sexuality.
• Foster research to know what happens to pediatric epilepsy disorders in adulthood.
• Support, support groups – after your patients leave you, support groups will inform them about new developments – will anyone else?
Tasks before transition to adult care for the mentally handicapped
* stay tuned for Rebecca Schultz *

Guardianship – a formal legal process to establish who makes decisions for a mentally handicapped adult.

Will – establishes guardians and finances.

Trust fund – funds opportunities.

Involvement of younger family members and friends: avoid “well known by no one”, insist on comprehensive care, prevent abuse by demanding accountability. (Bigby J Intellect Dev Disabil 2008)
What needs to be done?
Lewis SA BMC Pediatr. 2010

Get some decent data
Impact on Clinical Care and Practice

1. Solve the issues for your patients to allow for transition
2. Establish a transition clinic that allows for eventual transfer