How to make professionals aware of transition from adolescent to adult neurology

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Learning objectives and key message

- Be familiar with the distinction between transition and transfer
- Consider 4 approaches – generate data about the adult outcome of childhood onset neurological disorders, document the results of poor transition, educate families and create a transition clinic
- Appreciate that education of youth and families is the key ingredient

What are the problems?

1. Many children with chronic neurological disorders grow up to be adults. The disorders may be quite unfamiliar to adult professionals.

2. These youth often have serious social problems and little understanding of how to navigate and benefit from the adult health care system.

What are the problems?

3. In pediatrics they have not taken responsibility for their care or are unable to do so. *Pediatrics is family focused*.
4. *Adult medicine focuses on the individual* and does not cope well with “children” especially those with intellectual disability.
5. Children with neurological disorders may have multiple co-morbidities that are dealt with in multi-disciplinary clinics in pediatrics – a rare concept in adult care leading to chaos.

How to increase awareness amongst professionals of the need for transition

Important Distinction

- ***Transition*** – a process beginning in childhood to prepare youth with chronic illness and families for “adult’ health care.

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

How to increase awareness amongst professionals of the need for transition

1. Produce data about the adult outcome for childhood onset neurological diseases.
2. Provide convincing data for what happens if transition/transfer is poorly managed.
3. Educate families/patients from the time of diagnosis and introduce a program in pediatric hospitals
4. Develop a transition program that involves both adult and pediatric services

There are many neurological disorders in childhood – what happens in adulthood ?

- **Epilepsy** – 50% have complete remission but 75% have unsatisfactory social outcome
- **Tourette** – Most seem to do pretty well; ADHD and OCD are the important concerns (Erenberg 1987)
- **ADHD** – Many have stormy adulthoods.
- **Cerebral Palsy** – About ½ have increasing gait problems as they get older – pain, balance, deformity (Opheim 2009)

There are many neurological disorders in childhood – what happens in adulthood ?

- **Duchenne** – 85% survival to 35 years with ventilation starting age 19 years (Kohler 2009)
- **Intellectual Disability** – "Known well by no-one" - closing of a large institution with adult patients moved to small community residences, parents die, siblings move away, staff turns over quickly, no one knows anything about the previous history (medical and social) (Bigby 2008),

There are many neurological disorders in childhood – what happens in adulthood ?

- **NF1** – early adult deaths from cancer (sarcomas) and stroke: median survival = 59 years vs 74 for general population (Rasmussen 2001)
- **Migraine** – 40% still have migraine 20 years later (Brna 2005)

What happens if transition/transfer is badly managed ?

- **Virtually no data for neurological disorders**
- **Kidney transplant** – *(Harden BMJ. 2012)*

  - Between 2000 -2006, 9 youth with kidney transplants were transferred to adult care. 6/9 lost their graft

  - In 2006, transition program developed. 2006-2010, 12 were transfered 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

Introducing a transition program to a pediatric hospital/clinic

- Relatively easy because

  - transition is a developmental process

  - pediatric hospitals/clinics want their patients to grow up to be successful adults

  - pediatric hospitals/clinics typically have a lot of support services to help with education and logistical issues

Introduce a transition program in pediatric hospitals

- **The British Columbia On TRAC**

  http://ontracbc.ca

- **Ready Steady Go – Southampton Children's Hospital UK**

  http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx

- **Good2Go Hospital for Sick Children**

  http://www.sickkids.ca/pdfs/good2go/38913-Neuroscience-Timelinehandout.pdf

- **Transition readiness questionnaire**

- **The "medical home"**

- What are specific tasks that youth with epilepsy need to master during transition and prior to transfer?
- An example of why transition has to be a lengthy process

4. Develop a transition program that involves adult and pediatric services

Families are terrified. Both services need to understand the issues. There is little value in trying to “educate” the entire adult neurological care system. Heart disease/cancer/stroke dominate adult care, transitioned patients are not common. Target the key health care providers.

How to develop an adult/pediatric transition clinic

- Identify key individuals (dual qualifications)
- Spend a few afternoons in each other's clinic to understand each others reality
- Concept: Patient is seen by the adult and pediatric physicians together, focus is on being ready for transfer, once ready the pediatric team "bows out".
- Clinic in the adult hospital
- Extensive transfer note

How to develop an adult/pediatric transition clinic

- Government and Hospital issues
  - Deal with credentialing issues in the adult hospital for the pediatric specialist
  - Time, space, support staff in the adult hospital (you need data)
  - Compensation (long visits, adult and pediatric specialists) (you need data)

Special issues for those with intellectual disability

- Finding a setting that is appropriate – toys, large enough for wheel chair and caretakers
- Extra time
- Formal guardianship (a legal process)
- Formal last will and testament
- Financial plans such as a trust fund

Conclusions

- Distinction between transition and transfer
- 4 approaches – generate data about the adult outcome of childhood onset neurological disorders, document the results of poor transition, educate of families and create a transition clinic
- Appreciate that education of youth and families is the key ingredient

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