The Challenge of Transition in epilepsy

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My aim
- To have discussed the evidence base relating to the transition of children with epilepsy into adult care
- To review transition of another childhood onset chronic condition (insulin dependent diabetes mellitus)
- To consider how we can change our approach to this issue

How to approach this topic?
Consider the cast
- The person with epilepsy
- The family
- The paediatrician
- The adult specialist
- The GP
- The paediatric specialist nurse
- The adult specialist nurse
- The teachers

Avoid polarisation

Avoid anecdote

Structure
- Set the scene
  - Define
  - Look at the epidemiology
  - Look at the pathway and nature of health care
- Explore the evidence for transition in epilepsy
  - Attitude, beliefs
  - Nature of services
- Explore future direction
  - Look at transition in other conditions; IDDM
  - Assess how well epilepsy care fits a transition model
  - Suggest a plan
Set the scene

Transition: "movement, passage, or change from one position, state, stage, subject, concept, etc., to another. "
"A period during which such change takes place"

Paediatric care
Specialist
Community
Non specialist
CAMHS

GP
School

Epilepsy 12 key findings for transition

• Approximately 17% (347/2027) of whole time equivalent general paediatric consultants were reported as having defined ‘expertise in epilepsy’. 47% (91/193) of audit units had no Epilepsy Specialist Nurse. 58% (112/193) of units had epilepsy clinics. 18% (35/193) had a specific clinic for ‘young people’ or ‘teenagers’ with epilepsies.

• 78% (249/319) of parent/carers and 82% (111/136) of children and young people who responded to the question, stated overall satisfaction with the care received from their epilepsy service. 8% (26/319) of parents/carers and 7% (9/136) of children and young people stated they were not satisfied.

• 70% (110/158) of children and young people reported that they had received enough information on seizures or epilepsy. 23% (36/154) felt that information given was hard to understand.

• 38% pregnancy discussion
• 64% MRI
• 40% ECG

Who is transitioning?

Prevalence of active epilepsy in the national child development study

<table>
<thead>
<tr>
<th>Age</th>
<th>Proportion with active epilepsy</th>
<th>Prevalence (per 1000) 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>60/15438</td>
<td>3.89 (2.8-4.87)</td>
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<tr>
<td>11</td>
<td>66/15419</td>
<td>4.28 (3.25-5.31)</td>
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<tr>
<td>16</td>
<td>72/14661</td>
<td>4.81 (3.78-6.04)</td>
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<tr>
<td>23</td>
<td>78/12415</td>
<td>6.28 (4.89-7.68)</td>
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The nature of epilepsy health services: service gaps

- Children’s services-epilepsy 12
- Adult acute services-National Audit of Seizure management in Hospitals
- Adult learning disability services-CIPOLD

Epilepsy 12 key findings for transition

• describe and understand the organisation of care available for people presenting to Emergency Departments with seizures.
• describe the variations in care actually delivered.
• set out options and opportunities for improving care and to share those with the hospitals, with patient organisations and with NHS managers in the hope that together they can act to effect improvement.
NASH – National Audit of seizure Management in hospital-key findings for transition-findings

CIPOLD- Confidential enquiry into premature deaths of people with a learning disability

- The median age of death for people with learning disabilities (65 years for men; 63 years for women) was significantly less than for the UK population of 78 years for men and 83 years for women. Thus men with learning disabilities died, on average, 13 years sooner than men in the general population, and women with learning disabilities died 20 years sooner than women in the general population. Overall, 22% were under the age of 50 when they died.

CIPOLD- Confidential enquiry into premature deaths of people with a learning disability

- In the CIPOLD study, a death was considered as premature if, ‘without a specific event that formed part of the “pathway” that led to death, it was probable that the person would have continued to live for at least one more year’.
- Of the 238 deaths of people with learning disabilities for which agreement was reached by the Overview Panel, 42% were assessed as being premature. The most common reasons for deaths being assessed as premature were: delays or problems with diagnosis or treatment; and problems with identifying needs and providing appropriate care in response to changing need.

CIPOLD- Confidential enquiry into premature deaths of people with a learning disability

- Almost all (97%) had one or more long-term or treatable health condition, including 43% with epilepsy (31% had had a seizure in the previous 5 years), 39% with cardiovascular disease, 22% with hypertension, 14% with dementia and 13% with osteoporosis.
- Significantly more people with learning disabilities experienced difficulties in the diagnosis and treatment of their illness than did the comparator group. All aspects of care provision, planning, coordination and documentation were significantly less good for people with learning disabilities than for the comparators.

Summary of the healthcare background: out of the frying pan into the fire?

- Significant number of adolescents with epilepsy will transition
- They do not transition from perfection to peril
- We need to recognise the needs of people and the strengths and weakness of the services they leave and join

Explore the evidence for transition in epilepsy

Views and attitudes
Patient and carer experience
Cognitive impairment
Clinics
Professional views

Canadian neurologists-all neurological conditions

Current practice and views of neurologists on the transition from paediatric to adult care*

- Self administered postal questionnaires
- 209 adult and 22 paediatric neurologists in Quebec identified
- 103 (49%) adult neurologists and 16 (73%) paediatric neurologists responded
- 12.2 patients transferred per year
- 60% paediatricians found it very difficult to find an adult provider

*Oskoui & Wolfson. J Child Neurology 27 912) 1553-1558

Barriers to care (5 agree, 1 disagree)

Knowledge and needs young PWE and their parents*

- Evidence synthesis
- Mixed-method evidence
- Literature review
- They found a paucity of evidence for interventions, 5 studies, and proposed from these 3 “propositions”

* Lewis et al BMC pediatrics 2010, 10:103

Interventions-propositions

Propositions based on quantitative and qualitative studies A

- Age appropriate psycho-educational programmes for young people with epilepsy show potential in increasing medical knowledge and improvement in health related quality of life
- Being educated and being knowledgeable about epilepsy empowers parents to be as advocate for their child
- Young people need accurate information about epilepsy to aid psychosocial adjustment
- Young people need practical advice about lifestyle management but think that healthcare professionals are only interested in medical management of epilepsy
- Young women are not consistently receiving gender specific advice
- Parents need practical advice but think that healthcare professionals are only interested in medical management of the epilepsy
- Young people do not receive the right information in the right frequency and at the right time during their teenage years
- Misinformation leads to misconceptions and uncertainty about epilepsy and inability to cope with stigma

- Being educated about epilepsy makes parents realize what knowledge they do not possess and motivates them to seek more information
- Misinformation leads to misconceptions and uncertainty about epilepsy and inability to cope with stigma
Propositions based on quantitative and qualitative studies B

To be able to self-care and be independent of their parents, young people realise they need to know more about epilepsy and take responsibility. Young people do not know how to ask questions about their epilepsy. The clinical encounter mainly acts as a barrier to information exchange.

Healthcare professionals lack facilitative skills of working in partnership with young people, with or without their parents. Lack of effective partnerships and interruptions to continuity of care are having a detrimental effect on information exchange and knowledge use by young people. Parents are unaware of what epilepsy knowledge they do not have.

Method
• Qualitative grounded theory methodology
• Seven parents of adolescents 18 years or older with epilepsy and cognitive impairments

Journey of Advocacy

A substantive theory (derived from a specific social process studied in relation to a narrow, empirical area of study)
• The Journey of Advocacy has five temporally sequenced but interactive categories

Parental experience transitioning adolescents with cognitive impairment*

Method

Journey of Advocacy

• A substantive theory

Parents in turmoil
• Fear
• Rejection
• Uncertainty

Parents as advocates
• Information gatherer
• Quarterback

Web of information
• Health care provider
• Support groups
• Agencies

Captive waiting
• Waiting

What happens in the UK: a survey*

Method
• Online survey of the British Paediatric Epilepsy Group
• 15/23 centres provided auditable data

Domains
• Frequency and timing of clinics
• Staffing
• Clinic lists and waiting time
• Criteria for referral to the clinic
• Support for families

Findings—of most interest!

Staffing
• 14/15 joint adult and paediatric neurologist
• 1 supervised by paediatric and adult nurse
• 5/15 supported by paediatric and adult nurses
• 4/15 supported by adult nurse
• 6 no nurse support

Lists and waiting time/ref criteria
• 3-5 new and 3-8 follow up
• 13/15 epilepsy and epilepsy plus
• 14-20yr age range
• 47% transfer to adult after the first appointment
• 20% accepted GP referrals

*Shultz. Journal of Paediatric healthcare 2012

Iyer & Appleton Seizure 2013
Findings - of most interest! staffing

- Paed neuro
- Adult neuro
- Cons paed
- Paed ENS
- Adult ENS
- Adult Dis nurse
- Careers adv

<table>
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<th>Number of Clinics</th>
<th>No</th>
<th>Yes</th>
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<tbody>
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<td>Paed neuro</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Adult neuro</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Cons paed</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Paed ENS</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Adult ENS</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Adult Dis nurse</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Careers adv</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Individual descriptions of clinics: Alberta*

Design/background
- Transfer mandatory age 17
- Aim to attend a transition clinic before this!
- 97 adolescents seen in 33 months
- 22 cognitive deficits
- Applied a questionnaire on teaching and learning needs

Result - independence


Alberta a “working knowledge” model of care

- Sexuality, Alcohol/drugs, driving, Life choice
- Career planning, daily activities, health maintenance
- Health care team, medication and side effects, triggers, seizure precautions

Explore future directions

The story from diabetes

Evidence synthesis

Evidence from diabetes*

- To identify the continuity mechanisms central to a smooth transition from child to adult diabetes care, the service components through which these can be achieved and their inter-relations in different contexts.

Method - realistic evaluation

- Realistic evaluation is an alternative approach to experimental methods for researching models of health care. The primary concern is not with producing a pass/fail verdict but with identifying what produces a particular effect. The intention is to develop an understanding of associations between variables by identifying the mechanism producing an outcome. Continuity of care is the mechanism central to current concerns about 'smooth' transition.

Seven relevant continuities:
- experienced
- information
- Cross-boundary
- flexible (adjustment to individual need)
- Longitudinal (care from as few professionals as possible)
- Relational (therapeutic relationship with a named professional)
- developmental (care which reflects and facilitates changing needs).

Identifying models of care:

- Survey of diabetes services- 5 models identified
- Interviews with
  - 38 health care professionals
  - 46 young people
  - 39 carers
  - Survey of 82 young people
  - Cost and consequences analysis

Relational and longitudinal continuity

- Emerged as the mechanisms central to smooth transition. Most young people and carers preferred to be seen by a professional with whom they had a therapeutic relationship, and a smaller number appreciated familiarity of service provider but wanted more detached associations
- Where these continuities were sustained, young people and carers were able to negotiate service interfaces and cope with other changes with relative ease.

Management continuity

- Continuity of diabetes management consistent with needs through a common purpose and plan
- Formal written communication was a key management continuity feature in models where young people transferred to the care of a new consultant; however the content tends to be exclusively clinical and experiences of transition are deeply embedded in psychosocial understanding
- Nursing teams provided more continuity than medical
- Carers contribute to this but it is not formally recognised

Cultural continuity:

- Seamless progression from a child to adult service culture across service interfaces
- Continuous
  - Where paediatric and adult services were culturally continuous transition was relatively seamless and there was little need for interventions to prepare for transfer
- Discontinuous
  - Despite a long history of joint working and high levels of structural integration between services there were marked cultural differences between paediatric and adult services.
  - Clinical leadership and a commitment to adolescent health appeared to be the additional active ingredient in those services exhibiting highest levels of cultural continuity.
- Informational continuity
  - Each model had different requirements for informational continuity. In those with highest levels of cultural continuity

Informational reality

- Information leaflets were produced by the paediatric service, but these were based on stereotypes of adult services and did not include specific information on the new arrangements for care. Families in this model expressed the highest levels of anxiety about transfer.

Flexible and developmental continuity

- All models recognised that young people who had transferred to adult services required high levels of access and support and there was a diversity of arrangements designed for this purpose: more frequent clinics, access to on-call nurses and email mentoring. There was little formal education in any model, although staff aspired to develop this component of the service. However, whereas carers viewed formal education favourably, young people were less enthusiastic. Most were reluctant to attend events beyond routine clinic appointments and few expressed a desire for peer-based support.

What does epilepsy need to fit a transition model?

- Knowledge
- Continuity
- Adapting to service and individual variation
Knowledge

- Carer education
- Education of PWE
- Staff education

Continuity: the good the bad and the ugly

Good
- Longitudinal: as few professionals
- Relational: named professionals

Bad
- Informational
- Management

Ugly
- Cultural

Adapting to service and individual variation-some cases 1

Patient
- Well controlled but previous failed withdrawal
- Women with epilepsy about to go to university

Issues
- Primary care or specialist
- Key risks: lifestyle/teratogenicity
- Culture change

Adapting to service and individual variation-some cases 2

Patient
- Refractory focal epilepsy
- Leaving school
- Poor school attendance
- Suicide attempt

Issues
- GP AND psychiatry/specialist epilepsy
- Knowledge
- Support
- Surgery?

Adapting to service and individual variation-some cases 3

Patient
- 17yr old boy severe LD and Lennox Gastaut

Issues
- GP-health-PEG fed
- Tertiary neurology?
- LD specialist?
- LD team
- Continuity of prescription

Conclusion

- Transition is a key phase in the pathway of an individual with epilepsy
- Our division of paediatric and adult care is most probably essential (at least before adolescence)
- But we have an obligation to heal the damage this division causes