Adolescent Epilepsy Transition and the Role of Nursing

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Disclosure

No Disclosures
Learning Objectives

• Identify the role of nursing during adolescent transition in regards to health education, support of normal adolescent development, increasing independence and role changes.

• Highlight a successful nurse-led adolescent epilepsy transition program.
Goals of Transition

“Well planned and coordinated transition between pediatric and adult services”

Alberta Health and Youth Initiative, 2007; American Academy of Pediatrics, 2002; Betz, 1998; Betz, 2004; Blum et al., 1993; Blum, 1995; Canadian Pediatric Society, 2007; McDonough, 2007

“To provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound before and throughout the transfer of youth into the adult system.”

Canadian Pediatric Society (CPS) “Transition to adult care for youth with special health care needs” Position Statement, November 2007
Evidence for Coordinated Transitional Care

For youth....
• Development of self determination skills
• Support for psychosocial dev
• Support with developmental tasks
• Focus on strengths

For parents and caregivers....
• Family centered approach
• Parental involvement in planning
• Support to parents for changed relationships and roles

(BJA Model), 2009; Flume et al., 2004; Freed et al., 2006; Tuffrey & Pearcel 2003; Weissbery-Benchell et al. 2007.
The Adolescent Brain...in transition!

ANATOMY OF A TEENAGER'S BRAIN

THE BIRDS AND THE BEES LOBE

MEMORY FOR MUSIC

REBELLION CENTER

Super Turbo Rebellion Center

Self Image

Fitting In Gland

Peek Pressure Resistance

Every Episode of the Simpsons

Indestructibility Cortex

Memories for Chores, Homework, etc.,

Judgment Gland

Love for Parents

Slam Door Reflex

Car Keys Craving

Ability to be Seen in Public With Parents

All the Answers

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Parents and Caregivers....

“It’s you who don’t understand me—I’ve been fifteen, but you have never been forty-eight.”
Nursing Role in Adolescent Transition

• Health Education
• Anticipatory Guidance
  • Equip adolescents and caregivers with ‘tools for the toolbox’
• Promotion of independence and achievement of normal developmental milestones
• Family support
• Preparation for transition begins in pediatrics and continues into adult program
  • Emphasizes the ‘process’
  • Individualized
The primary goal is to develop a ‘working knowledge’ of developmental, clinical, and life skills that would prepare adolescents with epilepsy for their upcoming transfer to adult epilepsy services. In our conceptualization, a working knowledge of life with epilepsy requires the integration of three spheres of knowledge.

Adolescent Development
- Sexuality
- Alcohol/Drugs
- Driving
- Life Choices

Epilepsy Management
- Health care team
- Medication
- Seizure Precautions
- Triggers
- Safety/Independence

Independent Living
- Envisioning
- Career Planning
- Daily Activities
- Health Maintenance
- Role Changes

Jurasek, Quigley & Rey, 2010
Barriers for Transition

- Reluctance of pediatric providers to ‘let go’ and trust the adolescent and adult health care providers
- Anxiety in leaving familiarity (HCP’s, location)
- Independent vs. Family centered focus of adult healthcare
- Healthcare documentation and communication (organizational obstacles)
- Fear of the adult services
  - Decreased quality of care
  - Less supportive
  - Less accessible
  - ‘the dark side’

Callahan et al., 2001; Conway, 1998; Hauser & Dorn, 1999; Warnell, 1998

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Why Create a Transition Program?

- Ensure adolescents and care providers have standardized information
- Promote role changes and independence
- Provide information on differences b/w pediatric and adult programs
- Address common barriers to transition
Transition Clinic Process at the Stollery/University of Alberta Hospitals in Edmonton, Alberta

- All adolescents (aged 16-18yrs) referred from the pediatric to adult epilepsy clinic
- Nurse-led
- Prior to seeing adult epileptologist
- Clinic or telehealth
  - pediatric/adult programs w/i same building

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Transition Clinic Process at the Stollery/University of Alberta Hospitals in Edmonton, Alberta

• Questionnaire:
  – Assess learning need
  – Adolescent’s ability to manage own health

• Formalized education

• Individual needs taken into consideration
  – Dependent (finances, guardianship, trusteeship, resources) vs Independent
Transition Clinic – Client Questionnaire

Please circle yes or no.

1. I know the names of the doctors I see.  Yes  No
2. I know how to book a doctors appointment.  Yes  No
3. I can get to my own appointments.  Yes  No
4. I know the names of my medications, the dose and what they do.  Yes  No
5. I know my pharmacy phone # and how to refill a prescription.  Yes  No

Please rate from 1-5 how important the following information is to you, 1 being least important and 5 being most important.

1. How important is it to know the name of your condition and information about it?

| 1 | 2 | 3 | 4 | 5 |

2. How important is it to know about the use of tobacco, alcohol and drugs in relation to epilepsy?

| 1 | 2 | 3 | 4 | 5 |

3. How important is it to know about effective birth control and your epilepsy medications?

| 1 | 2 | 3 | 4 | 5 |

4. How important is it to know about bone health and epilepsy medications?

| 1 | 2 | 3 | 4 | 5 |

5. How important is it to know about finances, employment and/or school in relation to epilepsy?

| 1 | 2 | 3 | 4 | 5 |

6. How important is it to know about driving and epilepsy?

| 1 | 2 | 3 | 4 | 5 |

7. How important is it to know about triggers for seizures?

| 1 | 2 | 3 | 4 | 5 |

What type of care should be or should not be provided during a seizure?

What types of general precautions should be used for someone who has seizures?
Formalized Education

- Seizure type
- Seizure first aid/status epilepticus
- Medications/side effects
- Seizure triggers
- Work/school/finances
- Driving
- Women and epilepsy
- Alcohol and drugs
- Home safety
- Nutrition/exercise
- Bone health
- Community resources
Role Changes and Independence

- Assess how adolescent currently managing own health
- Expectations in adult care
- Provide ideas for adolescent/care providers on how to promote independence
Differences B/w Adult and Pediatric Programs

• Frequency of testing (i.e. drug levels and EEG’s)
• Appointment structure and discussion will be geared more towards adolescent
• Goal: adolescent successfully managing own health care (months-years)
Referral to Adolescent Epilepsy Transition Clinic. Continues under pediatric care until seen by adult Epileptologist.

Seen by Adult Epileptologist 1-3 months post-transition clinic

Evaluations obtained post-transition clinic and post-Epileptologist clinic appointments

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Our observations...
Independence

• Skills needed for management of their epilepsy
  – Names of physicians
  – Booking appointments
  – Getting to appointments
  – Medication and doses
  – Obtaining refills on prescriptions

Assessment of Independence in Epilepsy Management N=97

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I know the name of the doctors I see</td>
<td>73%</td>
<td>27%</td>
</tr>
<tr>
<td>I know how to book a doctors appointment</td>
<td>63%</td>
<td>37%</td>
</tr>
<tr>
<td>I can get to my own appointments</td>
<td>63%</td>
<td>37%</td>
</tr>
<tr>
<td>I know the names of my medications, the doses and what they do</td>
<td>83%</td>
<td>17%</td>
</tr>
<tr>
<td>I know my pharmacy telephone number and how to refill a prescription</td>
<td>59%</td>
<td>41%</td>
</tr>
</tbody>
</table>

Bone health

• Most adolescents and parents are unaware of the effects of long term AED use on bone health

• At initial evaluation usually rated as a low learning need

• Adolescents and parents indicate information regarding supplements and diet beneficial at evaluation

Sex, drugs and rock n’roll...

- Issues regarding to birth control/pregnancy, alcohol and drug use in relation to epilepsy
- Lifestyle and “risky behaviors” (medication adherence, overall well being)
- Driving

Discrepancies between parents and adolescents

- Discrepancies identified regarding benefits of education
  - Driving (R.D.)
  - Birth control/pregnancy (A.M.)
  - Alcohol use (A.M.)

Overall observations...

• “wonderful to have one to one appointments”
• “this clinic relieves a lot of stress for parents. Please continue, this is a great program”
• Felt comfortable (?informal, ?environment)
• Not rushed
• Accommodating
Impact on Clinical Care and Practice

Patients and families
- Ease fears of unknown
- Familiarize with new environment
- Connect with someone from adult program
- Define expectations
- Provided with standardized education
- Broadening awareness towards “adult issues”
- Initiating ‘conversations’ with families
- Promotes ‘living well’

Impact on Clinical Care and Practice

Epilepsy Team

- Adolescents/care providers are better prepared (i.e. knowledge)
- Time utilized more efficiently at first adult visit
- Expectations clearly defined (i.e. Roles of adolescent and parent)
- Improved self management
- Enhances continuity of care
- More seamless ‘transfer’


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References


Jurasek, L., Quigley, D., & Rey, L. (2010). Development and implementation of an adolescent epilepsy transition clinic Journal of Neuroscience Nursing,


Adolescent Epilepsy Transition: Conclusions

December 1, 2012

Janelle L. Wagner, PhD
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Disclosure

No Disclosures
Learning Objectives

• Summarize current state of the literature on adolescent transition to adult epilepsy care

• Highlight suggestions and recommendations for practice
Where are we?

- No consensus on a model of transition
- Paucity of data on transition process and outcomes
- No guidelines available
- Preliminary data on
  - what factors are important to consider
  - suggested ages of transition
  - Benefit of nurse-led transition clinic
  - Peds/Adult neurologist clinic
Factors to consider

- Adolescent
  - Developmental and cognitive skills
  - Quality of life, self-management & self-care
  - Risky behaviors
- Family
  - Level of family epilepsy management
  - Guardianship
  - Stress/strain on caregivers
- Health Care System
  - Differences between adult and pediatric care
  - Health-care coverage
  - Communication

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Barriers

- Chronological vs developmental age
- Teen and family anxiety about leaving familiar care
- Transportation
- Changes in health care coverage
- Communication
- Level of caregiver involvement needed vs provided
- Perceptions and realities of adult care
Suggestions for Practice

• No consensus statements or guidelines
• At a minimum
  – Have a protocol for transition
  – Transfer/summary note
  – Individualized transition plan
• Transition Clinic
  – See adult and child neurologists in adult setting for several visits
  – Nurse-led clinic bridge between peds and adult clinic
  – Social work, psychology, psychiatry
Suggestions for Practice

• When to transition
  – Adolescent attitude to transition and self-efficacy in management care important
  – ≥ age 16 ≥ age 18-19
    • Begin discussions early- birth, diagnosis, teenager

• Time of transition and continued focus on
  • Education
  • Coping skills & self-management, independence
  • Advocacy, guardianship
Revisit Case Examples
Future Directions

• ILAE
  – Commission on Pediatrics
    • Raise awareness about the need to support patients as they transition from pediatric to adult specialty medical care
    • Provide written recommendations to ILAE regarding transition to adult health care for pediatric patients with epilepsy

• Institute of Medicine Report on the Epilepsies
  – Recommendation 8: Improve the Delivery and Coordination of Community Services
    • Services include transitional care
Future Directions

• Questionnaires to assess readiness to transition
• Testing of transition models
• Measurable outcomes - more data!
• Develop consensus statements or guidelines for practice
Questions, Comments