Transition education in adolescents with epilepsy – is it effective?

Claire Frizzell,
Anne Connolly, Erin Beavis,
John Lawson and Annie Bye

Transition

- The current health system generally does not manage the movement between paediatric and adult health care well.
- Lack of well-planned, effectively coordinated transition processes lead to young people opting out of health services which may then result in poor health care outcomes and crisis presentations.

Background research

- In Adolescents low levels of epilepsy knowledge were significantly associated with higher levels of depression, lower levels of self esteem and higher levels of anxiety

(Baker et.al, Epil and Behav 2005;6:556-562)

Background research

- Research shows that adults who develop epilepsy in childhood often do not receive adequate education at the time of diagnosis or subsequently

(Ridsdale et.al, Patient Education and Counsel 1999;37:43-47)

Background research

- Shortfalls in knowledge include an understanding of :
  - Individual seizure type
  - Medication regimen
  - Safety precautions
  - Education and career choice
  - How epilepsy impacts on issues such as driving and pregnancy

(Goldstein et al, Seizure 1997;6:435-442; Long et al, Epilepsia 2000;41:727-731)

Background research

- Studies adults & children show epilepsy education improves knowledge

(May et al, Epilepsia 2002;43:539-549. Austin et al 2002, Lewis et al, 1990, Tiffenberg et al, 2000)

- Research in adolescents on the impact of education alone on psychosocial factors is limited
  - Uniqueness of our study

Aims

1. Develop and deliver an epilepsy educational intervention for adolescents with epilepsy (transition tool)

Aims

2. Investigate whether:
   a) The intervention increases patient knowledge
   b) If increased knowledge impacts on self-efficacy, self-esteem and attitudes towards illness
   c) The adolescents find the knowledge intervention useful and worthwhile

Method

- Recruited cohort of 30 adolescents over 1 year, from SCH neurology outpatient clinics
- Aged between 12-19 years of age
- Who will live independently as adults
  (excludes profound to moderate mental retardation).

Method Measures

- Pre- to Post-intervention measures evaluate the usefulness of the intervention.
- Focus groups – explored the intervention process from the adolescents' viewpoint.

Epilepsy Self-Knowledge Questionaire

- What epilepsy Syndrome do you have?
- What happens when you have a seizure?
- What triggers your seizures?
- What medications are you taking?
- Does it matter if you miss a dose?
- What does an MRI scan show?
- What are the results of your MRI scan?
- What does and EEG show?
- What are the results of your EEG?

Adolescents' General Knowledge of Epilepsy Scale

(Baker et al. Epilepsy and Behavior 2005;6:556-562)

- 50 items - epilepsy general knowledge – medical, social, safety, lifestyle and vocational aspects
- Based on validated adult epilepsy knowledge questionnaire
  (Jarvie et al. Seizure 2003;2:179-185)

Child Attitude Towards Illness Scale

(Heimlich et al. Journal of Paediatric Psychology 2000;25:339-345)

- 13-item epilepsy specific questionnaire measuring attitudes and adjustment to their epilepsy

Rosenberg Self-Esteem Scale

(society and the adolescent self-image. Princeton,NJ:Princeton University Press. 1965.)

- 10 items assess - feelings self-acceptance and self-worth
- Well established psychometric properties – widely used in both healthy & disease pop.

Epilepsy Self-Efficacy Scale

(Caplin et al. Children's Health Care 2002;31:295-309.)

- 15 items, seizure specific, measuring adolescent's belief and confidence in ability to manage and control seizures

Intervention
Session 1

- Individual one-on-one:
  - Creation of Personal Epilepsy Medical Record (written + electronic record + fact sheets)
    - Epilepsy syndrome, seizure type
    - Medications (current, past and side effects)
    - Investigation results
  - Education
    - Epilepsy general knowledge (types sz, causes, what happens in brain, what to do in sz)
    - Role and side effects of medications
    - What a CT/MRI scan is, what an EEG is

Intervention
Session 2

- Interactive - small group:
  - Review generic material covered in session one
  - Education:
    - Lifestyle and epilepsy
    - Training / employment and epilepsy
    - Driving and epilepsy
    - Contraception and Pregnancy and epilepsy

Analysis

- Paired samples *t*-tests (or non-parametric equivalent where indicated), assessed improvement in knowledge and psychosocial factors from pre- to post-intervention
- Qualitative data from the focus group discussion, had its content analysed for important themes

Patient Demographics

- 42 contacted after referral by Neurologist
  - 30 completed education + assessment (71% RESPONSE RATE)
  - 3 lost during process
  - 3 failed to complete final questionnaire
  - 6 Not interested in education session

Results

- Age:
  - mean = 16 years (range 12 – 19 years old)
- Gender:
  - female = 24
  - male = 6

Results

- Syndrome:
  - Partial Symptomatic Epilepsy = 15
  - Generalised Idiopathic Epilepsy = 15
    - Juvenile Myoclonic Epilepsy = 6
    - Juvenile Absence Epilepsy = 3
    - Childhood Absence Epilepsy = 1
    - Generalised Idiopathic Epilepsy without further classification = 5

Results

- Medications:
  - 1/30 Not on medication
  - 29/30
    - 17/30 - 1 medications
    - 10/30 - 2 medications
    - 1/30 - 3 medications
    - 1/30 - 4 medications

Sodium Valproate (12), Lamotrigine (9) and Carbamazepine (8)

Results

- Timing Session 1 to Session 2:
  - Median days = 67 (range = 10 – 166)

73%(22/30) completed session 1 and 2 within 3/12

- Timing Pre to post assessment:
  - Median days = 110 (range 42 – 225)

67% (20/30) completed education sessions and assessment within 4/12

Results

	Pre	Post	Sign
	M (SD)	M (SD)	p
Self Knowledge (range = 0 – 20)	6.90 (2.43)	14.40 (3.28)	<0.0001

Results

	Pre	Post	Sign
	M (SD)	M (SD)	p
General Knowledge (range = 0 – 50)	28.60 (7.35)	39.30 (3.61)	<0.0001

Results

	Pre	Post	Sign
	M (SD)	M (SD)	p
Attitudes (CATIS) (1 negative – 5 positive)	3.47 (0.60)	3.66 (0.55)	0.008

Results

	Pre	Post	Sign
	M (SD)	M (SD)	p
Self-Efficacy (SSES) (1 low – 5 high)	4.22 (0.63)	4.46 (0.51)	*0.049

*Non-parametric test - Wilcoxon Signed Ranks Test

Results

	Pre	Post	Sign
	M (SD)	M (SD)	p
Self-Esteem (RSES) (10 low – 40 high)	31.67 (5.20)	33.00 (5.00)	0.103

Focus group (n=15)

- What did you like about your individual session?
  - "Information relevant and clear"
  - "Rumours and misconceptions cleared up"
- What did you like about the group session?
  - "group interaction"
  - "opportunity to ask questions"
  - "book to keep"

Focus group cont…

- What didn't you like?
  - "the reality check regarding driving was hard to hear"
- Mechanism of follow up in place for confronting or new information

Focus group cont…

- How will this info make a difference to living with epilepsy?
  - "hope to put the information into practice"
  - "empowering – take control"
- Will this information help to improve your self-esteem?
  - "feel much better about myself"

Outcome

- Record assist transition
- Increased self knowledge ✓
- Increased general knowledge ✓
- 1st study to show education alone improved attitude towards having epilepsy and ability to manage epilepsy ✓

- No Previous study has correlated knowledge with attitude to illness, self efficacy and self esteem.

Conclusion

- Widespread application
  - Ongoing use at SCH
  - Adaptation other chronic illnesses
- Importance of medical educational model

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Effect of Age

Analysed using Pearson's *r*:

- Self-Knowledge: $p = 0.969$
- General Knowledge: $p = 0.376$
- Attitudes: $p = 0.560$
- Self-Esteem: $p = 0.661$
- Self-Efficacy: $p = 0.931$

Effect of Syndrome

Analysed using Mixed Between-Within ANOVA (Between = Syndrome SPE vs IGE; Within = Pre to Post):

- Self-Knowledge: $p = 0.028$ → IGE higher mean Pre evaluation (IGE = 8.58 vs SPE = 5.81; $p = 0.012$), no difference at Post evaluation (p = 0.877)
- General Knowledge: $p = 0.164$
- Attitudes: $p = 0.579$
- Self-Esteem: $p = 0.080$
- Self-Efficacy: $p = 0.685$

Slides Not Using

References

1. Long L, et al. Epilepsia 2000;41:727-731
2. Hayden M, et al. Seizure 1992;1:191-197
3. Ridsdale L, et al. Patient education and counselling 1999;37:43-47
4. Goldstein LH, et al. Seizure 1997;6:435-442.
5. May TW, Pfaffin M. Epilepsia 2002;43:539-549
6. Helgeson DC, et al. Epilepsia 1990;31:75-82
7. Baker GA, et al. Epilepsy and Behaviour 2005;6:556-562

SCH Transition Plan

- Preparation phase (12-16 yrs)
  - Development of knowledge and skills required to manage their health through adult care services
- Active phase (16-18 yrs)
  - Paediatric and Adult services engage in partnership with young person and carers to begin formal process transferring care to Adult health care clinicians
- Integration Phase (18-19 yrs)
  - Completion, follow-up and evaluation of transition care after discharge to adult services

Lifestyle Issues

- General Practitioner
- Seizure Triggers
  - Sleep deprivation
  - Medication Compliance (tips to remember)
  - Alcohol and Drugs
  - Flashing lights (3-5%)
  - Illness
- Safety issues
  - Swimming
  - Bathing
  - Sports
- Depression / Anxiety
- Community Supports

Driving

- Plan/Discuss with your neurologist
- Crucial factors for driving
  - Seizure free
  - Medication compliance
  - Adequate Sleep
  - Avoid circumstances increase risk of seizures
- Guidelines – conditional private licence
- Taxi subsidy scheme

Pregnancy and Contraception

- Interactions between AED's and oral contraceptives
- PREGNANCY PLANNING – Key
  - Adjustment AED's – Minimise risks
    - Increased incidence birth defects on sodium valproate monotherapy above 1100mgs
  - Folic Acid – 5mg/day
  - Monitoring
- DON'T STOP AED's IF PREGNANT

Study & Employment

- How to access
  - Extra assistance with exams
  - Guidance for career choices
  - Info on Apprenticeships, Uni, TAFE
  - Assistance gaining employment
  - Discrimination advice
  - Centre Link – health care cards, mobility allowance, youth allowance, rent assistance, disability allowance

Results

- Duration:
  - 27/30 Diagnosed > 2 years
  - 3/30 Diagnosed 1-2 years
- Control:
  - 25/30 Seizures controlled
  - 5/30 Seizures intractable