All Grown Up: Social Outcomes After Pediatric Epilepsy Surgery

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Every child deserves a healthy start, a strong mind, and a bright future.
Faculty/Presenter Disclosure
Mary Lou Smith

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Objectives

- Review outcomes of epilepsy surgery in childhood
  - Examine different aspects of social function
  - Impact of length of follow-up
  - Effect of seizure freedom
Social Problems in Pediatric Epilepsy

- Huge concern of both parents and children

- Compared with healthy controls, siblings, other chronic illnesses:
  - Less popular, less socially accepted
  - Lower social competence
  - Greater social problems
  - More peer difficulties
  - More socially isolated

Drewel & Caplan, 2007
McCagh et al., 2009
Social Isolation

Reduced opportunities for social interaction

- Hinder important life skills development
- Reduced independence and self-esteem
- Difficulty gaining / retaining employment
- Hinder development of friendships / intimate relationships
Risk factors

- Epilepsy co-morbidities
- Social communication deficits
- Cognitive deficits

- Drewel & Caplan, 2007
Social Outcomes

- Successes / challenges in social relationships and social behaviours
- Educational attainments
- Vocational attainments
- Participation in community life
Pediatric surgical patients – prospective, longitudinal study

- Surgery < 18 years
- Comparison group evaluated for surgery < 18 years
- Follow-up at 1 and 2 years

Childhood-Onset Epilepsy Evaluated for Surgery

- Surgery
  - N = 30
- No surgery
  - N = 21
Pediatric surgical patients – outcomes in young adulthood

- Cross-sectional
- Surgery < 18 years
- Comparison group with seizure onset < 18 years; still having seizures
- Follow-up of 2+ years
- 18 to 30 years old at follow-up

Childhood Onset Seizures

- Surgery
  - No seizures in last year
  - N = 38
- Surgery
  - Seizures in last year
  - N = 33
- No Surgery
  - Seizures in last year
  - N = 31
Pediatric surgical patients – long-term follow-up

- Surgery < 18 years
- Comparison group evaluated for surgery < 18 years
- Follow-up of 4-11 years

- Surgical and non-surgical Ss had baseline data
  - Longitudinal analyses
What children and teens feel: Sense of social isolation

2 sources:

- **internal constraints**
  - lack of self-confidence
  - feeling “alien” or different

- **external constraints**
  - exclusionary behavior by peers
  - perceived excessive parental monitoring and limit setting

Elliott, Lach, Smith, Epil & Behav, 2005
The Children’s Experiences

I have thought that I don’t really belong. I feel like I should have never been born . . . sometimes I’ve thought that I could just be invisible and nobody would really care . . . or I could not be here and nobody would notice and I just felt basically like a nobody” [f, 14]

Sometimes well, some people just like think that I’m weird cause I have epilepsy [m, 12]

They think I’m really different . . . how I have my seizures [f, 13]

All the time, the kids at school never play with me” (f, 7)
What Happens After Epilepsy Surgery?

CBCL Social Competence and Social Problems: mean scores from baseline to 2 yr. follow-up

Elliott, Lach, Kadis & Smith, 2008
Relation to seizure outcome

Social Competence

Seizure Status at Time 3

Seizure free

not seizure free

CBCL Social Scale Change Score (T3-T1)

SURGICAL

NONSURGICAL
# Epilepsy & Social Outcomes

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<th>Baseline</th>
<th>Year 1</th>
<th>Year 2</th>
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<tr>
<td><strong>Quantitative</strong></td>
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<tr>
<td>(CBCL) : Parent report</td>
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<td>↓ Social function</td>
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<td>No change</td>
<td>↑ Social function</td>
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<td>(Smith et al., 2002)</td>
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<td>(Smith et al., 2004)</td>
<td>(Elliott et al., 2008)</td>
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<td><strong>Qualitative</strong></td>
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<td>(Semi-structured interview): Self-report</td>
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<td>Profound isolation</td>
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<td>(Elliott et al., 2005)</td>
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Youth’s Perspectives on Social Function after Surgery

- Seizure free:
  - Most did not report improvements in quality of social experiences
  - Improvements:
    - increased confidence
    - decreased fear/worry about seizures
    - Increased autonomy

- Continuing seizures:
  - No improvements reported
  - The majority continued to report epilepsy–related limitations in daily function

Hum, Smith, Lach & Elliott, 2010
Increased Autonomy

“I’m able to stay home by myself. Oh yes big time change. I love staying at home by myself, it’s so fun. I like going shopping in the mall by myself, oh yeah, I can do that too.”

“Before I couldn’t go anywhere without my mom or dad going because they were afraid that I was going to have a seizure or something. And now hopefully when I’m sixteen I can drive a car.”

“It feels good just to be able to hear you can go for your license, you can live by yourself, you can have showers by yourself, you can have an independent life. Alright, I’ll take it.”
FES Independence

Smith et al., 2004
Seizure Free

Supportive Factors

↑ Autonomy

↑ Confidence

↑ Opportunities for Social Interaction

Supportive Factors

↑ Social Function

Future??

Hum, Smith, Lach & Elliott, 2010
Social Outcomes:
Benefits of Seizure Freedom

Young Adult Study

Lach, Elliott, Giecko, Olds, Snyder, McCleary, Whiting, Nimigon & Smith, 2010
Social Outcomes: Benefits of Seizure Freedom

Long-term Outcomes Study

Significant effect of seizure status (*p < .01)

QOLIE-31 / QOLIE-AD
Social Well-Being

Surgical without Seizures
Nonsurgical without Seizures
Surgical with Seizures
Nonsurgical with Seizures

Puka & Smith, Epilepsia, 2016
No Relation to Seizure Status

- involvement in a relationship
- number of friends
- frequency of visits with friends
- principal activity (i.e. student, employed or unemployed)

Lach et al., 2010; Puka & Smith, 2016
Social Difficulties By Seizure Status - % In Clinically Significant Range

Higher % than in the general population

Puka & Smith, Epilepsia, 2016
Social Outcomes By Seizure Status

Puka & Smith, Epilepsia, 2016

- Postsecondary education: Provincial Census Data 57, Seizure-Free 64, Has Seizures 57
- Employed or student: Provincial Census Data 87, Seizure-Free 89, Has Seizures 76
- Income ≥ $10,000: Provincial Census Data 58, Seizure-Free 28, Has Seizures 13
- In a relationship: Provincial Census Data 42, Seizure-Free 33, Has Seizures 33
- Living independently: Provincial Census Data 36, Seizure-Free 14, Has Seizures 10

Significance levels: *p<.05, **p<.001
Relation to IQ

- Post Secondary Education
- Employed / Student
- Income > 10,000
- In a relationship
- Has driver's licence
- Living Independently

Puka & Smith, Epilepsia, 2016
Conclusions

- Social competence increases with seizure freedom
  - Increased autonomy and confidence
  - Social relationships may take a long time to improve
- Social problems persist, even into adulthood
- Income negatively impacted
- Social outcomes affected by cognitive status
Acknowledgements

The Epilepsy Team at SickKids

Klajdi Puka
Surgical and Non-Surgical Groups

Heterogenous – Site of Surgical Resection – Pathology

- Age (baseline, follow-up)
- Age at seizure onset
- Sex
- Laterality of focus
- Cognition and behaviour at baseline
- Focality of seizures
- # AEDS at follow-up (related to seizure outcome)

No differences

Differences