“I AM WHO I AM BECAUSE OF IT”

Experiences of Adolescents Living with a Parent who Acquired a Brain Injury

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OVERVIEW

- Introduction
  - Hello, my name is...
  - The topic and why it is important
- How did we research the topic?
- What did we find?
- What does it all mean?
  - Practical recommendations for practitioners and family members
WHO AM I?

- My background and my story
  - My professional and academic background
  - My personal experiences
In Alberta, approximately 10,000 new cases of acquired brain injury (ABI) each year (Brain Injury Group, 2005)

Few services are available for children of parents with ABI
The family as a machine with parts - aka the Family System

What happens to the family then?

- Role changes and role reversals (Carnes & Quinn, 2005; Charles et al., 2007)
- Relationship changes and relationship strain (Charles et al., 2007)
- Increased familial stress (Carnes & Quinn, 2005; Elbaum, 2007)
- Ambiguous loss (Landau & Hissett, 2008)

It can’t all be bad!!
ADOLESCENCE

• Transition to adult life
  • A transitional period resulting in physical, psychological, emotional, cognitive, and social changes (Arnett, 1999)
  • Identity exploration and formation (Beyers & Goossens, 2008)
  • Guidance from parents, older siblings, and peers (Faber et al., 2007)

• Storm and Stress?
  • Not true (Arnett, 1999)
  • It can be depending on individual resilience (Compas, 2004; Rutter, 1990)
Resilience is the combination of risk and protective factors (Rutter, 1990)
- Risk Factors - increase the likelihood of a negative outcome in a challenging situation
- Protective Factors - offset the risk encountered in a challenging situation

Risk and protective factors are different for each person.

Coping styles can contribute to resilience (Compas, 2004)
WHY SHOULD WE CONSIDER THE IMPACT OF A PARENT ACQUIRING A BRAIN INJURY ON THE ADOLESCENT CHILDREN?

- Parents inevitably change after an ABI
- Families inevitably change after an ABI
- Adolescents are in the midst of developmental changes

NON-NORMATIVE CHANGES ON TOP OF A TRANSITION CREATES MORE RISK FOR MALADJUSTMENT (ROLLAND, 1999)

- Parents with an ABI are no longer available to provide guidance immediately following injury
What is it like for adolescents to grow up living with a parent with an acquired brain injury?

- Explore their subjective experience which is lacking in the research literature
- Give these individuals a chance to share their stories and create new meaning
- Raise awareness of the occurrence of this phenomenon
HOW DID WE EXPLORE THE QUESTION?

 Heuristic Inquiry (Moustakas, 1990)
   A qualitative research methodology that allowed me to use my personal experience to guide my research process as well as many intuitive structures to enhance the research.

 Recruited participants from the University of Calgary, and three Calgary based brain injury service providers

 Six participants aged 18 to 32 were interviewed for 1-2 hours

 Participants had the opportunity to review their individual depiction
FINDINGS

• 22 themes were divided into 4 categories
  - All four categories exemplify the experience
FINDINGS

Parental ABI Impacts Adolescents

ABI as a life changing event
Uncertainty of the future
Feeling unheard or disregarded
Complex emotional experiences including grief and guilt
Personal growth and acceptance
FINDINGS

Parental ABI Changes the Family System

- Views of injured and non-injured parent
- Changes in family relationships
- Changes in family roles and responsibilities
FINDINGS

Parental ABI and External Supportive Resources

Informal supports

Formal supports
FINDINGS

Tackling the problems
Tackling the emotions
Avoidance and distraction
Compartmentalizing stressors
Maintaining a sense of normalcy
Optimism and hope
Parental ABI is a transitional event for all individuals involved, including the children.

- No transitional models account for the complexity of the adolescent experience.
- The whole family system is affected by parental ABI and teens continue to be heavily influenced by the family system.

Adolescents need:
- Support
- Information
- Inclusion
Grief is a common and unnamed experience
- Normalizing the sense of loss and encouraging the youth to name it to start to deal with it

Resilience and coping are essential concepts when considering the adolescent experience
- Dual Process Coping Model (Stroebe & Schut, 1999)
  - Loss oriented coping
  - Restoration oriented coping
RECOMMENDATIONS

- Interprofessional collaboration and consultation
  - Various professionals from various backgrounds come together to work towards a common goal (Oandasan & Reeves, 2005)
  - Better, more holistic support for the family
- Include the children in rehabilitation practices
  - Inclusion fosters the development of a shared meaning and understanding of the injury as a family
Recommendations

- Information, information, information!
  - Youth need information just as much as adults do
    - About their parent’s condition and what to expect
    - What might change in their parent and their family
    - Resources for the youth

- Counselling psychologists need to acquire competence in disability issues
  - Support the youth as they progress through this transitional experience

- Formal support group for youth living with parents with an ABI
All of the participants stated that they would not change what had happened

**WHY?**

- “I feel like I’m a stronger person because of it”
- “I like the person I became because of this experience”
- “I’m a pretty optimistic person now”
- “I don’t stress about the little things”
- “I am who I am because of it”
Questions?

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