The Family Experience After a TBI
Back to School 2013 Conference

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Objectives

• Dispel common misperceptions and myths about families after TBI
• Highlight the need for family system intervention after brain injury
• Introduce two empirically-based family system interventions for families of adults and adolescents after brain injury
Common Misperceptions and Myths about Families After Brain Injury

Godwin, Gan, Lukow, Wilder-Schaaf & Kreutzer (in press)
MYTH #1

It is not necessary to work with families after TBI. The focus should be on the survivor.
Importance of Paying Attention to the Family Post TBI

- Family members are typically the major support for individuals post TBI
- Long-term negative effects on family functioning (Anderson et al., 2002; Gan & Schuller, 2002)
- Survivor outcome is linked to family outcome (Sander et al., 2002; Taylor et al., 1995)
Depression After Brain Injury

(Mauss-Clum & Ryan, 1981)
Irritability After Brain Injury

(Mauss-Clum & Ryan, 1981)
Anger After Brain Injury

(Mauss-Clum & Ryan, 1981)
Myth #2

Family members have more insight and resilience than the person with the injury.
Family Reactions to Rates of Survivors’ Improvement (Lezak 1986) – Kreutzer 2013

Recovery Rate

- 0-3 months: Happy
- 6 months: Bewildered, anxious
- 12 months: Discouraged & depressed
- 24 months: Mourning
- 36+ months: Emotional reorganization
Impact of TBI on Caregivers

- Family strain, psychological distress in 47% of relatives (Kreutzer et al., 1994)
- Negative life change in 67% of spousal or parent caregivers (Wallace et al., 1998)
- Symptoms of depression (73%) & anxiety (55%) in spouses (Linn et al., 1994)
- 47% of caregivers had altered or given up jobs @ 1 year post injury (Hall et al., 1994)
- Increased use of alcohol & medications (Hall et al., 1994)
Ten Problems Most Frequently Reported by Relatives (Brooks et al., 1986)

<table>
<thead>
<tr>
<th>Problem</th>
<th>Percent Relatives Reporting</th>
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<tbody>
<tr>
<td></td>
<td>1 year</td>
</tr>
<tr>
<td>Personality change</td>
<td>60</td>
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<tr>
<td>Slowness</td>
<td>65</td>
</tr>
<tr>
<td>Poor Memory</td>
<td>67</td>
</tr>
<tr>
<td>Irritability</td>
<td>67</td>
</tr>
<tr>
<td>Bad Temper</td>
<td>64</td>
</tr>
<tr>
<td>Tiredness</td>
<td>69</td>
</tr>
<tr>
<td>Depression</td>
<td>51</td>
</tr>
<tr>
<td>Rapid mood change</td>
<td>57</td>
</tr>
<tr>
<td>Tension &amp; anxiety</td>
<td>57</td>
</tr>
<tr>
<td>Threats of violence</td>
<td>15</td>
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Family Needs After TBI

- Unmet needs around health information, professional support, and community support (Armstrong et al., 2002)
- Unmet health care needs associated with increased caregiver burden (Aitken et al., 2009)
- Physical and cognitive recovery stabilizes, psychosocial and behavioral difficulties emerge → increased stress on families (Anderson et al., 2005)
- 2/3 of parents report unmet needs around health information, medical support, family support and return to school 2 – 4 years post-rehab (Hermans et al, 2012)
Myth #3

Families require short-term intervention. 12 – 15 sessions should suffice.
## Family Burden

<table>
<thead>
<tr>
<th></th>
<th>1 year</th>
<th>5 years</th>
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<tbody>
<tr>
<td>Low</td>
<td>43%</td>
<td>10%</td>
</tr>
<tr>
<td>Medium</td>
<td>33%</td>
<td>33%</td>
</tr>
<tr>
<td>High</td>
<td>24%</td>
<td>56%</td>
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</table>
Family Burden (cont’d)

• Family burden remained significant @ 7 years post-injury (Brooks et al., 1987)
• Physical changes cause the least burden
• Emotional, behavioral, and personality changes in survivor cause the most burden, NOT injury severity
Episodic Loss Reaction

Family Life Cycle

- Anniversary Date
- Graduation
- Getting married
- Launching of Children
- Birthday

(Williams, 1991)
Need for Life Course Perspective After Pediatric TBI

- Children’s brains are still developing
- Recovery patterns differ from those of adults
- Children often “grow into” their disabilities
- Adolescence is a time of heightened vulnerability
- Attainment of life skills and transition to adulthood more challenging

(Gan et al, 2012)
Myth #4

Children who sustain brain injuries recover more easily than adults because of neuroplasticity.
Adolescent Brains – Works in Progress
Timing of TBI in Childhood

- Recovery is influenced by age of injury
- **Children injured in middle childhood (7 – 9 years) appear to be particularly vulnerable**
- Preschool age (3 – 6 years) and infancy (2 mo. – 2 years) are also times of vulnerability
- Sustaining a TBI in late childhood (10 – 12 years) displayed best outcomes

(Crowe et al, 2012)
Impact of Pediatric TBI on Families

- Significant levels of anxiety and depression in 40% of parents (Wade et al., 1998)
- High levels of psychological distress and family burden (Anderson et al., 2005)
- Injury related burden persisted up to 6 years post injury (Wade et al., 2006)
- Struggles with work and finances are significant family stressors (Aitken 2009)
Myth #5

Involvement of the entire family is not critical to the rehabilitation process.
Increased parental stress

Poorer family outcome

Behavior problems in child with ABI

Taylor et al, 2001
Impact of TBI on Family System

- Disruption of family roles
- Shifting responsibilities
- Safety issues
- Family strain
- Financial strain
- Social isolation
- Prolonged caretaking demands

Holland Bloorview
Kids Rehabilitation Hospital
Impact on Spousal/Marital System

Decline in sexual functioning
Loss of companionship
Caregiver strain
Increased dependency
Loss of intimacy
Loss of partnership
"married to a stranger"
Impact on Parenting (injured parent)

- Alienation
- Loss of parental authority
- Loss of parent-child relationship
- Rejection
- Feelings of loneliness
- Treated like a “child”
Impact on Parenting (non-injured parent)

- Divided loyalties
- Juggling multiple demands
- Disruption of power balance
- Feeling overwhelmed
- Discipline problems
- “I feel like a single parent”
- “It’s like having another child”
Myth #6

Children and siblings of survivors do not need to be involved as they are unaffected by the injury.
Sibling Response to Pediatric TBI

- 46% - emotional reactions, school problems or aggressive personality changes (Harris et al., 1989)
- Increase in personal responsibilities, family distress, concern for the future (Willer et al., 1990)
- Need for support, information about ABI, direction, and communication (O’Hara et al., 1991)
- Increased psychological distress and less effective problem solving (Orsillo et al., 1993)
- Loss of parental affection (Peretti et al., 1995)
Sibling Adjustments

- Needs often unrecognized
- May be target of inappropriate behaviour
- Added responsibilities
- Role reversal
- Limited supports
Effects of Parental Brain Injury on Children

- Negative behavioral change in 90% of sample (Pessar et al., 1993)
- Parents perceived as more lax in discipline (Uysal et al., 1998)
- Non-injured parent less actively involved
- Increased depression
Children Who Have a Parent With Brain Injury

- Fear around personality & behavioral changes
- Role changes - increased responsibilities
- Compromised social relationships
- Fewer positive interactions with injured parent
- Loss - one or both parents
Myth #7

The brain injury is the cause of all family problems and is the only goal that is important in rehabilitation.
It’s rarely just the ABI!
How can we be proactive around the needs of families after TBI?

• Involve other members of the family around TBI education
• Provide information and education around the common experiences of families after TBI
• Link families to local and provincial brain injury resources (i.e. BIST, OBIA)
• Encourage families to attend support groups and caregiver workshops
• Assess the needs of the family system and every family member, including the children in the family
• Put in separate claim for family members
Empirically-Based Brain Injury Family System Intervention Programs

• **Brain Injury Family Intervention (BIFI)**

• **Brain Injury Family Intervention for Adolescents (BIFI-A)**
Brain Injury Family Intervention Training (BIFI/BIFI-A): An Evidence-Based Approach
April 24 – 25, 2013

This two-day intensive workshop focuses on clinical intervention skills for professionals (e.g., social workers, psychologists, therapists, rehabilitation counselors) who work with families of persons who have sustained a brain injury.
From disability to possibility

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Select References


