Brain Injury Is A Family Affair: Supporting the Families of People With Brain Injuries

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Brain Injury is a Family Affair...

- Affects the entire family
- Confusing & complex!
- Affects personality & personal/relational functioning
- Amorphous & Changing
  - Sometimes subtle effects
  - Recovery process
  - Secondary issues develop
  - Internal & external micro-climates
- Unpredictable
Overview of Brain Injury:

Causes & Effects
Brain Injury, “The Silent Epidemic”

- The term “Silent Epidemic” is used to characterize the incidence of brain injury worldwide, in part because many cases are not recognized and are, therefore, excluded from official statistics.
- You typically can’t “see” the disability after brain injury (that is why hundreds of different tests have been developed).
- Most of the time the client isn’t aware of their disability, and therefore, they cannot report it.
- Medical records are not likely to provide the information necessary to determine current cognitive, behavioral and physical deficits and strengths or provide recommendations.
- Every brain injury is unique. Key is “Who’s brain is the injury in???”
ABI—Traumatic Brain Injury

• An alteration in brain function, or other evidence of brain pathology, caused by an external force. (BIAA)
ABI: Traumatic Brain Injury

- Causes
  - Falls
  - Vehicle accidents
  - Hit on the head by an object—piercing/contusion
  - Assaults—blunt force, shaking
  - Blast injuries
  - Sports Injuries
DIFFUSE AXONAL INJURY

Sudden acceleration-deceleration forces cause injury to the brain.

The injury is greatest in where the density difference is greatest. Most tearing occurs at the gray-white matter junction.
Other TBI Mechanisms

Subdural Hematoma

Intracerebral Hematoma
70% Moderate to Severe TBI
15% Mild with Persisting Sx
15% Mild w/o Persisting Symptoms
Traumatic Brain Injury Terms

- Diffuse axonal injury
- Concussion
- Contusion
- Coup-Contre coup injury
- Open or closed head injury
- Penetrating injury
- Shaken baby syndrome—really “abusive head trauma”
ABI—Non-Traumatic Brain Injuries

- Stroke
- Aneurysm
- Tumor
- Hypoxia or Anoxia
- Disease process (non-progressive)
- Neurotoxins
- Electric shock or lightening strike (including ECT)
Common Effects of Brain Injury

- **Cognitive**
  - Short term memory loss
  - Slowed processing speed
  - Attention & concentration
  - Executive functions
  - Communication Skills
Common Effects of Brain Injury

- Physical
  - Seizures
  - Headaches
  - Fatigue
  - Sleep disturbance
  - Balance problems
  - Speech & vision problems
  - Motor coordination, spasticity, paralysis
Common Effects of Brain Injury

- Emotional
  - Anxiety & depression
  - Impulsivity
  - Mood swings & difficulty moderating emotions
  - Agitation
  - Lowered self esteem
  - Restlessness
  - Emotional changes—apathy, silliness, irritability
Difficulty in Social Interactions

- Egocentrism
- Inappropriateness for the setting or situation
- Missing or misreading social cues, body language
- Difficulty empathizing with others or reading others’ emotional state or needs
Awareness

• Less serious injuries may not affect awareness of impairments
  • Embarrassment, frustration, depression
  • Able to develop compensatory strategies

• More serious injuries may impair awareness
  • Less emotional difficulty related to impairments
  • Not motivated to develop compensatory strategies because see nothing to compensate for

Lezak, 1988
The Challenges for Families
A Poem By a Mother…
Role Changes in Family

- Re-distribution of family duties
- Re-distribution of attention
- Parent with a brain injury…
- Spouse/partner with a brain injury…
- Sibling with a brain injury…
- WHAT IS THE NEW NORMAL?
Family’s Emotional Journey

- Traumatized from the event that caused the injury
- Deal with unimaginable situations
- Overwhelmed, scared, tired
- Anger
- Guilt
- Sadness, pain, complicated grief
- No time to process it all b/c of care-giving
- Often loss of supports
- CAREGIVER BURNOUT!
Complications

• Complicated grief

• Complicating cause of injury
  • Suicide attempt
  • Drunk driving
  • Drug/alcohol overdose
  • Victim of a crime
Challenges to Family Stability

- Financial Changes
  - Loss of income
  - Financial strains (medical bills, home modifications…)
  - Potential loss of health insurance

- Safety Issues
  - Judgment of family member with the injury
  - Sometimes potential for abuse/assaults

- Strained relationships, family conflict
Specific Challenges

- For spouses—changes in intimacy, emotional support, sexuality
- For parents of child with brain injury—navigating school system supports
- For children of a parent with a brain injury—changes in interactions, possible changes in childcare situation, other parent’s attention is divided, confusing responses
Dependency

- Often a reality for many after brain injury
- Can become dysfunctional
  - Reaction to loss of independence can result in assertion of authority over caregiver which leads to more dependency
  - Insecurity/fear can lead to clinging so caregiver never has time away and the BI survivor feels even more dependent.
Structure

- Some people require rigid routines to be able to function somewhat independently.
  - Means the FAMILY must also live with this structure & not disrupt it

- Other people require less structure but then have difficulty with novel or complex situations
  - Can be confusing for families
Confusion!

- Personality changes can be subtle, hard to pin down
- Changes can vary day to day or situation to situation
  - Improved behavior for short times or in structured environments
  - Able to maintain appropriateness around visitors but not consistently
- It can feel like the person doesn’t care enough about family to maintain their improved behavior

Lezak, 1988
Family in the Environment

- Outside people don’t understand
  - Opinions & suggestions
  - Misinterpretation & Judgment—”drunk” or “anti-social” or “why don’t you leave them?” or “how could you leave them?”
  - Don’t see the person long enough to observe the problems, so dismiss family’s concerns

- Isolation as family & friends stop coming by

- Dealing with neuro-behavioral issues in public
For the family and the person with the brain injury, it is a journey to acceptance of the “new normal”
Factors Affecting Outcomes
Pre-Injury Family Dynamics

- General cohesiveness
- Problem-solving style
- Reaction to stressors & conflict
- Rigidity vs adaptability
- Dependency issues
- Resentments & pre-existing dysfunction
Supports

• Extended family & friends
• Access to rehab therapies & counseling
• BI education
• BI Support Groups
• Assistance with transitioning back to work/school
• “Guide” through the system
Quality of Supports

- Knowledgeable!
- Compassionate
- Reliable
- Creative
- Active and advocate
- True continuum!
How to Help Families

• Be good at what you do—get education!

• Know when & where to refer
  • For rehab
  • Support groups
  • Specialized services

• Educate families

• Advocate for better services

• Let your understanding of these issues inform your work with families

• Be compassionate
Specialized Services

- Cognitive Rehabilitation
- Psychiatrists, Neuropsychologists
- Indiana Vocational Rehabilitation
- RHI Resource Facilitation
What will you commit to do to help families of people with brain injuries?
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