



NEURO
INSTITUTE

Continuing Education for Rehabilitation Professionals



Traumatic Brain Injury: Family Perspectives

Frank D. Lewis, Ph.D. and Patty Goolsby, BBA, COTA



NEURO
INSTITUTE

Continuing Education for Rehabilitation Professionals

This program is provided by the Neuro-Institute, the educational division of NeuroRestorative.

CE programs are offered all year on the last Friday of each month.

Email stephanie.tinnon@neurorestorative.com for credit. A quiz must be completed.



NEURO
INSTITUTE

This Presentation will Address:

1. TBI facts and understanding the disease process.
2. Consequences of TBI on the Domains of Human Functioning.
3. Impact on the Family:
 - Emotional
 - Caregiving Burden
4. Interactions to help families cope

Scope of the Problem: TBI - U.S. National Data

- 1.5 - 2 million individuals a year
- 5.3 million in US with TBI
- Unknown number of undiagnosed TBI's may result in long term disability

TBI facts and figures

- What are the leading causes of TBI?
 - Falls
 - Motor Vehicle Accidents - ETOH
 - Sports and Recreation injuries
 - Assaults
 - Shaken Baby Syndrome
 - Gun shot wounds
 - Military Actions

When?

- After School
- After 5:00 pm
- Friday nights
- Weekends
- Holidays
- Risks increase after 1st 3X greater,
- 2nd 8X greater

SOMEONE IS EFFECTED EVERY 23 SECONDS

- 26/thrown from bull during competition/contra coup +wife, new baby, new home, FT brick layer
- 41/sucked from home during tornado/contra coup +separated from spouse, 2 teens, FT carpenter
- 22/Coke can throw from bus hit head/temporal +2nd year college, living on campus
- 22/Baseball player hit in head during practice/ occipital-temp. +new wife, 1 son, going pro

Every 23 Seconds

- 33/FT-poison from inhalation, wife is FT professional, kid in military, building a life
- 25/College sophomore-summer vacation hit by lightning; Engaged, 3rd year college
- 26/ recognized pharmaceutical rep-in for routine surgery reaction to anesthesia wife of 4 months
- 20/college female, hood surfer

My family member survived. Why so much stress?

- Not just a singular medical event
- Not a final outcome
- Rather the beginning of a disease process
- Many organ systems may be involved, creating tremendous burden of care for family.

TBI a Disease Process

TBI can be causative of several chronic conditions in multiple organ systems:

- Neurological disorders (e.g. Epilepsy, Migraine, Ageusia)
- Neuroendocrine disorders (e.g. Panhypopituitarism, Diabetes, SIADH)
- Psychiatric disorders (e.g. Depression, Anxiety, Personality change, Behavioral Dyscontrol)
- Coronary disease (e.g. Hypertension, Hyperlipidemia)
- Sexual dysfunction (e.g. Hypersexuality, Hyposexuality)

Development Across the Lifespan

Humans develop and adapt across the lifespan

Human development is the result of several interacting forces.

These forces include domains of:

- Physical
 - Physical shape, size, sensory capabilities, motor skills
- Cognitive
 - Acquisition of skills in perceiving, thinking, reasoning, problem solving, language
- Social/emotional
 - How you behave (personality) and how you feel

Impact on Functioning

TBI can Disrupt Development and Functioning in each Domain.

Adapting to changes present great challenges for family members.

Added burden of care at an unexpected time in life. *(90% of caregivers report significant caregiver burden)*

Greatest Source of Stress

Research tells us that Behavioral Dyscontrol and altered social competency present the greatest source of stress for family members.

Mobile Mourning

- TBI may result in long-term changes in personality and functional capabilities.
- Many families report inability to find closure as they deal with the necessity of providing life-long care.
- Emotional experience referred to as “Mobile Mourning”: grief that persists over time without relief.

| The Emotional Response

Confusion

Denial

Avoiding

Anger

Depression

Isolation

Recognition

Panic

Blaming

Rescuing

Guilt

Fear

Grieve & Mourn

Hope

Stages of Adjustment for Families

- Stages are approximations
- Not all families go through stages in order or experience all of the stages
- Every family is unique in their recovery curve
- The following stages are base on typical responses.

Stages of Adjustment

Stage 1. Shock. Hope for survival and full recovery. Want everything to be the same. (1-3 months)

Stage 2. Recognition. Understanding of the severity of the injury. Things may not be the same. Frustration. (3-9 months).

Stage 3. Annoyance. May feel annoyed with the survivor. Not meeting recovery expectations. Reality setting in. (6 – 24 months).

Stages of Adjustment

Stage 4. Realism and Exhaustion. Mental and physical exhaustion sets in. Begin to reduce time with loved one. Grief may be stronger. (10 to 24 months)

Stage 5. Profound sadness. “Mobile mourning” begins. Mourn loss of the personality characteristics, loss of hopes and dreams for their loved one. (12 – 24 months).

Stage 6. Understanding adapting. Now understand the person may never be the same. Acceptance. Address needs of the entire family again.

Other Factors

Substance abuse

- Studies show as many as 50% admitted to rehabilitation post-injury report substance misuse.
- Damaged frontal lobe functioning may contribute to post-injury substance misuse.
- Additional burden on families – brain injury rehabilitation plus substance abuse treatment.

Other Factors

Siblings

- Young and old, lives profoundly affected but needs often overlooked
- Often experience:
 - Role changes
 - Loss related to prior relationships
 - Resentment
- Rehabilitation professionals need to include siblings in treatment planning.

Other Factors

Cultural Issues

- Culture shapes family perceptions of injury and treatment.
- African American caregivers more hours per week providing care, less likely to use community supports.
- Hispanic families open communication with all family members together.
- American minority individuals more likely to be unemployed after brain injury.
- Be sensitive to differences, don't be afraid to ask questions regarding preferences.

Other Factors

Military families

- Bring many pre-injury stressors into rehabilitation, e.g. multiple deployments, hazardous environments, family relocations.
- Often face poly-trauma (multi-systemic) injuries
- PTSD
- Family stressors unique to military
- Rehabilitation professionals must be aware of the uniqueness and complexity. Enlist the support of experts if they are not apart of the rehab team.

Helping Families

The Family Needs Questionnaire (FNQ):

- Helps to prioritize family goals
- Six domains including: health, emotional support, practical assistance needs, professional support, peer support.
- Identifies the immediate needs of family members.

Helping Families – Counseling Approaches

Family Centered Approach

- This approach emphasizes:
 - Injured person, family, professional are partners in care.
 - Effective care is comprehensive
 - Everyone's circumstances are unique, care should be tailored to fit those unique needs.

Helping Families - Counseling

Cognitive Behavioral Therapy

- Emphasizes how catastrophic events impact thoughts, beliefs and emotions.
- Examine beliefs to change thoughts, emotions, and behaviors.
- How we think is “Everything”
- Take control over what you think.

Helping Families - Counseling

Resilience Theory

- Characteristics of those who rise above catastrophic events.
- Resilience – a skill that can be learned.

Helping Families - Counseling

Resilient Skill Sets

- Belief that makes meaning out of adversity
- Maintain positive outlook
- Spirituality
- Supportive connections among family members
- Clear emotionally-open communication
- Collaborative approach to problem solving

Helping Families – Techniques

- Joining: Form a working alliance with families, respect point of view but guide with expertise.
- Active Listening: Don't get caught up with your own schema, focus on the family perspective. Stay away from advice and incorporate family in problem solving.
- Positive Reframing: “Focus on what you can do”
- Education: Reduce stress by providing information about brain injury. Gradually help formation of realistic expectations. Predictability reduces stress.

Family Perspective - Conclusions

1. Respect is key. Respect requires listening. No one can fully understand what the family member is experiencing. Know the limits of your knowledge.
2. Know brain injury. Know the consequence of a TBI to better help families face the challenges ahead.
3. Understand the range of emotions likely to be experienced by family members and when they are most likely to experience them. Understand, don't blame.
4. Assess family needs at admission.
5. Incorporate clinicians trained in family-focused TBI interventions.
6. Provide additional resources.

Additional Resources

1. *Getting Better (and Better) After Brain Injury: The Survivor's Guide for Living Smarter and Happier.* Kreutzer, Godwin, Schaff, & Wetsel. National Resource Center for Traumatic Brain Injury at Virginia Commonwealth University.
2. *Learning by Accident.* Rawlings R. Outskirts Pres; 2011, ISBN: 978-1-59385-186-6.
3. *Roadmap to Resilience: A Guide for Military, Trauma Victims and Their Families.* Meichenbaum, D. Institute Press 150 Belleview Blvd, Ste. 703, Belleair, FL, 33756.