Traumatic Brain Injury (TBI) Across the Lifespan: What Advocates Should Know

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THE VISION
Empower people of all ages to unlock their brain potential.

Center for BrainHealth®
MISSION
Lead scientific research to enhance, protect and restore brain health across the lifespan.

Brain Performance Institute™
MISSION
Deliver brain science innovations to enhance how people think, work and live.
Traumatic Brain Injury (TBI) Focus Areas

ID & MONITORING

REGENERATION

RESILIENCE
Why study brain injury?

• Every 15 seconds, a U.S. citizen sustains a brain injury (approx. 1.5 million people each year)

• 1 in 30 children will sustain a brain injury before age 21 (some prevalence data has yielded figures 10x that when following people from birth and including non-hospitalization injuries)

• TBI is the most common cause of death & disability among children in the U.S.
The Problem.

Comparison of Annual Incidence

Data compiled and arranged by the Brain Injury Association of America based on data from the Centers for Disease Control and Prevention, American Cancer Society and National Multiple Sclerosis Society

- Traumatic Brain Injuries: 1,500,000
- Breast Cancer: 176,300
- HIV/AIDS: 51,334
- Spinal Cord Injuries: 11,000
- Multiple Sclerosis: 10,400
Rates of TBI-related Emergency Department Visits, Hospitalizations, and Deaths — United States, 2001–2010

https://www.cdc.gov/traumaticbraininjury/data/rates.html
• Rate of emergency room visits for traumatic brain injury increased by 30 percent between 2006 and 2010
• Rose at a rate 8 times higher than that of ED visits overall
• Biggest increase seen in children under 3 and adults over 60
Rates of TBI-related Emergency Department Visits by Age Group — United States, 2001–2010

https://www.cdc.gov/traumaticbraininjury/data/rates_ed_byage.html
Brain Injury

Congenital Brain Injury
- Pre-birth
- During birth

Acquired Brain Injury
- After birth / during childhood

Traumatic Brain Injury
- Closed Head Injury

Non-traumatic Brain Injury
- Open Head Injury

Savage, 1991
Brain Injury & Other Disabilities: Differentiating Characteristics

- A pre-injury self-concept as normal
- Inconsistent patterns of performance
- Variability and fluctuation in recovery process
- Problems generalizing & integrating information
- Inappropriate behaviors that may be more exaggerated
- A previously learned base of information which assists in relearning
- Uneven areas of deficits
Impact of Injury on the Developing Brain
“TBI needs to be treated as a chronic condition. While acute recovery care is essential, long-term monitoring and effective interventions are necessary to mitigate persistent or later emerging deficits and ensure maximum brain regeneration and cognitive performance.”

- Dr. Sandra Chapman, Founder and Chief Director at the Center for BrainHealth
  Dee Wyly Distinguished Professor in the School of Behavioral and Brain Sciences
NIH-funded study: Neurobehavioral and Social Outcome of Head Injury in Children

- Collaboration with Baylor College of Medicine in Houston (Drs. Harvey Levin & Gerri Hanten—Principal Investigators)
- Recruit kids/teens at time of injury (mild to severe)
- Evaluate at time of injury and at various time points longitudinally
  - Cognitive assessment
  - Psychiatric assessment
  - Brain Imaging (MRI, DTI, fMRI, ASL/resting fMRI)
- Most recent focus on executive functions serving social cognition
- Also investigate social function & psychosocial outcomes
Neurobehavioral & Social Outcome of Head Injury in Children

- Executive Functioning
- Discourse and Strategic learning
- Social Cognition
- Motivation
- Academic Achievement
- Psychiatric & Behavioral Issues
What can affect performance on the road to recovery?

- Long-Term Effects
- Delayed Onset of Deficits
- Age Variability
Regions affected by Traumatic Brain Injury

Frontal Lobe:
- Planning
- Problem solving
- Social
- Emotional
- Impaired walking

Temporal Lobe:
- Learning
- Memory
- Language

Diffuse Injury:
- Disorders in Attention
- Impaired concentration
- Information processing
- Seizures
Consequences of Pediatric Brain Injury

- Inefficient discourse processing—gist vs. details
- Decreased problem solving skills
- Impaired Motivation and response to rewards
- Impulsive behavior
- Prospective and working memory deficits
- Emergence of maladaptive behavior
Typical follow-up for pediatric brain injuries

- Days to weeks in hospital ward
- Several weeks in rehabilitation
- Recommendations to schools
- Additional follow-up care may be limited
1. Prognosis for functional recovery of *old* skills is better in early brain injury

2. Prognosis for acquiring *new* skills after injury is worse after early brain injury
Pediatric TBI: Immediate Phase of Recovery

(Chapman, 2006, Brain Injury Professional)
Stages of Recovery

Immediate phase

- From injury up to 1 year post injury
- Gains in emergency medical treatment have increased chances of survival
- Often intensive rehabilitation
- Younger = better immediate prognosis

Latent phase

- From 1 year after injury to years after injury (even up to young adulthood)
Neurocognitive Stall

Pediatric TBI: Latent Phase of Recovery

Growing Up

(Chapman, 2006, Brain Injury Professional)
Neurocognitive Stall

- During latent phase
- Halting or slowing in later stages of cognitive, social, and/or motor development

Not necessarily loss of already acquired skills but rather failure or lag in developing later emerging cognitive milestones

(Chapman, 2006, Brain Injury Professional)
Child TBI: Not Just “Little” Adults

- Some impairments may get worse over time
- New difficulties can emerge years later
- Children may have to recover at each new stage of development
Symptom Domains in TBI

- Cognitive/Learning
- Behavioral/Psychosocial
- Physical
- Sleep
Cognitive/Psychosocial Difficulties and the Effect on the Family
The Adolescent Brain

“High Horsepower, No Steering”

• Hormone Changes
• Emotional Brain
• Brain’s reward system
• Frontal Lobe Development
Frontal Lobe Functions

Key to dynamic thinking capacity for life

Undergoes dramatic ‘wiring’ from teens to young adulthood

Most optimal and vulnerable brain stage

The combination of heightened reward center, emotionality, and a still developing inhibitory and planning system results in an extremely vulnerable state for the teenage brain.
The brain undergoes significant changes in adolescence.
The most significant brain changes occur in the frontal lobes.
The frontal lobes allow us to make sense of the massive amount of information flooding our brain constantly.
A SMART BRAIN IS FRONTAL LOBE INTEGRITY.

Our frontal lobe separates us from all other forms of life.
Our frontal lobe is our brain’s CEO (Cognitive Executive Officer.)
Executive System

- Awareness of cognitive strengths/weaknesses
- Ability to set reasonable goals
- Plan & organize behavior to pursue goals
- Initiate behavior to achieve goals
- Inhibit behavior incompatible with achievement of goals
- Monitor & evaluate behavior in relation to goals
- Think strategically & solve problems flexibly
Psychiatric Disorders

- Preinjury psychiatric disorders are very common in children who sustain TBI, with occurrence ranging from 33 to 50%.

- A study of children with severe TBI found that ongoing postinjury-onset depressive disorder occurred in 25% of children with severe TBI and that 1/3 of the children had a depressive disorder at some point after the injury.
Personality Change

A persistent personality disturbance that represents a change from the individual’s previous characteristic personality pattern.

The particular personality change can be specified by indicating the symptom presentation that predominates:

- Labile Type **
- Disinhibited Type *
- Aggressive Type *
- Apathetic Type
- Paranoid Type

Source: Diagnostic & Statistical Manual IV
Approx. 40% of children with severe TBI exhibit ongoing persistent personality change an average of 2 yrs. post injury. An additional 20% had more transient change. Change occurred in 5% of mild to moderate TBI, but was always transient. (Max et al., 2000)

Predictors:
- Severity of injury
- Superior frontal gyrus lesions (1st yr)
- Frontal lobe white matter lesions (2nd yr)
- Pre-injury adaptive functioning (2nd yr)

Source: Max, J et al. (2006)
Almost one third of children with severe TBI develop ADHD secondary to brain injury.

Predictors:
- Severity of injury
- Pre-injury behavior problems

The combination of severe injury and secondary ADHD predicted poor inhibition.

Source: Schachar, R et al. (2004)
New-Onset Depression after TBI

- The psychiatric outcome of children 6-months post-injury (mild to severe) revealed that novel depressive disorders occurred in ~11%
- Novel depressive disorder was significantly associated with older age at the time of injury, family history of anxiety disorder, left inferior frontal gyrus (IFG) lesions, and right frontal white matter lesions
- Forty-percent of children with novel depressive disorder had a comorbid novel anxiety disorder

(Max et al., 2012, International Journal of Developmental Neuroscience)
New Onset Anxiety after TBI

- The psychiatric outcome of children 12-months post-injury (mild to severe) revealed that novel anxiety disorders occurred in ~10%.
- Novel anxiety disorder was significantly associated with concurrent novel depressive disorder and with novel personality change due to TBI.
- Novel anxiety disorder was marginally associated with younger age at injury and with pre-injury anxiety disorder.
- Findings suggest that, although relatively infrequent, when anxiety disorders did emerge, they were significantly associated with the emergence of other forms of affective dysregulation, such as novel depressive disorders and personality change due to TBI, especially in younger children and those with pre-injury vulnerability to anxiety.

(Max et al., 2015, Journal of Pediatric Rehabilitation)
A Brain Under Chronic Stress

- Chronic stress reduces neuronal activity
- When a brain is stressed, it does not operate efficiently
- Associated with high incidence of depression, anxiety, and rage in the general population
- A brain exposed to chronic environmental stress is not as effective at learning new information or storing new learning in memory networks
Other Common Issues Post-injury

- Anger
- Social problems
- Perseveration
- Immaturity
- Legal trouble
TBI & Criminality in Juvenile Offenders

- Recent study in Texas (7 juvenile justice facilities)
- Administered Brain Injury Screening Questionnaire
- Linked results to offense history & psych. diagnoses
- Found that 1 in 4 met criteria for TBI (21.9% of state sample & 41.3% of county sample)
- Majority occurred prior to criminal offenses
- A history of TBI was related to more violent crimes as well as more mental health diagnoses and symptoms
- Need for preventative actions, interventions to compensate for challenges related to TBI, and programs to assist transition back into the community

Gordon et al., 2017, Journal of Head Trauma Rehabilitation
Comments from Parents

“Her friends are scared of her.”

“He used to take care of his younger brother, now I’m afraid to leave them alone together.”

“He has punched me a couple of times and punched several holes in the walls of our house.”

“When his friends were over, he suddenly dropped his pants in front of them.”

“Her physical recovery was a miracle but now she is a different person.”

“Since her injury, my daughter has no manners.”
“No words are adequate to express the comprehensive sorrow, pain, anger, disappointment, and hope shared by persons and families changed and challenged by the impact of a head injury.” (Dell Orto & Power, 1994)

Impact on Families

- denial of deficits, just want him/her to be the same
- depression and/or anxiety as a result of dealing with the injury and post-injury personality changes
- uncertainty and frustration in handling new problem behaviors

**Importance of Counseling**
Transition to Adulthood
Transition to Adult Life: Current Problems

• Lack of and/or access to knowledgeable adult medical providers and specialists

• Lack of and/or access to knowledgeable psychologists, psychiatrists, and community mental health providers

• Lack of insurance coverage for ongoing, post-acute PT, OT, SLP, cognitive rehabilitation or other psychological treatments

• Lack of and/or access to opportunities for positive peer relationships, social interactions, community integration

• Lack of and/or access to these services negatively impacts all facets of one’s Quality of Life
Transition in School to Work Process: Statistics

• High school dropout rates for students with disabilities are greater than 25%

• Unemployment or underemployment post-high school rates can exceed 75%
Successful Research Trends

- Transition appeared to be more successful for students who receive vocational education and early work experience.

- A series of vocational-education classes was associated with significantly higher wages and rates of employment.

- The presence of a transition goal (such as in an IEP) for either postsecondary academic or vocational training was related positively to achieving that goal.
Two Different Approaches

https://www.youtube.com/watch?v=BMX7IqXEYw4

https://www.youtube.com/watch?v=C8t27dFau_Y
Neuroplasticity: The Hope of Restoration, Regeneration, & Resilience
Recent Discoveries in Brain Research

The Good News:

• The brain continues to make new cells (neurogenesis) throughout our life
• The brain has the capacity to reorganize, forming new connections and strengthening weakened neural pathways
• New, sophisticated brain imaging technology is making it possible to understand the brain’s response to treatment
What can we do now?... A lot!

- Research regarding brain plasticity provides much hope
- Treatment can enhance functional and structural aspects in the brain
- Improvements can be made in meaningful real-life outcomes
Brain-based cognitive interventions

As we learn how the brain works, we can advance:

• Neurocognitive treatment development

• Educational teaching strategies and academic supports
## Restorative Approach

### What works:

- Active involvement/being engaged in something you like
- Being challenged – "sweating it"
- Being **strategic**

### What doesn’t:

- Passive repetitive tasks – *automatic*
- Mere involvement with sensory input
The Circle of Care
DePompeii, 2003

Acute Care
Hospital Rehab

Trauma Center
Rehab Facility

EMS
Discharge to Community

Injury
Doing OK in Community

Community
School

Social Interaction
Home

Life-Long Issues
Vocational

Education
Community

Medical
Community

Child and Family

(Prevention)
Family-Centered Care Principles

- The family is the constant in the child’s life
- Parent/professional collaboration is essential at all levels
- Complete & unbiased info should be provided to families in a supportive manner
- Appropriate policies & programs that provide emotional/financial support should be implemented
- Family strengths & individuality should be recognized & diverse methods of coping respected
Family-Centered Care Principles (cont’d)

• Developmental needs of infants, children, adolescents & families should be understood & incorporated in care

• Parent-to-parent support is encouraged

• Health care delivery systems should be designed to be accessible, flexible & responsive to family needs
Caregiving Notebook—Top 10 things caregivers don’t want to hear

• Doesn’t your insurance cover that?
• It must be hard to work and take care of your [child], so why don’t you just quit your job?
• Your [child] belongs in a nursing home. OR: I could never put my [child] in a nursing home.
• You have to take care of yourself; your [child] needs you!
• Why don’t you get your family to help out more?
• I don’t see what you’re complaining about. [Your child] seems fine to me.
• I don’t know how you do it. You must be a saint.
• Just call me if you need some help.
• I know just how you feel.
• God doesn’t give you more than you can handle.

http://www.texasbia.org/caregiving-notebook
Caregiving Notebook—Top 3 things caregivers do want to hear

• I have a friend who is having a lot of difficulty getting started as a caregiver. Would you be willing to talk to her?

• I haven’t seen you in awhile, and I miss our [lunches, shopping, volunteering, whatever].

• How are you doing?
Brain Injury Family Support Series

Communication Matters:
https://www.youtube.com/watch?v=exiB9TbJx2I

Brain Injury: What’s in Your TBI Toolbox?
https://www.youtube.com/watch?v=fBpLlENu5FY
Creativity in Caregiving

http://www.brainline.org/content/2013/05/creativity-in-caregiving.html?utm_source=Twitter&utm_medium=Hootsuite&utm_campaign=BrainLineSM

1. Utilize Your Resources
2. Maximize Your Time
3. Become an Expert
4. Set Goals Together
5. Involve the Family
Professional Pointers for working with TBI survivors

- Provide ample time for individuals to:
  - Process information
  - Respond
  - Complete tasks
  - Accomplish goals

- Offer many reminders

- Always have a pen/paper, calendar, or other organizational tool handy for them to use
Professional Pointers for working with TBI survivors (cont’d)

• Avoid too much complexity or “information overload” (Less is more!)
  • Keep instructions and explanations simple (not too many details)
  • Discourage overuse of too many calendars/e-mail addresses/credit cards (consolidate and streamline)
  • Avoid overstimulation (light/sound, activity, information)

• Encourage them to:
  • Prioritize daily tasks first thing in the morning
  • Complete difficult tasks first (e.g., schedule depositions in the AM)
  • Refrain from mentally taxing tasks after 4 PM
  • Avoid multitasking
  • Take “mental breaks” (at least 5-min. breaks 5 x a day)
S.C.O.R.E. for Brain Health

S = SELECT

Reduce # of activities, goals or domains to focus on most important and salient—reduce multitasking!

C = COMPENSATE

When experiencing mental loss or difficulties, use alternative means (calendars, cue cards, etc.)

O = OPTIMIZE

Use your talents and passions to maximize your abilities
S.C.O.R.E. for Brain Health

**R = REGENERATE**

*Build new brain pathways with meaningful mental and physical activities*
*Repetition builds stronger connections—whatever you practice gets better*
*Be sure to get plenty of rest*

**E = EMPOWER**

*Believe in yourself—You remember and un-forget a great deal more than you credit yourself*
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Want more information now?

General Information resources:

http://www.brainline.org/ -- General brain injury issues

http://www.brainlinekids.org/ -- Specific to pediatric issues

http://www.brainlinemilitary.org/ -- Specific to military issues
For more information:
www.centerforbrainhealth.org
www.brainhealthdaily.com

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