

Caregiver Burden and Traumatic Brain Injury

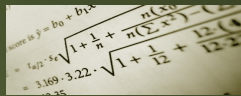


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Objectives

- ◆ TBI Overview
- ◆ Discuss Cognitive and Behavioral Sequelae
- ◆ Discuss TBI's Impact on Family Dynamics/ Caregiver Burden/Distress
- ◆ Caregiver Research
- ◆ Discuss Potential Therapeutic Intervention

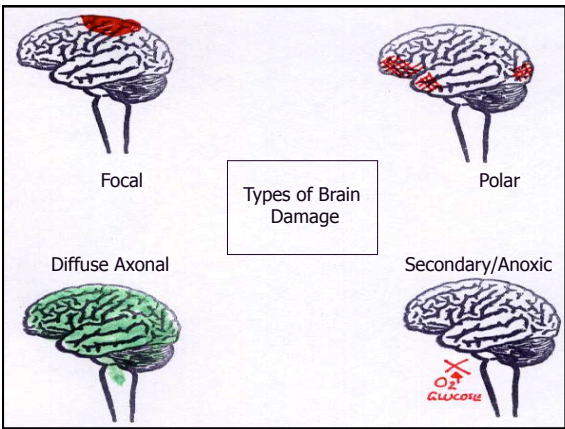
The Stats



- ◆ Approx. 1.7 million Americans will sustain a TBI this year
- ◆ 52,000 deaths/year
- ◆ 275,000 hospitalized
- ◆ 70-90 thousand with long term impairment
- ◆ TBI is among the leading killers and disablers of young adults < age 35
- ◆ Lifetime costs can exceed **\$4.5 million** per individual

TBI Overview

What Happens?



Open Head Injury

- Skull is fractured or penetrated by foreign object
- Majority of cases resulting from trauma
- Primary Effects – actual damage due to trauma (e.g., cortical damage)
- Secondary Effects – cascade effects of primary trauma (e.g., edema)
- Typically Better Prognosis

Closed Head Injury

- ✓ No skull fracture – vascular, hypoxic
- ✓ Primary Effect – contusion, axonal shearing, or bleed
- ✓ Secondary effect – edema or hydrocephalus (due to bleed or CSF collection) – can result in midline shift of structures

Brain Injury Severity

- ✓ LOC – loss of consciousness
 - Mild injury < 30 minutes
 - Moderate/severe injury > 30 minutes
 - Comatose

- ✓ **PTA** – post traumatic amnesia/delirium - significant disturbance of memory and mood/personality following TBI
 - mild PTA < 1 hour
 - moderate PTA 1-24 hours
 - severe PTA > 24 hours
- ✓ **Glascow Coma Scale** (out of 15)
 - mild = 13
 - moderate = 9-12
 - severe = 8 or less

Neuropsychological Sequelae

- ◆ Attention/Processing Speed
- ◆ Language
- ◆ Memory
- ◆ Visuospatial
- ◆ Executive Functions
- ◆ Psychological/Personality



Sensory/Motor/Neurological Sequelae

- ◆ Hemiparesis
- ◆ Visual deficits
- ◆ Muscle Spasticity
- ◆ Bowel and bladder dysfunction
- ◆ Seizures
- ◆ Poor Sensory Integration
- ◆ Pain



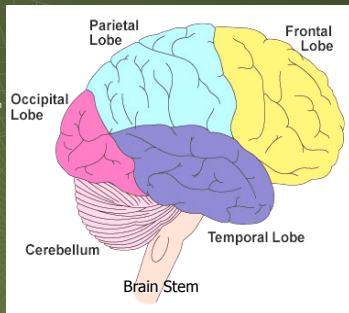
Cortical Functions by Region

Frontal Lobe

- Initiation
- Problem-Solving
- Judgment
- Inhibition of Behavior
- Planning/Organization
- Self-Monitoring
- Motor Planning
- Personality/Emotions
- Mental Flexibility
- Expressive Language

Temporal Lobe

- Memory
- Audition
- Receptive Language
- Emotion



Parietal Lobe

- Sensory input and integration
- Spatial perception

Occipital Lobe

- Vision
- Visual Integration

Cerebellum

- Balance
- Motor Coordination
- Skilled Motor Activity

Brain Stem

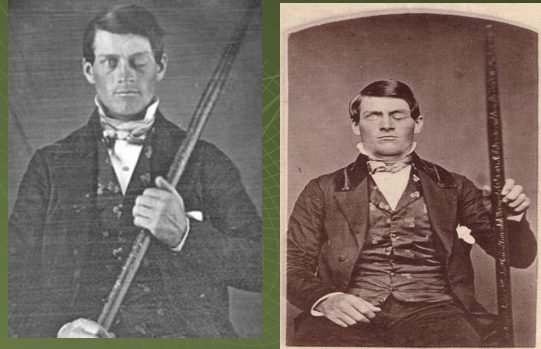
- Breathing/Heart Rate
- Arousal

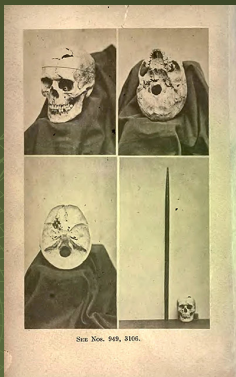
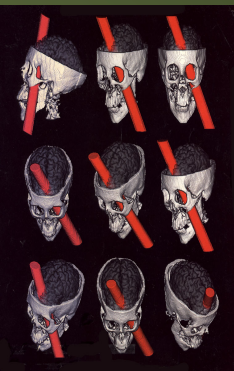
Neuropsychiatric Syndromes Associated with Neuroanatomical Lesions

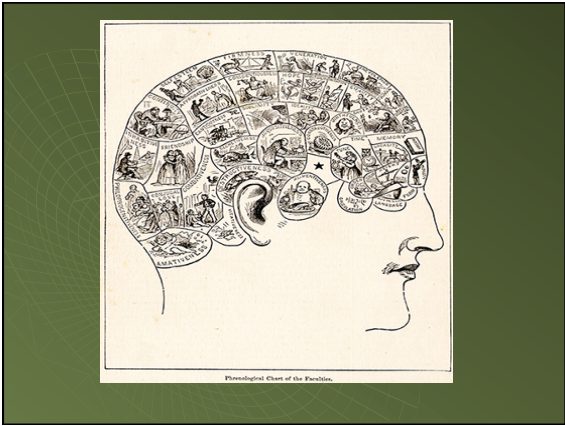
- ◆ Lateral orbital pre-frontal cortex
 - Irritability - Impulsivity
 - Mood lability - Mania
- ◆ Anterior cingulate pre-frontal cortex
 - Apathy - Akinetic mutism
- ◆ Dorsolateral pre-frontal cortex
 - Poor memory search - Poor set-shifting / maintenance
- ◆ Temporal Lobe
 - Memory impairment - Mood lability
 - Psychosis - Aggression
- ◆ Hypothalamus
 - Sexual behavior - Aggression

The Story of Phineas Gage

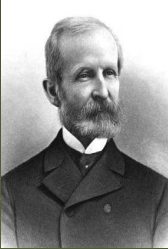
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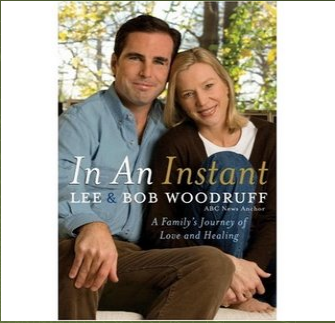




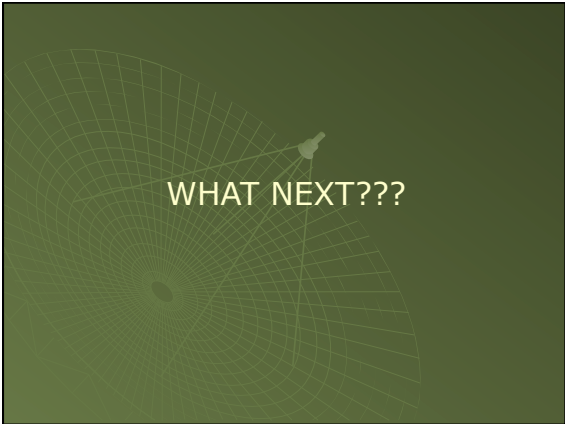
"He is **fitful**, irreverent, indulging at times in the grossest profanity (which was not previously his custom) capricious and vacillating, devising many plans of future operation, which are no sooner arranged than they are abandoned. Previous to his injury, although untrained in the schools, he possessed a well balanced mind, and was looked upon by those who knew him as a shrewd, smart businessman, very energetic and persistent in executing all his plans of operation."



-Dr. John Harlow



Bob Woodruff
"In An Instant"



TBI Continuum of Care

- ◆ Case by Case basis
- ◆ "If you have seen **one** TBI you have seen **one** TBI"
 - Acute Medical Care
 - Acute Rehabilitation
 - Post-Acute Rehabilitation
 - Out-patient Therapies
 - Community Re-integration
 - [Transition Stages]



Recovery

- ◆ Most gains seen in first 6 months
- ◆ However, research now demonstrates that spontaneous recovery can continue to occur for years post-injury onset
- ◆ Rate of recovery is dependent on pre-morbid ability, age, PTA, and magnitude of neurological damage

TBI Impact on Family

- ◆ Emotional distress
 - Not much time to react to the abrupt change
- ◆ Disrupt roles, communication, affection/warmth
- ◆ Social isolation
- ◆ Seek mental health
- ◆ Increased substance abuse
- ◆ Financial/Employment problems

TBI Impact on Family

- Patient loss of independence
- Re-definition of "roles"
- Parents, spouses, siblings, children
 - ◆ Impacted differently
- Who is the "caregiver"?
- What is the new impression of the injured family member?
- What is the new impression of the change in family dynamics?

Family Needs Immediately After TBI

- ◆ Most important need was to receive medical information
- ◆ Also rated high were needs for information on physical, cognitive, and emotional changes, and need for information presented in clear, honest manner

Kreutzer & colleagues, 1994, 1995, 1996

Life Changes

- ◆ Life changes are not simply attributable to the severity or type of a loved one's brain injury - we know families differ in their ...
 - personal and social resources
 - perceived degree of distress imposed by an injury
 - past medical and psychiatric histories
 - ability to cope with the changes they may encounter in everyday life.

Caregiver/Family Burden

- ◆ Families provide MOST support/care
 - Often w/o professional support and intervention
 - Negative impact on family dynamics
 - Anxiety, depression, shock, disbelief, denial, frustration, etc.

Caregiver Considerations

- ◆ Family Background
 - Age, race, SES, income, family dynamics
- ◆ Type of Care
 - Level of care (min/max)
 - Cognitive, Physical, Behavioral
 - Skill level, education, patterns of living, interaction style with patient
 - Medication management, management of challenging behaviors

Role Changes



◆ "Extended parenthood"

- Parents may attempt to "mend" pre-morbid issues (e.g., substance abuse)
- Most likely impact relations with other offspring
- Long-term issues re: independence
- Ongoing negotiations as child with TBI matures and recovers

Role Changes



◆ Spouses

- Injured person may not be the same person (e.g., intimacy, parenting)
- Single-parent status (more significant role changes)
- Decrease in financial & parenting support
- Loss of sexual intimacy
- Reduced empathetic communication
- Little opportunity to mourn and reflect on changes

Role Changes

◆ Children (offspring & siblings)

- May become primary caregiver
- Child becomes "parent" to parent
- May lead to anger, embarrassment, developmental delays, psychological distress, etc.
- Poorly treated, neglected
- Factors leading to poor outcome:
 - Gender of parent; poor parenting; depression in non-injured parent



Caregiver Distress/Burden Research

- ◆ Distress & Burden – varied definitions
 - Depends on the appraisal of the event **AND** one's use of coping strategies
 - May be difficult to operationally define
- ◆ Sampling
 - Ss will differ based on cause, type, severity, and outcome of injury
 - Ex: Stroke versus TBI
- ◆ Objective vs. Subjective Research

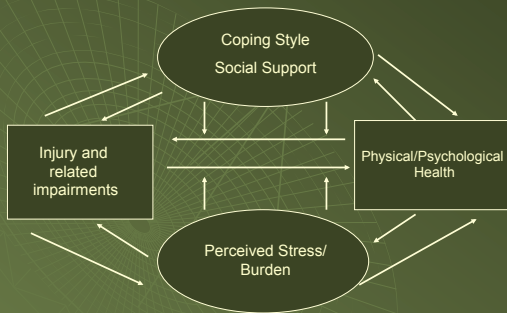
Caregiver Distress/Burden

- ◆ Brain injury rehabilitation programs routinely develop post-discharge plans for the patient and the designated caregiver
- ◆ The needs of the caregiver may not be entirely addressed (time constraints?)
- ◆ While several brain injury rehabilitation programs will incorporate some aspect of family training or counseling there are no coordinated "programs of care" for family caregivers of persons with brain injury upon community re-entry

Caregiver Distress/Burden

- ◆ This lack of caregiver assistance exists in spite of the research that suggests that caregivers are a great risk in developing severe problems with depression and ill health over the initial year of care-giving
- ◆ The bulk of the evidence to date for caregiver interventions is limited to scenarios that involve relatively time-limited and age-related conditions (e.g., neurodegenerative disorders)
- ◆ Most concerning is the fact that several individuals with brain injuries may not have any access to brain injury rehabilitation services. As a consequence some caregivers may receive little or no education, support, or counseling

Model of Family Adaptation to TBI



Caregiver Distress/Burden

- ◆ Research Areas of Focus
 - Predictors of Stress & Burden
 - Impact of Stress & Burden on differing family members

Caregiver Distress/Burden

- ◆ Injury severity does not consistently predict caregiver distress & burden
- ◆ Factors that are most predictive include: caregiver age, caregiver gender, pre-injury caregiver psychopathology, financial burden, type of coping styles used, social support, and problem solving style

Caregiver Distress/Burden

- ◆ Panting & Merry (1972)
 - One of the first studies to address TBI's impact on the family system
 - Increased stress
 - Increased use of sleeping medications
 - Increased negative impact on spouses compared to parents

Caregiver Distress/Burden

- ◆ Perlesz et al. (1999) – review
 - Longitudinal data (mixed findings)
 - Subjective burden increases from 3 months to 5 years
 - Marital functioning deteriorates after 12 months
 - Levels of anxiety and depression are sustained over first year and may decrease somewhat in the long-term
 - Family friction intensifies in first year but stabilizes by year 2
 - Sense of mastery and self-efficacy may improve after year 1
 - *****Not typical of ALL families*****

Predictors of Subjective & Objective Caregiver Burden 1 year post injury

- ◆ *Amount of social contact
- ◆ *Amount of behavioral problems
- ◆ *Physical changes
- ◆ Most burdensome
 - Anger, dependency, apathy
 - Objective complaints – “less time to myself”**, anxiety, change in sleep patterns, lack of privacy

Marsh et al., 1998

Caregiver Distress/Burden

- ◆ Davis et al (2009) - **predictors**
 - Premorbid medical and psychiatric illness in caregivers (predominantly female) – **distress**
 - Caregivers who received treatment for psychiatric illness and/or used an escape-avoidance coping strategy – **distress**
 - Greatest in caregivers with (a) brain-injured loved one presenting with poor functional status, (b) diminished perceived social support, and (c) use of an escape-avoidance coping strategy – **perceived burden**

Caregiver Distress/Burden

- ◆ Rivera et al. (2007)
 - Caregivers (predominantly female) with increased self-report of physical symptoms **and** a negative problem solving style were at **greater risk** for experiencing symptoms of **depression** independent of their time spent as a caregiver, caregiver age, and level of perceived burden
 - Caregivers who were “at-risk” for depression reported a **negative problem solving approach**
 - Those who exhibited a more positive problem solving approach were **NOT** significantly less “at risk” for having symptoms related to depression
 - ◆ “the absence of negative tendencies was much more important [in reducing risk of depression] than the presence of positive skills.”

Caregiver Distress/Burden

- ◆ Problem Solving Strategies
 - Negative versus Positive
 - Ineffective strategies → greater risk for depression regardless of time they spent with care recipient
 - Poor caregiver physical/mental health also a factor
 - Absence of ineffective (negative) strategies → lower risk for depression

Problem Solving Training (PST)

- ◆ 5 Basic Principles
 - Identify the problem
 - Brainstorm Solutions
 - Critique the Solutions
 - Choose and Implement a Solution
 - Evaluate Outcome
- ◆ Constructive Problem Solving



PST Goals

- ◆ Discuss value of having a positive orientation for solving problems
 - Optimistic attitude; Positive emotions
- ◆ Find meaning in their "new" or "different" role
 - Acknowledging that caregiving is a challenge
- ◆ Review any progress on the problems, goals, and planned activities identified from previous session; discuss feelings

- ◆ Neuroticism, Problem-Solving Abilities, and Family Caregiver Quality of Life
 - 12 females; 1 male caregivers
 - Ages 28-74 (M = 50 yrs); 62% Caucasian; 70% mothers; 50% work full-time
 - Cross-sectional; correlation field study
 - **SF-12** Health and Well-Being (Mental & Physical) - QoL
 - **NPO** Negative Problem Orientation Scale – from the Social Problem Solving Inventory (SPSI)
 - **BFQ** Big Five Questionnaire (trait Neuroticism)
 - **-.71** correlation (mental health vs. NPO) – $p < .05$
 - **.45** correlation (physical health vs. NPO) – $p < .05$

- ◆ Partial correlations with BFQ (trait neuroticism) reduced these correlations to **-.32** and **.23** respectively (not significant)
- ◆ Conclusions – trait Neuroticism (BFQ) may mediate the observed relationships between caregiver problem-solving ability (NPO) and quality of life (SF-12). Also, NPO appears to account for a huge amount of variability in health-related quality of life.
- ◆ Presence of trait Neuroticism may be a factor (“red flag”) in planning services for family caregivers

- ### Components of a Family Intervention Program
- ◆ Where will the research bring us?
 - General education re: TBI and consequences
 - Direct training in management of physical, cognitive, and emotional impairments
 - CBT/PST training – stress reduction
 - Discussion of relationship changes and strategies to improve communication/interactions
 - Training in stress management techniques
 - Education regarding local and national community resources, including support groups

Thank You!



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