A Family Affair: Effects of Brain Injury on Family Dynamics

Dr. Kyle Haggerty, PhD
Bancroft NeuroRehab
The Centers for Disease Control and Prevention reported that in 2010 that approximately 2.5 million ER visits, hospitalizations, and deaths were solely related to TBI’s or in combination with other injuries.

5.3 million individuals in the US are currently living with long-term disabilities due to Traumatic Brain Injuries.
Continued

- Twice as many males are affected by TBI as females
- Ages 15–24 and >60 are at the highest risk
- Individuals in rural areas are more at risk
Costs of traumatic brain injury in the U.S. have been estimated to be $48.3 billion annually.
- Survivors cost $31.7 billion
- Fatalities cost $16.6 billion

Lifetime cost per person is about $4 million.
- About 75% of patients with severe TBI do not return to work.
- About 66% require assistance with daily living.
- 90% report dissatisfaction with social integration.
Common Symptoms

- Pain
- Memory Deficits
- Word Finding Difficulty
- Fatigue
- Changes in Emotion
- Changes in Sleep
- Impulsiveness
- Attention/Concentration
- Etc.
Chronic Pain

- Headaches
- Spinal Cord Injuries
- Ineffectiveness of Pain Medication
Emotions

- Emotions can become flat or amplified
  - Neurological rage
  - Lack of Inhibition
  - Trouble analyzing social situations
    - Difficulty with facial expression or tone of voice
Language/Word Finding

- Aphasia
  - Circumlocution
  - Hand Gestures
  - Tip of the tongue

- Common due to anatomy of skull
Prevalence rates for psychiatric disorders are high after TBI:
- Depression rates have been reported in 14 to 77% of patients
- Substance abuse 5 to 28%
- PTSD 3 to 27%
- Other anxiety disorders 3 to 28%
Executive Functioning

- Executive functions are the skills people require to adapt to novel situations and pursue their life goals. Executive functioning encompasses a range of skills including: planning, initiation, and regulation.

- Executive dysfunction has been repeatedly seen and documented in acquired brain injury, and is reported as one of the more common difficulties facing this population.
Executive dysfunction has been implicated with poor social outcomes following an acquired brain injury.

Research in rehabilitation populations has found that poor executive functioning is strongly correlated with poor work adjustment.
Caregivers Stats

- About 75% of caregivers are women.
  - Spouses and Mothers most common caregivers for TBI Pts

- Two-thirds of caregivers in the United States have jobs in addition to caring for another person.

- Most caregivers are middle-aged: 35–64 years old.
Effects on Caregivers

- Dramatic Role Change
  - Vocation
  - Leisure
  - Relationships
  - Daily Routines

- Clinically significant levels of distress, including anxiety, depression, and poor social adjustment, have been observed in more than 30% to 50% of adults caring for individuals with TBI 1 year after injury.
Caregiver Mental Illness

- Studies have shown that between 35% and 49% of primary caregivers display a level of psychological distress high enough to warrant clinical intervention

  - Wives in particular, are at the greatest risk of distress and low family satisfaction
Differences Between Wives and Mothers

- Research consistently finds that wife caregivers experience more distress than mothers.
  - Numerous wives described their husbands with TBI as being more like children than an equal partner
  - Wives are more likely to assume more responsibility posttrauma than were other family members
  - Wives may have lost a peer-based, supportive, reciprocal partnership.
Social Stressors

- Permitted to Mourn?
  - Many spouses report feeling as if they lost their partner, but mourning is not appropriate.

- Spouses of persons with brain injuries also have difficulty divorcing with dignity or in good conscience, and marriages are often maintained through bonds of guilt and fear of disapproval.
What Influences Distress?

- Personality change in the Pt
  - Consistent finding is that family members generally are more disturbed by personality changes than by physical changes associated with TBI
  - Behavioral problems among individuals with TBI had the most severe and pervasive impact on all aspects of caregiver functioning, with the most distressing behaviors related to emotional control, such as sudden and rapid mood changes, aggression, and argumentativeness.
Social support of the caregiver

- Amount of perceived social support is inversely related to caregiver distress, regardless of level of enacted support.
- Many studies have found that the perceived adequacy of social support functions is the most significant predictor of family functioning
- Unfortunately TBIs are associated with social isolation in the Pt and caregiver.
Not Associated with Caregiver Distress

- Severity of injury
  - Many studies have failed to find a relationship between injury severity and caregiver psychological distress
  - No consistent pattern of association between specific cognitive impairments and caregiver distress has emerged
Other Interesting Correlations

- Caregiver distress has not been consistently related to time since injury.
  - Several studies have actually found that caregivers distress increases as time since injury increases.
- There have also been inconsistent findings of the effects of substance abuse.
  - This might be partially related to the prevalence of substance abuse pre-morbidly.
Cultural Differences in TBI

- Infrequently Studied

- Several cultural differences have been identified in Pts who have suffered a TBI.
  - Minority group members are more likely to have been injured by violence
  - Minority Pts were shown by research to more than twice as likely to show unstable employment patterns during the first 4 years after TBI than white participants.
  - Minority Pts were more likely to suffer from pre-morbid substance abuse.
In studies where white and African American persons with TBI were recruited from the same urban area, the aforementioned differences were no longer found.

However, the groups still differed on social integration outcomes, with African Americans reporting fewer contacts with friends and fewer recreational pursuits.
Caregiver Cultural Differences

- Compared to whites, African American caregivers express stronger cultural reasons for providing care.

- African American siblings have been shown to take more caregiving responsibility than white siblings, yet report less caregiving burden.

- African Americans have reported better well-being, less anxiety, and less use of psychotropic medications than whites as well as less subjective burden.
Continued

- Most African American caregivers are parents, while white caregivers are half parents and half spouses.

- African American caregivers reported more unmet needs and higher burden than whites.

- African American caregivers reported using prayer and avoidant coping patterns such as “walking away,” while whites were more likely to make use of counseling services.
Other Cultures

- Research has found lifetime TBI prevalence rates of 22% to 26% for males and 8% to 15% in females in two Native American Indian communities, rates that are much higher than those reported for the white population.

- Hispanic American survivors had more unmet basic needs and less on-the-job supports compared to their white counterparts, even though job placement-related services such as on-the-job support predicted higher competitive employment rates in both groups.
Mental Health of Caregivers and Its Relationship With Pt Wellbeing

- Better emotional function in caregivers is associated with greater Occupation and Social Integration for patients entering rehabilitation programs within 6 months of injury.

- Despite the findings about primary caregivers, family function has not been found to significantly affect Pt outcomes.
How Can We Help?

- Family caregivers in intervention groups have shown declines in distress over patient symptoms, lower levels of depressive symptoms, greater levels of self-esteem, and less use of physician services.

- Successful intervention programs provided families with a structured program of education (to address lack of knowledge); communication skills, problem-solving training (to reduce family strain), support groups, crisis intervention, and information referral (to reduce demands on caregivers).
What Helps

- Establishing a therapeutic relationship with families prior to the Pts discharge from acute rehab
- Periodic check ups (studies found that families often need to be prompted to seek services)
- Telephone therapies with families have been found to be effective
Family caregiver social problem-solving abilities have been found to be predictive of adjustment during the initial year of the caregiving role.

Several studies have looked at the D’Zurilla/Nezu model of Social-Problem solving.
Social Problem Solving

- Generally speaking, SPS can be seen as the means people use to adapt and cope with their environment.

- This ability to cope with daily problems plays a significant role in personal and social functioning.

- According to the theory of social problem solving, all life events are possible stressors.
There are multiple factors that determine how stressful a situation is perceived to be, and the patient's ability to appropriately address the situation: the characteristics of the situation itself, the individual’s appraisal of the situation, the individual’s appraisal of his or her own abilities, and the successfulness of attempted solutions.
D’Zurilla, Nezu, and colleagues developed a model of social problem solving consisting of two components: problem orientation and problem-solving style.

- Problem orientation refers to the set cognitive and emotional schemas people have about the problems they may face in their lives, and how they will be able to cope with them.

- Problem-solving style refers to the cognitive and behavioral activities an individual engages in when they are faced with problems in their life.
Problem Orientation

- Generally people are seen as either having a positive problem orientation (PPO) or a negative problem orientation (NPO)
  - Those with a PPO usually view problems as challenges, and are confident in their ability to overcome or face those challenges
  - Individuals with a NPO tend to view problems as threats, and have doubts about their own abilities to solve those problems. This is associated with a strong negative emotional response.
Negative Problem Orientation

- Individuals with a NPO are described as being at risk for having more chronic problems
  - While PPO can lead to increased motivation to attempt new problem solving strategies, NPO is associated with a decrease in motivation and an increase in avoidance
  - Individuals with NPOs therefore might experience a larger number of unresolved problems.
Problem-solving style

- There are three different problem-solving styles commonly seen in people
  - Avoidant style
  - Impulsive style
  - Rational style

- The avoidant and impulsive styles are commonly seen as being maladaptive, while the rational problem-solving style is seen as adaptive
Individuals who use the avoidant style attempt to escape their problems, or look for others to solve the problems for them.

- Procrastination and an overdependence on others are commonly seen as being a part of this style.

The impulsive style is associated with hurried decisions, with the individual often using the first solution that comes to mind without examining other potential solutions to the problem.
The rational problem-solving style entails the systematic use of skills to approach a problem and to carefully and thoughtfully discover a solution:

- Problem Definition
- Problem Analysis
- Generating possible Solutions
- Analyzing the Solutions
- Selecting the best Solution(s)
- Planning the next course of action (Next Steps)
More Problem Solving

- The relationship between problem-solving ability and psychological well-being is one that has been frequently studied.

- Many studies found a significant relationship between problem-solving ability and various forms of psychological well-being.
  - Specifically, the effectiveness of one’s problem-solving ability has been found to moderate the relationship between stress and distress.
Depression

- Individuals with problem-solving deficits (defined as having a NPO or a maladaptive problem-solving style) are more likely to suffer from depression

- Across different age samples problem solving deficits were significantly related to depression and anxiety
How Might Problem Solving effect Caregivers?

- Through the ability of patients to solve the problem’s they are faced with.
- Through the relationship between problem solving and mental illness
Studies Looking at Problem Solving and Caregivers

- NPO was predictive of the variability in the rates of change in caregiver psychological and physical adjustment during the inaugural year of caregiving.

- Caregivers with a higher negative orientation were more likely to experience more distress during the year at a greater rate than caregivers with a lower negative orientation.
Studies have also found that problem-orientation is predictive of distress experienced by mothers of children with disabilities.

Caregiver problem-orientation has also been found to predict acceptance of disability scores and risk of medical complications within care recipients with spinal cord injuries.