A WHOLE NEW LIFE

Supporting Families Coping with Brain Injury
Traumatic Brain Injury

- Incidence:
  - 1.7 million TBI’s annually in the United States
  - 282,000 of those are hospitalized
  - 43% of those with a related disability after 1 year

CDC, 2017
Rates of TBI-related Emergency Department Visits, Hospitalizations, and Deaths by Sex — United States, 2001–2010

Rate of TBI per 100,000 US population

- Total (Men)
- Total (Women)
• Typical causes:

  • **Falls** are the leading cause for all ages

  • **Assault**, young adults up to 64, next most common

  • **Motor vehicle accidents**, third leading cause
Traumatic Brain Injury

• Typical age (s) of moderate to severe injury:
  • 15-19 years old
  • 65 and older

CDC, 2017
Family stage

• Influences family adjustment to injury
  • Parents tend to remain involved
  • Spouses leave around 45% of the time

• Experience with caregiving role?

• Expectation of caregiving role with aging?
Today’s discussion

• The experience of the family
• Helpful practices for the family
• Helpful interventions from medical professionals

“If you’ve seen one brain injury, you’ve seen one brain injury.”

Injury is uniquely expressed, with some commonalities.
BARRIERS TO HELPING
Hope… Double Edged Sword

• Hope provides necessary energy

• Hope rallies support of others

• Hope may frame discussion of lasting deficits as “giving up”
Our credibility problem.....

- Initial call: Unlikely to survive............................but he does!
- ICU: Unlikely to wake up.................................but he does!
- Acute care: Unlikely to eat, walk, etc. ............but.....

Not surprising that families are skeptical of our information
Consistency in our message to families, helpful over time
Family Expectations…..

Emergency

Hospitalization

Rehabilitation

Pre-injury Status!
Change in Family Expectations

- Long Journey

- Complicated by the ever-growing need to be a good advocate for loved ones in a health care environment

- Complicated by the lay person’s concept of brain injury recovery

- Complicated by the “system” that comprises the family
Advocacy

• Family fear that health system “isn’t trying”
  
  • Acknowledgement and reframing of the fear
  
  • Reassurance

• Exposure to other families of brain injury survivors who are farther in the journey

• Reliability and consistency of the health care providers
Media Accounts of Recovery

• Military focus on TBI has been helpful for some

• Visibility of former Congresswoman Gabby Giffords helpful

• Generally unknown:
  • Timeline
  • Lasting effect of the injury
Family Systems Theory 101

- One person’s change is the family’s change - interdependence

- Change in one person followed by reciprocal changes somewhere in the system

- System will STRIVE to return to prior state

- Failure to accomplish the return to “old normal” happens before “new normal” develops
Family Systems Theory and Adaptation

• We can facilitate, but we can’t impose.

• We can see that early understanding would be helpful – but we can’t “make” that happen.
  • Challenge for young clinicians

• For most families, there is a sequence that occurs as they move toward their “new world”.
PHASES OF FAMILY REACTION

Muriel Lezak
Prior relationships and issues

• Influence family response

• Has survivor “spent” family resilience prior to injury?
  • Character disorder
  • Addiction

• May change the timeline of responses

• Sometimes, families hope TBI will improve situation.
One to three months: Happy and Relieved

- Expecting full recovery
  - Regardless of education provided

- Thankful for survival of loved one

- Understanding of symptoms as part of recovery

- Happy to self-sacrifice for loved one
One to nine months: Anxious / Bewildered

- Dawning awareness that changes are not resolving

- Often blame self for “poor caretaking”
  - “If I was better at this....

- May blame others for “poor care provision”
  - If you healthcare people were better at this...”
One to nine months: Anxious / Bewildered

- Begin to feel frustrated and angry
  - May be directed at survivor, more often at the provider

- **May** begin to be able to see loved one’s behavior more objectively (versus taking personally)
Helplessness

- Expectation of full recovery is in contrast to experience

- Begin to recognize how the survivor has changed
Helplessness

• Strategies successful in the past – not successful

• Efforts not working
  • Academic Explanation
  • Emotional Appeals
  • Repetition of Concerns

• May begin to be able to acknowledge the changes are due to non-resolving aspects of the brain injury
Depression

- Lezak: “A time of misery without plans”

- New reality is observed/ acknowledged
Depression

- **Pivot from “all will be recovered” to “what now?”**
  - Health care professionals sometimes perceive as “denial has ended”
  - Perhaps more accurately is simply a learning curve and normal shift of perspective with experience

- Perseveration on “Why?”
Mourning

• Loss of the person once known

• Loss of hope that the prior person will return

• Saying good-bye to the prior person, while remaining involved with the survivor
Reorganization

- “Adam 2.0”
- New roles for each family member
- Highly emotional involvement of early stages diminishes
- New normal emerges
CHALLENGES
Ambiguous Loss

• “I miss you!”...............“But I’m right here!”
  • Survivor both changed and the same
    • Appearance
    • Verbal mannerisms
    • Areas of passion or conflict

• End point unclear
  • Family roles
  • Future plans
Unsupported Mourning

• Grieving may be negatively viewed by others
  • Lack of gratitude for survival of loved one

• No standard way of acknowledging ambiguous loss
  • Loss of what was (aging, dementia)
  • Loss of what might have been (miscarriage)

• Intimate losses not visible to those outside the situation
  • Nature of relationship
  • Daily routine
  • Life plan
  • Financial status
Distressing Symptoms

- Behavioral, personality changes are more distressing to family than physical or intellectual changes.

- **Limbic system** operating without “filters” distressing

- **Frontal lobe dysfunction** produces the symptoms that families rate as the most distressing.
Limbic System

- Generates emotion
- Responses usually modulated by frontal lobes
- Unfiltered emotional responses can be frightening
Frontal Lobe Functions

- Established later in developmental timeline
- Important for planning, problem solving, social interaction
Specific Frontal Lobe Skills

Navigating the impersonal world…..

- Attention (sustained)
- Planning/ problem solving
  - Prioritizing
  - Generating options
  - Weighing options
- Abstraction
Specific Frontal Lobe Skills

Navigating the interpersonal world…

• Self awareness
  • How coming across
  • Elapsed time

• Use of non-verbal cues

• Filtering impulses, emotions, reactions
• Discussion of frontal lobe symptoms in a manner respectful to the survivor can be challenging

• Isolating for family members to be unable to express their experiences

• If not identified and expressed, not possible to begin to address
• Discussion of the injury is a SKILL that can be acquired

• Talk about the injury as separate from the person
  • “The injury is getting in the way of your…(sensitivity/ flexibility, etc.)

• Support for the survivor and for the family members, to create the resilience necessary to do that hard work
  • Peer mentors
  • Social skills groups
  • Support groups
  • Education materials
  • Individual/ couples/ family psychotherapy
• Acknowledgement that we ALL have experience with temporary frontal lobe dysfunction sometimes helpful

• Frontal lobe function can be overwhelmed by fatigue or emotion, as well as injury

  • My experience: Family member illness
  • High emotional arousal overwhelms frontal function
That looks like:

- Every conversation is about that topic (co-workers)
- Emotion overriding decision making skills (plane ticket)
- Less able to access and weigh alternatives (dinner)
- Filter for emotions not strong (teary in normally neutral situations)
- Usual prioritizing not working → overwhelm (cranky)
Symptoms of Frontal Lobe Dysfunction

• **Self focus**: Every conversation is about that topic

• **Decreased self control**: Emotion overriding frontal lobe

• **Decreased flexibility**: Less able to access and weigh alternatives

• **Lability**: Filter for emotions not strong

• **Irritability**: Usual prioritizing not working → overwhelm
  Matches up with…………..
Symptoms Most Distressing for Families

- Self-centeredness
- Decreased self-awareness
- Decreased self-control
- Behavioral rigidity
- Lability
- Irritability
- Apathy
Aspects Most Distressing for Families

• Invariable nature of the symptoms

• Improvement – with coaching and practice - may occur with very specific issues

  • Unlikely to generalize to related issues
Unsought role changes

• Gravitate to “comfort zones” in family roles, pre-injury

• Injury demands role changes – less comfortable arenas
  • Wage earner
  • Disciplinarian
  • Organizer
  • Financial planner
New social presence

• Others may not be informed about brain injury

• Fatigue/overstimulation may reveal symptoms at awkward times

• Non-injured family members may assume ‘social navigation” role: tiring, lonely

• “Always know where the exits are!” – Survivor’s family member
HOW DO WE HELP?

Starting soon after injury
Permission

• Articulate permission for the family to grieve

• Permission to be angry

• Permission to feel afraid
Normalize Family’s Feelings

- Discuss/ share how others in their situation have felt

- Predict those feelings

- If available, connect with experienced families
Normalize/ Depersonalize Symptoms

- We’re all “wired that way”

- Responses are the result of an injured brain, not a result of the caregiver’s action/ inaction/ value

- Other families have also found that…..

- May be hard to believe that…..
Urge and support focus on own needs

• Predict that this will be challenging

• Predict that others may not understand

• Articulate the importance of caregiver health (mental and physical) to the survivor’s quality of life

• Remind that, pre-injury, survivor would have wanted this
Social Contact and Activity

• Essential for caregiver

- Social support is the best predictor of post-injury family functioning
  - Independent of assistance with caregiving
Importance of Social Support (Ergh, 2002)

In absence of adequate social support:

- Caregiver distress increases with increased time post-injury
- Caregiver distress greater if cognitive dysfunction of survivor greater
- Caregiver distress greater if self-awareness of survivor is less

With adequate social support:

- Above factors are not associated with caregiver distress
Importance of social activity  (Godwin, 2014)

Regular activity NOT related to brain injury or caregiving

• Scheduled social time, “rain or shine”

• Associate with long term stability of mood for caregiver
Importance of Respite Options (Kreutzer, 2015)

Sense of “punctuation” in caregiving is useful

- Length of respite less important

- Challenging for families to accept “less” than they would provide

- Once the associated renewal experienced, caregiver more likely to utilize respite again

- How?
  - Private pay caregiver, friend and family, private pay residential
Encourage a daily routine for survivor

- Good for survivor’s self sufficiency
- Allows minimal disruption when respite occurs
- Facilitates assistance with care needs
  - Rides
  - Supervision
Model positive reframing (Kreutzer, 2010)

- Reframing:
  - She’s being a jerk...............her brain won’t allow her to see what I need

- This happens every time ........sometimes this goes better

- I’m a terrible caregiver............I’m doing a very difficult job, and I keep rising to the occasion
Deliberately join / validate experience

- Acknowledge the change and loss
- Acknowledge the uniqueness of the family’s loss
- Listen/ validate caregiver distress
Direct families to venues to build skills

• Brain injury management specific skills
  • Annual brain injury association conferences
  • Support groups
  • Online resources

• Coping skills – via counseling or classes
  • Communication
  • Stress management
  • Managing intense emotion
A WHOLE NEW WORLD
Successful adaptation

- Articulation of change
  - Adam 2.0
  - “The New Us”

- Humor
  - Before “the head”

- A broader definition of “family”
  - Paid caregivers included

- New roles and relationships within the family
  - Striving for the “old” has ceased
The ZEN of beginning again....

- Letting go of the old
- Forming the new
Human beings are resilient and brave. Brain injury survivors and their families show us that every day.

References
