Life After Traumatic Brain Injury: Putting the Pieces Back Together

Presented by Mary Tibbets, LMSW
Stormont-Vail Health Care
Stormont-Vail HealthCare

- Serving multi-county region in North Eastern Kansas
- 586 bed acute care facility
- Primary Care and Specialty providers in system
- Employs more than 200 physicians
- 4,000 Employees
- On-site School of Nursing
- Magnet Redesignation in 2014

- Level II Trauma Center
- Level III NICU
- 2014 VHA Excellence Award for Clinical Care
- Chest Pain Center of Excellence from Society of Cardiovascular Patient Care
- Joint Commission Center of Excellence for Stroke
- Joint Commission Center of Excellence for Knee and Hip
- Blue Distinction Center for Cardiac Care
- Joined Mayo Clinic Care Network in 2014
Trauma
Learning Objectives

- Review causes of TBI
- Review TBI Statistics
- Define Traumatic Brain Injury (TBI)
- Examine the TBI recovery process
- Identify TBI Community Services
- Discuss the importance of community collaboration to TBI service delivery
Causes of TBI according to the CDC (Centers for Disease Control and Prevention)

- Falls (35.2%);
- Motor vehicle – traffic (17.3%);
- Struck by/against events (16.5%);
- Assaults (10%).

\(^1\)
Figure 1: Percentage of Annual TBI-Related Deaths, Hospitalizations and Emergency Department Visits by External Cause, KS 2012

Deaths
- 7% Suicide
- 41% UNT Motor Vehicle
- 25% UNT falls
- 19% Homicide
- 8% Other
- 3% Struck By/Against

Emergency Department Visits
- 20% Suicide
- 11% UNT Motor Vehicle
- 14% UNT falls
- 8% Homicide
- 8% Other
- 47% Struck By/Against

Hospitalizations
- 3% Suicide
- 13% UNT Motor Vehicle
- 47% UNT falls
- 29% Homicide
- 7% Other
- 7% Struck By/Against
Stormont-Vail TBI Statistics 2014

Total = 289

- Falls: 133
- MVC: 59
- MCC: 27
- Unspecified/Other: 16
- Assault: 15
- Bicycle: 9
- GSW: 6
- ATV/Off Road Vehicle: 5
- Pedestrian: 5
- Sports: 5
- Animal: 5
- Farm/Heavy Equipment: 2
- Watercraft: 1
- Railway Injury: 1

FALLS: 46%
MVC: 20%
MCC: 9%

Other Interesting Statistics 2014

• 14% of patients with TBI were intoxicated when injured
• 20% of MVC were intoxicated
• 33% of assaulted patients were intoxicated
Other Interesting Statistics 2014

- 8% of TBI patients were 15 and under
- 56% of TBI patients were 16-64
  - 28% were uninsured
  - 3% patients needed charity rehab placement
  - 28% needed placement or died
  - 67% went home (resources??)
- 36% were over the age of 65
  - 79% of these were due to falls
  - 58% needed placement or died
Discharge Planning with TBI Patients and Their Families

- Acknowledge their shock/trauma
- Attend to their basic needs
- Assess the severity of the brain injury
- **Educate** and explore options with the patient’s family
- Apply for disability, Medicaid and HCBS waivers as appropriate
- Arrange discharge to a facility or home
- Arrange follow up outpatient therapy/clinics
Mild Traumatic Brain Injury

- The result of the forceful motion/impact of the head
  - causing a brief change in mental status (confusion, disorientation or loss of memory)
  - or loss of consciousness less than 30 minutes.
- Most prevalent TBI
- Often missed at time of initial injury
- 15% of people with mild TBI have symptoms that last one year or more.
- Post injury symptoms are often referred to as post concussive syndrome.
Mild TBI/Post-Concussive Symptoms

- Difficulty thinking (cloudy)
- Difficulty concentrating
- Feeling slow
- Difficulty remembering (new information)
- Balance Difficulty
- Headache
- Blurry Vision

- Nausea/Dizzy
- Light/noise issues
- Tired/Sleep issues
- Irritable
- Sad
- Emotional
- Nervous/Anxious
Mild TBI/Post-Concussive Symptoms

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Role of the Healthcare Provider
Education and Early Intervention

• Positive expectations for recovery
• Why specific symptoms are present
• How to adjust behavior accordingly
• Specific guidelines for ADL’s including **return to activity**
• Closely monitor symptoms and refer for further assessment as needed
Simple Concussion Recovery

- Progressive recovery over 7-10 days
- Most recover in 5-7 days
- Mental status testing helpful/balance testing

Recovery Recommendations

- Physical Rest
- Mental/Cognitive Rest
- **Total rest**
- For a few days and ease back into activities
- Avoid alcohol/drug use
- Avoid further concussion
Severe TBI

Meet Cavin
Fell 20ft from a rooftop hitting the front of his head on the way down and the back of his head on the concrete. Cavin was in a coma for 12 days.
Diffuse Axonal Injury
Day 12: Waking up
Rehab is hard work
4 months learning to talk, walk, eat, and live again.
Cavin has made an incredible recovery.
Severe TBI Recovery Process

Rancho Scale
Level I
Level II
Level III

Coma/Sleeping

Rancho Scale
Level IV
Level V
Level VI
Level VII

Waking up
Agitation/Confusion

Rancho Scale
Level VIII
Level IX
Level X

Higher functioning

Severe TBI Recovery Process
Apply for SSDI/SSI
Apply for Medicaid
ADRC TBI FAI Screen
PMDT Reviews

Moderate to Severe TBI
No insurance
Assess level of function
Refer to Rehab
Charity Status
DC home with outpatient rehab

Has insurance
Assess level of function
Connect with community services
TBI Waiver
Voc Rehab

Refer to rehab of choice
DC home with outpatient rehab
Connect with Community services
TBI Waiver
Private Providers
Voc Rehab

Home with KanCare & HCBS TBI Waiver Services

Refer to
Rehab of
choice
DC home
with outpatient rehab

Connect with
Community services
TBI Waiver
Private Providers
Voc Rehab

Apply for SSDI/SSI
Apply for Medicaid
ADRC TBI FAI Screen
PMDT Reviews
Levels of Care

• Long-term acute care (LTAC)
  • Patient is on a ventilator and has tube feedings

• Acute rehabilitation hospital
  • Patient is off the vent and can participate in 3 hours of therapy daily
    PT/OT/ST
Levels of Care

- Post-acute rehabilitation
  - Patient has graduated acute rehab stage but needs more cognitive rehabilitation
- Skilled nursing facility
  - Patient either is not waking up or not progressing (the gray area)
Facilities in our Area for TBI

- **Madonna Rehabilitation Hospital**
  - Specialty Pediatric Unit
  - Has a LTAC unit and CARF accreditation
  - Mild TBI Outpatient Clinic

- **Children’s Mercy (Peds Rehab)**
  - Mild TBI Outpatient Clinic

- **Meadowbrook Rehabilitation Hospital**
  - Only state recognized TBI Waiver program and CARF accreditation

CARF (commission on accreditation of rehabilitation facilities)
Facilities in our Area for TBI

• Kansas Rehabilitation Hospital
  • inpatient for teens and up
  • outpatient for infants and up

• St. Francis Inpatient Rehab
  • must be 18 for inpatient
  • outpatient for children and up
From Facility to Home
Kansas HCBS Waivers

• Traumatic Brain Injury (TBI) Waiver
  • Ages 16 - 65

• Technology Assisted (TA) Waiver
  • Ages 0 - 21
TBI Waiver Services

1. Personal Services
   - Assistance with ADL’s and IADL’s

2. Assistive Services
   - Adaptive equipment, home modification, assistive technology

3. Transitional Living Services
   - Training in ADL’s and IADL’s

4. Rehabilitation Therapies
   - Behavioral, cognitive, physical, occupational, and speech therapies
Other Possible Resources

- Vocational Rehabilitation Services
- Work with the school to make modifications:
  - 504 Plan
  - Individualized Education Plan (through school district) (ages 3-21)
- Individualized Family Service Plan (ages 0-3)
Problems…

System Breakdown!!
Solution: Community Collaboration

In October 2011 the Traumatic Brain Injury Community Work Group was created with the following objectives:

1) Identify the needs of the individual with a TBI;

2) Identify various agencies/systems involved in accessing these resources;
Solution: Community Collaboration

3) Identify the barriers to accessing these vital resources, particularly for the uninsured.

4) Examine system processes that take place at each service provider; and

5) Partner together to streamline access to these resources.
Solution: Community Collaboration

- Stormont-Vail Trauma Social Worker/Case Manager
- Stormont-Vail Patient Financial Advocate
- Hospital Assistance Program (HAP)
- Department of Children and Family Services (DCF)
- TBI Community Service Providers
- Presumptive Medical Determination Team (PMDT)
- Kansas Department on Aging and Disability Services (KDADS)
- Aging and Disability Resource Centers (ADRC)
- TBI LTAC and Rehab Facilities (KRH, Madonna, Meadowbrook)
- Skilled Facilities (North Pointe)
Celebrating and Persevering

• Result of collaboration and process improvement efforts:
  • Reduced length of stay for uninsured;
    • 2008 – 2 charities AVG LOS 39 days
    • 2009 – 4 charities AVG LOS 24 days
    • 2012 – 9 charities AVG LOS 20 days
    • 2013 – 7 charities AVG LOS 10 days!!
    • 2014 – 5 charities AVG LOS 18 days
  • Often secured TBI Waiver and Medicaid eligibility within 30 days of application or less.

➢ All new system change in 2013, we are learning all over again!
Questions?
References

3. Stormont-Vail HealthCare Trauma Services Data Analysis
5. Madonna Rehabilitation Hospital. Traumatic Brain Injury Family Information Booklet (2nd ed.). Lincoln, NE.
<table>
<thead>
<tr>
<th>Rancho Level</th>
<th>Suggestions for Caregivers</th>
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<tbody>
<tr>
<td><strong>Level I</strong> - No Response</td>
<td><strong>Level I, II, III:</strong></td>
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<tr>
<td>- no response to sounds, sights, touch or movement.</td>
<td>- Keep the room calm and quiet.</td>
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<td><strong>Level II</strong> - Generalized Response</td>
<td>- Low stimulation-limit visitors.</td>
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<td>- begin to respond to sounds, sights, touch or movement;</td>
<td>- He may understand parts of what you are saying. Be mindful of what you say in front of the individual.</td>
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<td>- respond slowly, inconsistently, or after a delay;</td>
<td>- Talk in soothing tones, about normal things, have familiar people visit, bring familiar items.</td>
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<td>- responds in the same way to what he hears, sees or feels.</td>
<td>- Explain to the individual what you are about to do. For example, &quot;I'm going to move your leg.&quot;</td>
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<td><strong>Level III</strong> - Localized Response</td>
<td>- Orient the person time, place, date</td>
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<td>- Awake more and reacts more to what is happening around him or her.</td>
<td>- Try to get them to look at you.</td>
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<td>- May turn toward sounds such as a door closing or to look at objects. May look at the TV as if they are watching it.</td>
<td>- Keep comments and questions short and simple. One-step directions.</td>
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<td>- May begin to recognize familiar faces.</td>
<td>- Provide stimulation when awake-5 to 15 minutes-stop if they look tired.</td>
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<td>- Engage him in familiar activities.</td>
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<td><strong>Level IV Confused, Agitated:</strong></td>
<td><strong>Level IV Reducing Agitation:</strong></td>
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<td>• Very confused and frightened;</td>
<td>• Tell the person where he is and reassure him that he is safe.</td>
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<td>• Overreact to what he sees, hears, or feels by hitting, screaming, using abusive language, or thrashing about.</td>
<td>• Provide a calm, soothing, predictable, structured environment, avoid surprises. Turn TV, radio off. Limit visitors.</td>
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<td>• May need restrained;</td>
<td>• Offer simple choices.</td>
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<td>• Highly focused on basic needs; eating, relieving pain, going back to bed, going to the bathroom, or going home;</td>
<td>• Help them succeed with simple tasks they can do.</td>
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<td>• May not understand that people are trying to help him;</td>
<td>• Do not ignore them when agitated, human contact with reassuring people is calming.</td>
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<td>• Can’t concentrate, or only for a few seconds;</td>
<td>• Allow him as much movement as is safe.</td>
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<td>• Difficulty following directions;</td>
<td>• Take him for rides in his wheelchair,</td>
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<td>• Recognize family/friends some of the time;</td>
<td>• Try familiar activities that are calming: listening to music, eating, etc.</td>
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<td>• With help, try simple activities: feeding, dressing or talking.</td>
<td>• Do not force him to do things. Instead, follow his lead, within safety limits.</td>
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<td>• Give breaks and change activities frequently.</td>
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Level V Confused, Inappropriate, Not Agitated:
- More alert and beginning to follow simple directions.
- Step-by-step instructions helpful
- Unfamiliar or difficult situations or activities may trigger restless behavior or outbursts, but this happens less frequently.
- May forget what they were just doing.
- Unsure of date, where he is or why he is in the hospital;
- Very poor memory, remember past events before the accident better than his daily routine or information he has been told since the injury;
- May try to fill in gaps in memory by making things up (confabulation).
- May get stuck on an idea or activity (perseveration).

Rancho Level

Level V:
- Repeat things as needed. Don't assume that he will remember what you tell him.
- Tell him the day, date, name and location of the hospital, and why he is in the hospital when you first arrive and before you leave.
- Keep comments and questions short and simple.
- Help him organize and get started on an activity.
- Bring in family pictures and personal items from home.
- Limit the number of visitors to 2-3 at a time.
- Give him frequent rest periods when he has problems paying attention.

Suggestions for Caregivers
Rancho Level

Level VI Confused, Appropriate:
- Confusion because of memory and thinking problems,
- Follows a schedule with some assistance, but becomes confused by changes in the routine;
- Knows the month and year, unless there is a severe memory problem;
- Pays attention for about 30 minutes,
- Trouble concentrating when it is noisy or when the activity involves many steps.
- Brush teeth, get dressed, feed self etc., with help;
- Aware of need to use the bathroom;
- Impulsive;
- Knows they have an injury, but will not understand all of the problems their having;
- Associate problems with hospital and thinks they will be fine at home.

Suggestions for Caregivers

Level VI:
- Conversations more normal, but concrete, specific, and 1-2 step ideas or directions.
- Typical to show periods of near-normal abilities and digress into agitation later.
- May show signs of insight into deficits and the grief that comes with it.
- Emotional support more important.
- Begin slow process of social reintegration.
- Lots of praise and encouragement.
- Keep life routine, organized, predictable.
- Frequent rest periods needed.
- Use memory log. Repeat things.
- Ask them to tell you the steps to complete ADL’s, IADL’s, directions to places. Assist as needed.
- Stress need for ongoing therapy.
### Rancho Level

**Level VII Automatic, Appropriate:**
- Appears appropriate and normal on the surface.
- Goes through daily routine automatically, but may have little recollection of what has been happening day to day or week to week.
- Improving self-awareness and environment.
- Lack of insight and judgment for safety.
- Cannot plan realistically for the future.
- May continue to fatigue easily.
- May be unable to keep up with work.
- Judgment and concentration skills remain too poor to safely drive a car.

### Suggestions for Caregivers

**Level VII Community Reintegration:**
- Increase abilities to care for self.
- Stress need for ongoing therapy.
- Use a memory log.
- Discuss possible dangerous situations and have them explain how to handle them.
- Practice using telephone directory and reading a map.
- Take the person to gift shop or cafeteria and find items and estimate what they cost.
- Once home have them assist with ADL’s and IADL’s for practice and rehabilitation.
Level VIII: Purposeful-Appropriate, Standby Assistance:
- Oriented to person, place, time, space, personal information and their situation.
- Attention skills are improving.
- Able to complete familiar activities in a distracting environment for short periods of time.
- Uses memory device with help.
- May still require supervision for some familiar executive tasks.
- Depression, irritability, and frustration common as person becomes aware of the changes from the injury.
- Needs help to recognize and correct socially inappropriate behaviors.

Suggestions for Caregivers
Level VIII:
- Encourage family/patient involvement with a counselor and/or support group.
- Organize the day, provide structure and a variety of activities.
- Encourage use of memory device.
- Have the person become involved in regular activities within their capabilities.
- Encourage use of posting a calendar and remind the person of planned appointments, events, and important dates.
- Provide education to school about the effects of the TBI.
### Rancho Level

**Level IX Purposeful-Appropriate, Standby Assistance at Request:**
- Able to shift attention back and forth between activities without help.
- Uses memory device independently.
- Assistance with problem solving.
- Occasional help for socially acceptable behavior.
- Depression, irritability and low tolerance for frustration.

### Suggestions for Caregivers

**Level IX:**
- Encourage family/patient involvement with a counselor and/or support group.
- Organize the day, provide structure and a variety of activities.
- Encourage use of memory device.
- Have the person become involved in regular activities within their capabilities.
- Encourage use of posting a calendar and remind the person of planned appointments, events, and important dates.
- Encourage person to take breaks to help reduce fatigue and frustration.
Level X Modified Independence:
• Completes activities from before injury independently with extra time and compensatory techniques.
• Requires periodic breaks for fatigue.
• Anticipates and independently solves problems.
• Recognizes the needs and feelings of others and responds in a normal way.
• May still have periods of depression and frustration especially when tired, under stress, or sick.

Suggestions for Caregivers

Level X:
• Encourage family/patient involvement with a counselor and/or support group.
• Organize the day, provide structure and a variety of activities.
• Encourage use of memory device.
• Have the person become involved in regular activities within their capabilities.
• Encourage use of posting a calendar and remind the person of planned appointments, events, and important dates.
• Provide education to school about the effects of the TBI.

Rancho Level
TA Waiver Services

• Financial Management Services
  • Required service when self-directed attendant care service is chosen

• Health Maintenance Monitoring
  • Licensed Practical Nurse (LPN)
  • Registered Nurse (RN)

• Intermittent Intensive Medical Care Service
  • Licensed Practical Nurse (LPN)
  • Registered Nurse (RN)

• Specialized Medical Care
  • Licensed Practical Nurse (LPN)
  • Registered Nurse (RN)
TA Waiver Services

- Long-term Community Care Attendant
  - Agency-directed attendant - Medical Service Technician (MST)
  - Self-directed attendant - Personal Service Attendant (PSA)
- Medical Respite Care
  - Licensed Practical Nurse (LPN)
  - Registered Nurse (RN)
- Home Modification Services
  - Licensed contractor, for compliance with city/county ordinance
  - Durable Medical Equipment Provider (DME)
Other Interesting Statistics 2014

- 56% of TBI patients were 16-64
  - 17% or 26 were uninsured
  - 32% or 50 needed placement or died
  - 7 patients needed charity placement
  - 66% or 104 patients went home (resources??)

- 36% were over the age of 65
  - 79% of these were due to falls
  - 58% needed further care or died