Living with the Invisible

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Objectives

* Provide a (non-TBI specialist) healthcare professional perspective surrounding post-TBI education and care
* Share the story of a TBI survivor
* Identify ways to support TBI survivors whose symptoms are not easily discernible
Disclaimers

* I have no financial relationships to disclose
* I will not discuss any off-label drug use
* I *do* have a dog and a love of pictures/ClipArt/Google images! 😊
Friday, October 9th, 2015 –
The Day I Became a TBI Statistic

- T-boned in back half of driver side while driving through an intersection
- Car spun at least 270 degrees
- Head impact against door frame and rebound against headrest
- Felt brain sloshing between ears
- Saw stars but did not lose consciousness
- Able to walk away
- Shock/Adrenaline apparent, but otherwise “looked fine” according to witnesses
Summary

- Symptoms: HA, neck & back pain, decreased visual field, dizziness, photosensitivity, phonosensitivity, tinnitus, shoulder & hip pain, left elbow & left knee pain
- Imaging: x-ray (elbow) & CT (head)
- Dx: contusion of left elbow & closed head injury (“not concussion”)
- Despite symptoms and diagnoses, told “you look fine”

Discharge instructions

- “Take it easy” over the weekend
- No restrictions with returning to work on Monday
- If HA worsens or persists, contact primary MD or go to ED
Following week...

- All original symptoms ongoing
- Difficulty concentrating
- Difficulty word-finding
- Occasional slurred speech
- Fatigue
- Difficulty sleeping
- OTC analgesics ineffective
- ... “but you look fine”
Follow-up

* PA – no assessment, just asked “What do you want me to do?”, cut down to “1/2 time” at work
* PMR MD referral – general neuro assessment, acknowledged symptoms, gave the option of decreasing to 4 hrs/day at work or taking time off
* Otherwise, “you look fine”
The First Year (10/2015-10/2016)

- Referrals/Evals
  - [General] PMR MD
  - Psychologist
  - PT (dizziness)
  - Headache specialist (2-3 mo. after PMR MD signed off)
  - Psychiatrist
  - Ophthalmologist
  - Neuropsychologist
- “Symptoms will go away in [2 weeks, 4 weeks, 3 months, 6 months...]”
- “but you look fine”
 Persistent symptoms:
- Chronic, constant headaches (OTC analgesics ineffective)
- Neck & back pain
- Chronic, constant tinnitus
- Fatigue
- Dizziness
- Photosensitivity
- Phonosensitivity
- Difficulty concentrating
- Word-finding difficulty
- ...

2016: “Why am I not getting better?”
“But you look fine”

- Able to work... but symptoms increase as the day progresses
  - Difficulty predicting productivity
  - Concentration affected by headaches, tinnitus, fatigue, and sensory sensitivities and overload
  - Need for “time outs,” but no time and limited places to take them (bathrooms, elevators)
- Exhaustion
  - Affected stress tolerance
  - Problems keeping up
  - Unable to drive home at times
  - Nothing left once at home, evenings/weekends spent recuperating
October 2016

- 2nd LOA
- Referral to neurologist who referred to TBI clinic
- Finally accepted mental health sequelae from TBI
TBI clinic

- PMR TBI specialist
- SLP – energy management
- Developmental optometrist
- OT – vision therapy
- Vestibular testing
- PT – balance
- Phototherapy
- Neuropsychology reassessment after 5-6 mo. of therapies
- Social work

Hope emerges
### 2017 – Answers and Ongoing Questions

<table>
<thead>
<tr>
<th>Answers</th>
<th>Ongoing Questions</th>
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<tbody>
<tr>
<td>• Visual processing, convergence, and accommodation issues</td>
<td>• What is temporary?</td>
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<tr>
<td>• Peripheral vision affected</td>
<td>• What is permanent?</td>
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<td>• Higher-level thinking/tasks – still capable, but takes its toll</td>
<td>• Why do I have “bad days” when I’ve done everything I can to try and prevent them?</td>
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<td>• Physical activity affected by balance, dizziness, stamina</td>
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Things I’ve Learned about Myself

- I’m fortunate to have a primary MD who excels in managing complex cases
- I’m not crazy or alone
- TBI affected more things than I had realized
- Topamax and Depakote aren’t for everybody 😞
- Acceptance ≠ giving up or losing hope
- Self-advocacy (saying “no,” “I can’t,” “I need/need to not do [x] in order to do [y]”) isn’t a sign of weakness or selfishness, but a sign of strength
Things I’ve Learned that Other Healthcare Professionals Should Consider

* Just because a TBI survivor *looks* fine, it doesn’t mean he/she *is* fine
* Need to develop a pathway (follow-up &/or referrals) for survivors who were never hospitalized &/or seen in the ED
* Embrace what you don’t/can’t know
* Recognize and support the grieving process
* Appointments and/or “interventions”
* CAM/Integrative therapies
Living with the Invisible

* Just because a TBI survivor looks fine, doesn’t mean he/she is fine


    * Mild TBIs (mTBIs) make up about 80% of cases
      * Doesn’t include underreported or undetected cases
    * “Mild” is an often misleading description, as cognitive changes, headaches, dizziness, & other “invisible,” subjective symptoms can significantly impact daily functioning/activities
Slipping through the Cracks/Delayed Care

- Need to develop a pathway (follow-up &/or referrals) for survivors who were never hospitalized &/or seen in the ED
  - Referral to TBI specialty clinic sooner?
  - Not all PMR/neurology specialists are well-versed in TBI cares or include access to TBI-specialized multidisciplinary teams
  - Clear need for systematically developed clinical practice guidelines (CPGs) to help manage pts w/ persistent symptoms post mTBI (Marshall, Bayley, McCullagh, Velikonja, & Berrigan; 2012)
    - High quality CPGs have been developed (on national and international levels), but knowledge gaps exist (Tavender, et al.; 2011)
Stepping into the Unknown

* Embrace what you don’t/can’t know
  * Exactly which areas of the brain are/have been affected by TBI
  * CT and/or MRI results typically negative with mild TBIs (mTBIs) (Wintermark, et al., 2014)
    * Do not predict accurately which patients remain symptomatic for weeks or months after trauma
* When a survivor will “get better”
  * Avoid/be careful about giving specific “due” dates
  * Post-concussion syndrome (PCS) (U.S. Dept. of VA, 2017)
    * Approx. 20% of people do not recover within “usual” 3-6 months
    * Can result in providers not recognizing symptoms as TBI
  * Adaptation vs. cure
Recognize and support the grieving process

- Not everyone will accept diagnosis and sequelae (including limitations) right away
  - Denial is a powerful thing (beware underreporting of symptoms)
  - Lack of awareness, agitation, aggression, disinhibition, apathy, etc. may adversely affect treatment success (Institute of Medicine of the National Academics Press (IOMNAP), 2011, pp. 62-63)

- Depression common during the first year (U.S. Dept. of VA, 2017)
  - Post-TBI depression rate almost 8x higher than those without a TBI (53.1% vs. 6.7%) (IOMNAP, 2011, pp. 62-63)
  - Will sometimes manifest as anger – “I’m not depressed! I’m frustrated!”

- Psychology referral – the sooner, the better
- Connect with [appropriate] support groups
Working as a Team

- Appointments and/or “interventions”
  - Encourage having “tough discussions” early in the morning
  - Suggest having an appointment buddy/note taker
- Functional support from family and/or friends important
  - Transportation, housework, etc.
  - Social isolation can occur due to TBI symptom-related limitations

- Returning to work
  - Supportive environment key to success
  - Functional adaptations, compensations, ability to complete tasks at own pace
  - Difficult due to “multi-faceted” nature of deficits (e.g. memory, information processing speed, executive functions) (Spitz, Ponsford, Rudzki, & Maller; 2012)
  - “…returning to a job requiring multitasking may have difficulty succeeding despite” pre-TBI abilities (Bootes & Chapparo, 2010)
Exploring All Options

CAM/Integrative therapies

- Acknowledge that some survivors may turn to/prefer these to Rxs or other “traditional routes”
- Most commonly used CAM therapies by most common subgroups (Purohit, Wells, Zafonte, Davis, & Phillips; 2013)
  - Mind-body therapies: deep breathing exercises, meditation, yoga
  - Manipulation therapies: chiropractic care, massage therapies
  - Alternative medical systems: homeopathy, acupuncture

- “Studies suggest that the use of CAM is greater when conventional treatments are unsatisfactory or ineffective” (Purohit, et al.; 2013)
- 70% of adults w/ ≥ 1 neuropsychiatric symptom did not discuss their mind-body therapy use with a conventional provider (Purohit, Wells, Zafonte, Davis, Yeh, & Phillips; 2013)
- Multiple preliminary studies assessing the efficacy of specific CAM therapies have been performed, but more needed due to small, non-generalizable samples and/or limited control groups
Brain injuries are not like muscle/bone/joint injuries, BUT

Like wounds, TBI healing
- Requires the right environment
- Has a timeline that isn’t always predictable
- Occasionally involves setbacks
- Getting back on track when experiencing recalcitrance involves assessing and treating the cause (e.g. bioburden)
- May involve “scarring” or other characteristics that do not go away
- Naturopathic options exist, but important to be informed (both pt and providers)
“The Road Goes Ever On and On…”
Thank You!

* To my family and friends for your constant love and support!
* To my superstar multidisciplinary team!
Questions?
References

References, cont’d


