Disability and identity: Lost pieces in a post-concussion syndrome diagnosis

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Non-Disclosure statement

I have no relevant financial or non-financial relationships to disclose.
Learning Objectives

• Identify major elements of biopsychosocial etiologies/maintenance factors of post-concussion syndrome (PCS)

• Explore perceptions of illness, disability, and bias in PCS experience and Tx

• Describe integrated, coordinated PCS Tx recommendations

Traumatic Brain Injury

• Disruption of brain function resulting from physical force

• Severity: mild, mod, severe based on
  • Duration of LOC
  • Duration of posttraumatic amnesia
  • Glasgow Coma Scale score at time of hospital admission
    • 3-15

(Silver, McAllister, & Arciniegos, 2009)
Mild TBI/Concussion

• Mild injury (GCS: 13-15) may lead to:
  • LOC/AOC (only 10% experience LOC)
  • Posttraumatic amnesia ≤24 hrs: retrograde or anterograde
  • Focal neurological deficit

• 75-90% of TBI/year are mild (of 1.5 million) but likely more unreported

• Pt. sent home with little info, some don’t know they had BI

• MRI, CT rarely show evidence of injury
  • Best practice to only CT pts. at risk of intracranial injury

(Bergman et al., 2013; Haydel, 2012; Silver, McAllister, & Arciniegos, 2009)

Mild TBI/Concussion

• Neurometabolic changes cascade after impact
  • Excitatory NT released
  • Swelling, stretching of white matter
  • Disruption of cellular membranes
  • Repairs require increased glucose, but cerebral blood flow/02 reduced
  • Microglia activated, producing neurotoxins during cleanup
  • Acidity raises, fluid accumulates, axonal disconnection
  • These normalize in minutes to 4 wks

(King, 2003; Wright, 2014; Domínguez & Raparla, 2014)
**Mild TBI/Concussion**

Deficits common in acute phase

- Impaired attention, memory, concentration
- Slowed processing speed
- Executive dysfunctions
- Balance issues
- Headache and dizziness
- Irritability
- Sx up to 3 mos., usually resolved in minutes to weeks

(Fear et al., 2008; Snell et al., 2011; Sorg et al., 2014)

**Usually Spontaneous Symptom Resolution**

- 5-15% show Sx > 3 mos., may not ever fully recover
- Predictors of prolonged Sx include
  - Skull fracture
  - Increased serum 100B levels
  - Dizziness, headache immediately after injury, not LOC
  - Pre-injury psych issues/mental illness
  - Lower neurocog scores, lowered testing effort
  - Over-activity/return to work-school-play in acute period
  - Seeking litigation/compensation
  - Being female (there is Hx of illnesses being “hysterical” or psychogenic)

(Belanger et al., 2005; Bergman et al., 2013; Korn, 2014; Lipson, 2004; Marshall et al., 2012; Wright, 2014)
Post-Concussion Syndrome

- Cognitive
  - Executive dysfunction
  - Attention deficit
  - Difficulty with concentration, memory

- Somatic
  - Dizziness
  - Headache
  - Insomnia
  - Pain

- Psychological/Behavioral
  - Emotional dysregulation
  - Depression/anxiety

What’s the big deal?

“The only reason they’re making a big deal about concussions right now is because the league is getting sued over it….Before this, you never heard about it….Let’s not make something out of nothing. Yeah, people are getting messed up. That happens. Most of the time it’s because they’re not wearing mouth pieces and they’re probably doing some other stuff.”

---Maurice Jones-Drew

- The big deal is the NFL is a ticket out of poverty, worth the risk.
  - 39% of African-American children under 18 live in poverty

(U.S. Census, 2012; Brown, 2012; Smith, 2013)
Post-Concussion Syndrome Dx Dilemma

• mTBI is acute ABI. Beyond that, little agreement in literature and practice

• Media confound reality of mTBI as brain injury with potential sequelae
  • “Dexter”: 2 rollover crashes, 1 concussion
  • Peyton Manning tanks baseline testing, Brian Urlacher fakes foot injury
  • Jane McGonigal (TED), Tom Shadyac (“I Am”) endorse suicidality as normal

• The question has been debated since at least the 1860s:
  Is chronic PCS organic, psychogenic, or malingered?

(Bigler, 2013; Macleod, 2010; Farnall & Smith, 1999; Silver, McAllister, & Arciniegos, 2009)

Post-Concussion Syndrome Dx Dilemma

• No standardized test to Dx mTBI
• Underlying mechanism(s) for Sx unclear
• When depression/PTSD controlled for, mTBI insignificant as etiology of physical health complaints (military study)
• Pts., general public endorse vague PCS Sx in absence of head injury
• Cellular-level changes, tissue damage don’t show on MRI/CT
• Test scores often normal range on isolated tasks

(Belanger et al., 2005; Fear et al., 2008; Kasahara et al., 2012; MacDonald & Johnson, 2005; McCauley et al., 2005; Snell et al., 2011)
Biopsychosocial model by WHO

- A health condition exists within the context of a person’s life
- Perception of disability or disablement contingent on intersecting factors

Etiology and Maintenance Factors of PCS: Psychogenic Dysfunction

- Pre-injury mental health problems retriggered or exacerbated
- Difficulties coping and adjusting to mild cognitive impairments
- PTSD or trauma from the incident whether mTBI occurred or not
- Undiagnosed, untreated mTBI becomes a stressor, esp. when Dr. tells pt. the injury was insignificant
- Expectation of disability

(References: Belanger et al., 2005; Ferguson et al., 1999; Macleod, 2010; Pavawalla et al., 2013; Silverberg et al., 2013; Wright & Telford, 1996)
Etiology and Maintenance Factors of PCS: Organic Dysfunction

- Post-mortem exam positive for axonal beading, myelin destruction (1968)
- Axonal elongation, stress, and strain
  - Visible on MR diffusion tensor imaging (DTI) but not traditional MRI or CT
- White matter differences corresponding to reduced EF
  - Lower WM integrity in fractional anisotropy & higher radial diffusivity
  - Controlling for PTSD and depressive Sx does not account for reduced EF
- Focal contusions, atrophy, whole brain volume loss
  - Diffusion kurtosis imaging, voxel-based analysis, atlas-based analysis
- Deposition of hemosiderin from microhemorrhages
  - Detectable on susceptibility weighted imaging

(Bigler, 2013; Haydel, 2012; Sorg et al., 2014)

Common Symptoms Checklist

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>PCS</th>
<th>Anxiety/Depression/PTSD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Vegetative</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Emotional</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Somatic</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Nonspecific</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Stigma</td>
<td>✔</td>
<td>✔</td>
</tr>
</tbody>
</table>

- Post-traumatic depression reported in 10-77% of mTBI cases
  - Can exacerbate PCS symptoms (irritability, cognitive dysfunction, sleep)
  - Perception of severity + neg. psychosocial changes exacerbate depression

(King, 2003; Silver, McAllister, & Arciniegas, 2009; Tiersky et al., 2005; Verfaellie, Lafleche, Spiro, & Bousquet, 2014)
“Pass the test but fail at life”

- Cog processes in decontextualized tasks may show no deficit (or deficit but WNL)
- MRI/CT usually unremarkable
- Stereotype threat leads to lower scores if those are found

- High cog load tasks show deficits in those endorsing Sx
- Naturalistic, integrated tests of higher order cog skills show subtle deficits
- Modern research imaging reveals neurobio markers of chronic damage

(Isnis-Pop et al., 2012; Kit, Tuokko, & Mateer, 2008 Sorg et al., 2014; McDonald & Johnson, 2005)

Is it a brain injury or a concussion?

- “Concussion” preferred to “mTBI”
  - Avoid raising expectations of severity and long-term disability
- “mTBI” preferred to “concussion”
  - Includes non-concussive events
  - Validates scientific findings of true acute—maybe chronic—injury

What if this does not have to be a binary?

Does any of the research include perspectives of people with mTBI?

(Hoge et al., 2008; Kovalsky, 2008)
Describing Identity

• Words to describe ourselves reflect how we perceive selves, situations

• Descriptions of pre-injury, post-injury, and future life/self are biased, but that does not invalidate them
  • E.g. “good old days bias”

• Some ppl need the certainty that comes with a Dx label to validate change

• Some ppl do not want to shift personal schema to view selves as changed
  • Accepting trauma, impairments can lead to despair, doesn’t fit sense of self-worth

(Iverson et al., 2010; Stephens, 2011; Snell, 2011; Wright & Telford, 1996)

Irrespective of Etiology

• We construct a mental picture to help us make sense of an experience

• Distress, anxiety draw attention to Sxs, strengthen injury perceptions, search for illness label: often that label is psych

• Stigma against ppl with mental illness & invisible disabilities w/contested medical legitimacy (e.g. MCS) prompts ppl with PCS to deny psych role, claim “real” brain injury
  • For some reason we think psychological = always faking it

• Access to correct info, support crucial in realistic mental picture

(Haydel, 2012; Lipson, 2004)
### ‘Windows of vulnerability’: psychological factors play a greater role in PCS

<table>
<thead>
<tr>
<th>Time after injury</th>
<th>Possible emerging factors</th>
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<tbody>
<tr>
<td>0-24h (immediate Sx)</td>
<td>Mainly organic factors</td>
</tr>
</tbody>
</table>
| 1 day-4 wks (early Sx) | Overdoing, failing tasks  
                        | Increase in life demands  
                        | Misattribution of Sx to missed malignant causes by Drs.  
                        | Difficulties coping w/cog impairments  
                        | Concerns about longevity of Sx/disabilities  
                        | Dissonance re: severity of TBI & severity of Sx/disabilities |
| 1-6 mos (medium-term Sx) | Unhelpful premorbid schemas/coping responses to managing abnormal life events; frustration; coping concerns re: potentially permanent Sx and uncertainty (particularly uncertain etiology of Sx)  
                        | Misperception of having had severe TBI |
| Over 6 mos (long-term/permanent Sx) | Lack of understanding/belief from others  
                        | Compensation-claim factors  
                        | Issues relating to adjustment to long-term disability |

(King, 2003)
Microaggressions are the everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, that communicate hostile, derogatory, or negative messages to target persons based solely upon their marginalized group membership.

(Nigatu, 2013; Sue, 2010)

Disability Microaggressions Create Vulnerability

From Disability.gov on FB on 8/29/14

From The Body Is Not An Apology blog 2/11/14
Disability Microaggressions in Bingo Form

We hear so many annoying and unpleasant things as physically disabled people. Wouldn’t it be nice if we could leap to our feet (or fall out of our chairs) and yell: BINGO! This body of literature is so vast and rich, we decided to divide it into categories for easy referencing:

- General Annointing Ignorance
- Misperception/Condescending
- Accountably Informed Ignorance
- More Annointing Ignorance
- Outright Racial

<table>
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<tr>
<th>General</th>
<th>Misperception/</th>
<th>Accountably</th>
<th>More Annointing</th>
<th>Outright Racial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ignorance</td>
<td>Condescending</td>
<td>Informed</td>
<td>Ignorance</td>
<td>Racial</td>
</tr>
<tr>
<td>You’re too young to have that disease.</td>
<td>Mislabeled condition (e.g., spinal cord injury).</td>
<td>Must be in need.</td>
<td>Must be sick.</td>
<td></td>
</tr>
<tr>
<td>My (disability) isn’t real.</td>
<td>You have a problem.</td>
<td>Must be much</td>
<td>Must be killed.</td>
<td></td>
</tr>
<tr>
<td>I wish I had diabetes.</td>
<td>It’s better.</td>
<td>much better.</td>
<td>Right now.</td>
<td></td>
</tr>
<tr>
<td>I wish you would just accept the disability.</td>
<td>I wish you would be cured.</td>
<td>I wish you would be better.</td>
<td>It’s not my fault.</td>
<td></td>
</tr>
</tbody>
</table>

Illness Perception on Identity: Leventhal’s Common Sense Model

- CSM: Coping, making sense of health condition is cognitive & emotional
  - Identity (illness label & associated Sx)
  - Expected consequences
  - Timeline perceptions
  - Perceptions of controllability
  - Causal attributions

- What about the Illness Perception Questionnaire (adapt IPQ-R for CFS?)
  - Articulate fears related to injury, uncover personal, environmental factors
  - Determine pts.’ beliefs about what is causing their complaints
  - Gauge where education needed, pt. buy-in to recover, and level of hope

- Drs inexperienced in concussion mgmt. can lead to iatrogenic disability

(Craton & Leslie, 2014; Leventhal, Diefenbach, & Leventhal, 1992; Snell et al., 2013)
Consensus Statement on Concussion in Sport

The 4th International Conference on Concussion in Sport, Zurich, November 2012 guidelines

• Symptomatic > 10 days post-injury
  • Multi-disciplinary approach: cog, vestibular, physical, psych as needed
  • Rule out other causes of Sx
  • Graded exercise and return that don’t exacerbate Sx
  • Concussion (negative scan) distinguished from TBI (positive scan)

(Bigler, Diebert, & Filley, 2013; McCrory et al., 2013)

Efficacious Tx for mTBI/PCS

2014 Systematic Review by American Congress of Rehabilitation Medicine
Results of the International Collaboration on Mild Traumatic Brain Injury Prognosis

• 77,914 titles and abstracts for consideration
• 2 studies (RCTs) were accepted based on inclusion and exclusion criteria
• Conclusions
  • Pts. with mTBI should be provided with educational info early
  • Pts. should become active as soon as possible after the injury, w/ mod rest

(Nygren-de Boussard et al., 2014)
Positive Interventions

• Early intervention for prevention of PCS in those w/out intractable PCS

• Supervised rest, Sx management

• Determine how much pt. is bothered by Sx, not just presence or frequency, to determine where to focus Tx (even if Tx is educational)

• Teach more balanced coping and expectations + compensations
  • Approach coping ______ distress when pt. expects they should be better
  • Biopsychosocial Tx for pt., family: CBT + support groups + cog rehab
  • SSRIs beneficial for perception of impairment severity

Positive Interventions

• Holistic Tx (inter- or trans-disciplinary)
  • Regardless of teasing out etiology of cog-communicative Sx (military pop.)
  • Consider personal, environmental factors and individual learning styles

• Attention Process Training

• Mindfulness Training
  • Improve self-efficacy, reduce reactivity to impairments w/ no Sx reduction
  • Locus of control internalized

(Azulay et al., 2013; Bergman et al., 2013; Cornis-Pop et al., 2012; Helmick et al., 2010; Marshall et al., 2012; Macleod, 2010; Moss-Morris et al., 2002; Silver, McAllister, & Arciniega, 2009; Silverberg et al., 2013; Snell, 2011; Tiersky et al., 2005)
Therapeutic Alliance

- Rehabilitation is more than retraining and compensation
  - Positive inter-personal experiences have value, between other pts. or between pt. and clinician

- Compliance with program associated to alliance and motivation
  - Motivating goals and activities foster higher engagement

- Can positively influence outcomes in post-acute TBI care
  - Stronger alliance correlated with fewer rehab drop-outs and increased productivity regardless of function

(Cornis-Pop et al., 2012; Evans et al., 2008; Fraas & Calvert, 2007; Schönberger, Humle, & Teasdale, 2006)
Limitations

- Psychogenic school doesn’t acknowledge imaging studies in papers
- Missing studies describing Dx, Tx of people with multiple mTBI
- Missing social participation level Tx, including mTBI support groups
- Missing peer mentorship opportunities w/ others with mTBI or those with mod/severe to help get that more realistic disability perspective
- Some studies don’t separate PCS+ group from PCS- group
- Some studies endorse PCS Sx to participants, priming them
- Missing role of internalized stigma from public/providers in PCS maintenance

Personal Experiences

- I don’t find anyone like me in any studies, someone with 6+ mild TBIs, 27 years of sub-concussive hits in sports
- In conversations w/ ppl w/ PCS, I hear nearly identical stories from people despite 3 huge differences:
  - Some had Dx of mental illness pre-injury, some did not
  - Some had scores all WNL in neurocog testing, some had multiple areas of below normal scores even 1+ year post-injury
  - Some deeply invested in maintaining identity of someone with severe impairments and representing selves as powerless and disabled, some are deeply invested in returning to as normal as possible, some don’t care
I hit my head.
   My memory went away.
   My speech went away.
   My ability to move freely went away.
   You tell me these things don’t make sense.

I cannot keep my balance.
   The ringing in my ears won’t stop.
   My head is constantly aching.
   I cannot process what you are saying.
   You tell me this must just be depression?

I cannot bare the noise around me.
   The lights stab my eyes.
   Movement around me is making me spin.
   I cannot complete a simple test.
   You tell me it must be PTSD?

I have a brain injury!
   I have an injured brain!
   I fell and landed on my head.
   I have a mild traumatic brain injury.

You tell me I will get better in a month
   You tell me I will get better in three months.
   You tell me I will get better in six months.
   You tell me you know I will completely heal.
   Do you have the powers of G-d to know these things?

Only my heart can heal, but my brain, it will take my lifetime to heal from the injury, and from your damaging words.
References


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Thank you!

Questions?