Contesting Health Policy:
Rethinking Brain Injury Rehabilitation

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Outline

- Why I care about brain injury
- Describe brain injury epidemiology and policy landscape
- Challenge outdated rehabilitation paradigms
  - Develop new outcome measures
  - Explore lived experience with brain injury
- Interactive exercise
- Discussion
- Conclusion
Why I Care
Some Statistics

- 650 brain disorders\(^1\)
- Affect 50 million Americans per year\(^1\)
- Account for more long-term healthcare costs and hospitalizations than all other diseases combined\(^2\)
- Disorder symptoms can be cognitive, emotional, behavioral, and physical
- Problematic: anger, irritability, and impulse control

1 – Boyle 2001
2 – Arlinghaus, Shoaib, and Price 2005
• **50,000** will die annually as a result of TBI
• **80,000** annually experience the onset of long-term disabilities following TBI
• **5,300,000** Americans currently live with a disability as a result of a TBI

Factoid: 40% of TBIs involve alcohol

How many people here know someone who has had a TBI?
Brain Injury Stats in US Society

Individuals aged 15-24 are at highest risk of TBI – falls most affect under 5 and over 80

About 2% of the greater population suffers disability because of their injury - Rehab goals may be compensation or recovery(1)

8.5% of US adults NOT in prison have a history of TBI(1)

About 60-75% of incarcerated adults have had TBI(1)

In the New York State substance abuse program, about ½ of patients have a record of TBI(1)

Implications

Individuals aged 15-24 are at highest risk of TBI

Misdiagnosis and attribution of behavioral issues to personality and personal failings

About 2% of the greater population suffers disability because of their injury – Rehab goals may be compensation or recovery(1)

Slower brain processing speed and memory challenges – need more repetition and reinforcement of learning or treatment

Temporary plateaus do not always mean permanent ones!  

Implications

In prisons about 60% of adults have had at least one TBI(1)

In the New York State substance abuse program, about ½ of patients have a record of TBI(1)

Train staff in criminal justice system and prisons to better handle individuals with TBI – especially juvenile offenders

Provide screening and treatment in prisons

Work with outside services to provide needed support after release


Texas – Wayne Gordon
COSTS OF BRAIN INJURY

ANNUAL COST: $76.3 Billion in 2010 (1)

Medical Care: $11.5 Billion
Indirect: $64.8 Billion (includes lost productivity)

Medical costs are highest for BI fatalities: an average of $454,717 per fatality

The lifetime costs for one person surviving a severe TBI can reach $4 million or more

Costs for survivors receiving medical and long-term care services are 10x higher than for survivors receiving NO rehabilitation services: $196,460 compared to $17,893

1 – Finklestein et al. 2006
2 – Coronado et al. 2012
Traumatic Brain Injury Legislation – Federal Examples

TBI Act of 1996
Reduce incidence of TBI
Improve psychological treatment
Support state-level tracking of incidence/prevalence

Expansion in 2000:
Education about prevention for parents
Determine methodology for measuring incidence and prevalence of mild TBI in the US

2008 Reauthorization
Study TBI prevalence among institutionalized populations (prisons and nursing homes)

*These do not address rehabilitation*
Traumatic Brain Injury Legislation – “Lifetime” Brain Injury

- Massachusetts Acquired Brain Injury Waiver Program - 2010
- Spurred by a lawsuit
- Intended to move 300 people from nursing homes to community living over three years
- Was implemented by UMASS Medical School – Long-term Care group
- New lawsuit (MFP) transitioning 1,200 people to community living over next 5 years

These do not address rehabilitation
Other Legislation/Policy Examples

**DoD** – mandatory baseline and post-deployment screenings
Improve psychological treatment
Reduce long-term disability

**Education/Schools (Story of a Mom)**
Baseline cognitive testing for athletes
Individual learning plans

**Professional Sports**
Taking injured players off the field or ice!
Providing better equipment
Lawsuits
Has anyone here had personal, family, or other experience with brain injury? What happened?

Has anyone had experience with any of these policies? If yes – what were the circumstances? Outcomes?
Brain Injury Rehabilitation

What are the goals?
What clinical professions are involved?
What do they do?
Brain Injury Rehabilitation

Is intended to help people to

• return to optimal effectiveness in daily living\(^1\)
• reach and maintain their optimal functional levels\(^2\)

Goals may be compensation or recovery

Involves three phases: acute, subacute, and chronic\(^3\) care

Access limited to 1-3 years post-injury – many receive little to no cognitive rehabilitation\(^4\)

Implications of ACA are uncertain to date

1- Burton 2000; 2- Raskin 2011; 3- IOM 2011; 4- Cope, Mayer, Cervelli 2005
Purpose: Examined the effectiveness of four levels of post-hospital care (active neurorehabilitation, neurobehavioral intensive, day treatment, and supported living) and the functional variables most important to their success.

Do people improve?
Post-Hospital Continuum of Care

- Post-hospital Community Neurorehabilitation Care (NR) since 1970; neurorehabilitation programs following the hospital course within an applied setting for skills use and generalization.

- Neurobehavioral Intense (NBI) – significant behavioral intensity programs; focus is on behavioral stability targeting irritability, impaired awareness, social contact, problem solving, goal-directed initiation.

- Day Treatment (DT) – extension from residential neurorehabilitation; live at home or in the community and focus on skills use.

- Supported Living (SL) – designed for those who require a longer level of care that is more gradual; focus is on quality and instrumental activities of daily living.
# Post-Hospital BI Continuum of Care

<table>
<thead>
<tr>
<th>Program Type</th>
<th>Sample Size</th>
<th>Mean Age</th>
<th>Gender M/F</th>
<th>Ave. LOS days</th>
<th>Onset</th>
<th>% TBI</th>
</tr>
</thead>
<tbody>
<tr>
<td>NR</td>
<td>808</td>
<td>43.5</td>
<td>76%/34%</td>
<td>129</td>
<td>21.6m</td>
<td>71%</td>
</tr>
<tr>
<td>NBI</td>
<td>122</td>
<td>38</td>
<td>83%/17%</td>
<td>294</td>
<td>80.3m</td>
<td>82%</td>
</tr>
<tr>
<td>DT</td>
<td>146</td>
<td>42</td>
<td>71%/29%</td>
<td>153</td>
<td>35.4m</td>
<td>65%</td>
</tr>
<tr>
<td>SL</td>
<td>86</td>
<td>45.7</td>
<td>80%/20%</td>
<td>348</td>
<td>83.7m</td>
<td>79%</td>
</tr>
</tbody>
</table>
Outcomes MPAI-4 Instrumental ADLs and Community Skills

Program Effectiveness: Reduction in Disability MPAI-4 Participation Scale

People at all levels improved to varying degrees. At chronic stage, maintaining function is key.
Evidence for BI Rehabilitation = Weak

Problems include:

• Small sample sizes
• Lack of standardization of variables and definitions
• Lack of representative samples
• Rehab outcomes as measured by clinical tests do not have real world value from funder (or patient!) perspectives!!

• IF ACCESS TO CARE IS DENIED TO SEVERE BRAIN INJURY SURVIVORS – THEN HOW WILL WE DEVELOP EVIDENCE??
Challenges:

(1) How show value of rehabilitation for individuals AND society?

(2) How reconceptualize rehabilitation to encompass physical fitness?

What would convince you to fund rehabilitation at the chronic stage of brain injury?

What outcomes matter to you? What outcomes should matter to society?
Challenging Outdated Paradigms

- 1998 NIH Consensus Conference
- 2006 BIAA Position Statement
- 2011 ACRM Review

To date: Much research focuses on technologies, providers, and costs related to providing services.

We need evidence of health-related improvements that show transfer to function in daily living.

1- Cicerone et al 2011; 2- Prigatano 2000; 3- NIH 1998; 4- Raskin 2011
Standardizing Outcome Measurement

- 32 outcome instruments on the COMBI website (NIDRR) [http://www.tbims.org/combi/list.html](http://www.tbims.org/combi/list.html)

- 165+ outcome instruments on the NINDS Common Data Elements for TBI website (NIH) (½ for adults) [http://www.commondataelements.ninds.nih.gov/tbi.aspx#tab=Data_Standards](http://www.commondataelements.ninds.nih.gov/tbi.aspx#tab=Data_Standards)
  - Few scales common to both websites
  - COMBI includes focus on family and community

- The NINDS CDE has few outcomes instruments of use to individuals living with chronic brain injury

  *A rehabilitation policy and practice challenge!!*
Standardizing Outcome Measurement

Streamlining TBI outcomes instruments\(^1\) may:

- Generate evidence across small sample sizes
- Reduce the \textbf{17-year (!)} delay from bench to bedside for RCT evidence\(^2\)
- Close the gaps in evidence for interventions across the life span – acute injury, post-acute, and lifetime
- Closing evidence gap for “lifetime” individuals is critical

\(^1\) Carlozzi et al 2011; \(^2\) Duncan 2011
Health-Related QOL Issues for TBI

<table>
<thead>
<tr>
<th>Function Domain</th>
<th>Participant Rating</th>
<th>Clinician Rating</th>
<th>Caregiver Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional</td>
<td>48%</td>
<td>34%</td>
<td>28%</td>
</tr>
<tr>
<td>Social</td>
<td>23%</td>
<td>26%</td>
<td>26%</td>
</tr>
<tr>
<td>Physical</td>
<td>14%</td>
<td>17%</td>
<td>20%</td>
</tr>
<tr>
<td>Cognitive</td>
<td>11%</td>
<td>13%</td>
<td>15%</td>
</tr>
</tbody>
</table>

- Used CBPR approach to identify issues
- BI-targeted item banks are needed – esp. on emotional & social function in community – HOW CONVINCE FUNDERS THAT EMOTIONAL AND SOCIAL MATTER?

1- Carlozzi et al 2011
We’ve seen some statistics

Now: Some Stories

What do individuals with brain injury say about their lived experience with these rehabilitation domains?

• See http://www.brainline.org/multimedia/presentations/photovoice/photovoice.html to view the exhibit in its entirety
Photovoice with adults with brain injury

Participants: 8 members of a brain injury survivor support group supported by BIA-MA; & 2 BI co-facilitators
What is photovoice?
What do photovoice research participants do?
They represent their lives, point of view, and experience using photographs and text -- **photovoice**\(^1,2\)

1- Wang & Burris, 1997; Lorenz, 2010
They represented their lives, point of view, and experience using photographs and text -- **photovoice**\(^1,2\)

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1- Wang & Burris, 1997; Lorenz, 2010
Nine themes, with 4 or more photos each

- Participants developed themes in collaboration with facilitators\textsuperscript{1,2}

- Describe the long-term nature of BI healing

- Acceptance was an important if elusive goal\textsuperscript{1}

- We did extensive outreach

1- Lorenz 2010; 2-Lorenz 2009
Now let’s see what people are trying to say with their photos…
Maybe there will be a good view
It’s a muddy, rutty, hands-and-knees crawl up to the first rung of the ladder that begins to make some semblance of sense—and then you get to begin to really struggle. The climb does not and will not end. There is no final healed bone or mended tear of the skin to get over. Sometimes weekly, and sometimes daily there is a new step to attempt to get to your “new self”. You can’t even ever hope to get back to your “old self”. Oh well! Maybe there will be a good view on this journey that I hadn’t expected........

What personal and policy issues does this illustrate?
(1) Working with a partner or two, look at a photo with the caption covered. What do you think the photo means? Why did someone take it? What do they want to tell you?

(2) Uncover the caption
Was your interpretation of the photo correct? Any surprises?

(3) Brainstorm implications
What (if anything) are the implications for medical practice? For the patient-provider relationship? For policy?
Now let’s look at both positive and negative experiences with the four domains of rehabilitation - emotional, social, physical, and cognitive – from the perspective of adults living with chronic brain injury.
...this picture symbolizes what living with brain injury can be like....On an overcast day...I gazed up at the sky and took this picture through a tube. ...In the minds of many of us there are thoughts that we will never achieve some of the dreams we once held so dear... (Brain Injury X-Posed: The Survivor’s View, 2007)
It's a beautiful day, but we ARE in a graveyard. My life now has great moments of beauty and peace, BUT I am not where I thought I would be. I feel both grateful and cheated by this turn of events.
Social Health

Having Mark in my life helps me to avoid “meltdowns”---episodes lasting hours during which I get severely confused, depressed and irrational…---by constantly and carefully observing my behavior and coaxing me back into reality…. What Mark communicates to me at these times is honest and comforting: “Your brain was damaged in a car accident. It’s not your fault. You are still a good person. And I love you very much.” Living with brain injury without Mark is unthinkable. (Brain Injury X-Posed: The Survivor’s View, 2007)
There is no removal of TBI; it would be fruitless to feel there ever will be complete physical and neurological recovery. As we each traverse our own paths toward the picture or image of the person we’d like to be, why not share our experiences with others? We can attempt to help raise public awareness of TBI as an ever-recurring human condition. We can try to help direct newer victims or their families toward available resources. In the process of sharing we may find reciprocal support for our own personal journeys. (Brain Injury X-Posed: The Survivor’s View, 2007)
Physical Health

This is the front steps of where I’m living. There are three stone steps. It makes it difficult to walk up them. Thank God there’s a handrail. (Brain Injury X-Posed: The Survivor’s View, 2007)
New Identity.

New passion of gardening. First baby step was planting in containers so as to not fall into dirt because of imbalance. My garden has progressed as my new life has. Now I not only can plant in the ground, I dig up grass and now have three perennial gardens. (Brain Injury X-Posed: The Survivor’s View, 2007)
Cognitive Health

To compensate for my poor memory and organizational skills, I need to put labels on everything in my home. Where are my socks? Which of these is my schedule book? On which shelf did I put my Bible?

These labels are necessary 3 years after my accident and probably for many years to come. It is painful to remind myself about all of the brain power which I lost at the time of my car accident.

(Brain Injury X-Posed: The Survivor’s View, 2007)
Cognitive Health

Using crossword and word searchers to reconnect pathways in the brain. (Brain Injury X-Posed: The Survivor’s View, 2007)
Our amazing capacity to save lives in emergency centers and trauma units means that more individuals survive moderate to severe head trauma. Yet our policies for the survivors have not kept pace. For too long, policies have relied on now-outdated scientific and clinical attitudes about brain plasticity. For too long, policies have focused on measuring and limiting, not encouraging rehabilitation potential. For too long, we have focused on - and paid for - saving lives without committing to pay for the consequences…
One Way to Make a Difference
SLI Wellness Center for Brain Injury – est. 2009

• Interdisciplinary group of professionals

Our Mission - To unite adults with brain injury and their communities with wellness benefits for all

8 research studies now – Physical, cognitive, and social fitness

• Research Council partners from academic, practice, policy, advocacy, and veteran domains

ALSO: Internships, volunteers, community-based partnerships for brain wellness, and policy advocacy
Conclusion

We ALL know someone living with brain injury

We CANNOT provide long-term rehabilitation for everyone who needs it, BUT...

We CAN rethink services and service delivery paradigms and challenge service limits.

We CAN generate evidence and partners at the community level – with or without gov’t funding

We CAN take action to foster communities of brain wellness – emotional, social, physical, and cognitive – with potential benefits for all – both inside and outside clinical settings
Conclusion

Figuring out ways to increase the community integration of individuals with chronic brain injury is a social justice imperative.

In the hands of patients and communities, the camera is a tool for justice.

HOWEVER

Justice is only possible if YOU are part of the equation – if YOU are ready to look, listen, and learn.
ON THE FAST TRACK  IN COLOR SUNDAYS

by Bill Holbrook

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http://www.onthefasttrack.com

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GASP! THIS DATA! IT... IT
REPRESENTS REAL PEOPLE!!!

KLUNK

TOMORROW... THE
HIDEOUS TRUTH
A VIDEO – HOT OFF THE PRESS

https://drive.google.com/file/d/0B8t6HW8_xSe0RFBmWV9QZ3A4NXM/view?usp=sharing
Any final thoughts?

• What (if anything) did you learn from this presentation or the reading?
• Did anything surprise you?
• What (if anything) would you like to learn more about?
• What are some policy issues related to brain injury from your perspective?
Thank you!

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