Contesting Health Policy:
Toward a Vision of Community-Based Rehabilitation for Brain Injury

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Outline

Why I care

Describe the brain injury epidemiological and policy landscape

Challenging outdated rehabilitation paradigms
  • Developing new outcome measures
  • Exploring lived experience with brain injury

Discussion

Interactive Exercise

Conclusion
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

40% of TBIs involve alcohol
How many people here know someone who has had a TBI?
Brain Injury Stats in US Society

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

Individuals aged 15-24 are at highest risk of TBI

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

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)

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 Goals may be compensation or recovery(1)

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

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

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

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

- Massachusetts Acquired Brain Injury Waiver Program - 2010
- Spurred by a lawsuit
- Is moving 300 people from nursing homes to community living over three years
- Being implemented by UMASS Medical School – Longterm Care group
- Lawsuit has resumed to ensure transition to community living for 1,200 people over next 5 years

These do not address rehabilitation
Other Legislation/Policy Examples

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

**Education/Schools**
- Baseline cognitive testing for athletes
- Individual learning plans – more recognition but not perfect

**Professional Sports**
- Taking players off the field or ice!
- Providing better equipment
Has anyone here had personal, family, or other experience with any of these policies?

If yes – what were the circumstances? Outcomes?
Brain Injury Rehabilitation
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 uncertain to date

1- Burton 2000; 2- Raskin 2011; 3- IOM 2011; 4- Cope, Mayer, Cervelli 2005
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

Challenge: Show value of rehab for individuals AND 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.

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)
  • Only 7 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 **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

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 domains?

• See http://www.brainline.org/multimedia/presentations/photovoice/photovoice.html to view the exhibit in its entirety
Participatory visual research with individuals with brain injury

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

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

Participants developed themes in collaboration with facilitators¹,²

Describe the long-term nature of BI healing

Acceptance was an important if elusive goal¹

We did extensive outreach

References

¹ Lorenz 2010; ² Lorenz 2009
Now let’s look at both positive and negative experiences with the four rehabilitation domains—emotional, social, physical, and cognitive—from the perspective of adults living with chronic brain injury.
Emotional Health

...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.
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)
Physical Health

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)
Discussion

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 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.
Discussion cont.

Supportive Living Inc Wellness Center for Brain Injury Rehabilitation and Research

• Interdisciplinary group of professionals

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

3 research studies under-way now - Transition to supported community-based, independent living, stroke rehabilitation, and intensive physical exercise

ALSO: Internships, volunteers, community-based partnerships for brain wellness
Now I want to hear from you...
Now I want to hear from you...

• What if anything did you learn from this presentation or the reading?
• Did anything surprise you?
• Is there anything you feel inspired to learn more about?
• What are some policy issues related to brain injury from your perspective?
Now let’s see if you can figure out 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........
Fitting the pieces into my life
What is photo of? Every week there is something in my life that was once obvious and easy to me, that is now confusing and almost unfathomable. How does it fit into my life now? Why is it so hard to understand? I need to stop asking these questions and move on to fitting the pieces into my life without answering all the questions. There is no good answer. It just is as it is—now.
In a glass booth in the middle of the room
Remember what it was like at a party. You are in a room full of people eating, dancing, talking, laughing—just having a good time. Ever since my brain injury, I never felt more alone than when I was in a crowded room full of people. It was as if I was all alone in a glass booth in the middle of the room. People would be all around me talking; however, I couldn’t remember what was being said. The more I tried to remember what was just said, everyone else in the room was now talking about something else. Thus, I was always one or two conversations behind. …I laughed along with everyone so as not to feel out of place. Yet, this made me feel even more alone and out of place.
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**
Thank you!

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