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

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Outline

Describe the brain injury policy landscape

Challenging outdated rehabilitation paradigms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

Discussion
  • Community-based solutions
  • Who is being left out?

Conclusion
Some Statistics

• 650 brain disorders¹
• Affect 50 million Americans per year¹
• Account for more long-term healthcare costs and hospitalizations than all other diseases combined²
• Disorder symptoms can be cognitive, emotional, behavioral, and physical

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

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

\(^1\) Burton 2000; \(^2\) Raskin 2011; \(^3\) IOM 2011; \(^4\) Cope, Mayer, Cervelli 2005
Evidence for Cognitive Rehabilitation = Weak

Problems include:

• Small sample sizes
• Lack of standardization of variables and definitions
• Lack of representative samples

In addition:

• Cognitive rehab as measured by clinical tests does not have real world value from funder (or patient!) perspectives
Challenging Outdated Paradigms

• 1998 NIH Consensus Conference
• 2006 position statement of the BIAA
• 2011 review by members of ACRM’s BI-ISIG¹

To date: Much research focuses on technologies, providers, and costs related to providing services³

Need evidence of health-related improvements that show transfer to function in day-to-day living⁴

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

• 32 separate outcome instruments are housed on COMBI website (funded by CDC)
• Federal interest in streamlining instruments (NIH & NIDRR)¹
• Individuals with BI are participating in challenge (as encouraged by WHO, NIDRR & PCORI, & some clinicians²)
• New instruments: May generate evidence across small sample sizes & reduce the 17-year (!) delay from bench to bedside for RCT evidence³

1- Carlozzi et al 2011; 2- Prigatano 2000; 3- Duncan 2011
## Health-Related QOL Issues for TBI

<table>
<thead>
<tr>
<th>Function Domain</th>
<th>Participant Rating</th>
<th>Clinician Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional</td>
<td>50%</td>
<td>34%</td>
</tr>
<tr>
<td>Social</td>
<td>23%</td>
<td>26%</td>
</tr>
<tr>
<td>Physical</td>
<td>14%</td>
<td>17%</td>
</tr>
<tr>
<td>Cognitive</td>
<td>11%</td>
<td>13%</td>
</tr>
</tbody>
</table>

- Used CBPR approach to review instruments and identify issues
- Domains parallel symptom domains – and echo interest of BCBS
- Current instruments do not capture complexity of HRQOL in TBI
- TBI-targeted item banks are needed – esp. on emotional & social function in community

1- Carlozzi et al 2011
A Closer Look at These Domains- Photovoice with Individuals with Brain Injury

Participants: 8 members of a brain injury survivor support group supported by BIA-MA; & 2 BI co-facilitators
A Photovoice Path

Ask people to represent their lives, point of view and experience using photographs and narratives\(^1,2\)

1- Wang & Burris, 1997; Lorenz 2010
A Photovoice Path

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

Participants developed themes in collaboration with facilitators

Describe long-term nature of BI healing

Acceptance was an important if elusive goal

Extensive outreach accomplished

1- Lorenz 2010; 2-Lorenz 2009
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-Exposed: The Survivor’s View 2007)
Having Mark in my life helps me to avoid “meltdowns”---episodes lasting hours during which I get severely confused, depressed and irrational. I can’t talk coherently, I take off some of my clothes in public, I feel like I want to die, etc.---by constantly and carefully observing my behavior and coaxing me back into reality whenever necessary---often several times a day. 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)
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)
Cognitive Health

Using crossword and word searchers to reconnect pathways in the brain. (Brain Injury X-Posed: The Survivor’s View, 2007)
Discussion

Participatory research findings provide evidence of “real world” lived experience with brain injury and rehabilitation.

Data about lives are grounded in homes and communities, where most rehabilitation work takes place.

For too long, policies have relied on now-outdated scientific and clinical attitudes and evidence that the adult brain has limited potential to heal and compensate after injury.

For too long, policies have focused on attempts to measure and limit rather than encourage rehabilitation potential.
Discussion cont.

I am part of a transdisciplinary group working to close the community-based rehabilitation gap for adults with brain injury in MetroWest Boston

3 small research studies under-way now

Also developing a pilot brain injury patient registry to understand -- do different services help? Do different living situations make a difference? What intersections and synergies exist between function and person-centered HR-QOL?

These data will contribute to greater understanding of BI outcomes over time and inform organizational, state, and federal investments in rehabilitation & supportive living
A Caution

The data and vision presented here is grounded in the experiences of middle-class white populations. Yet rates of TBI are highest in families with lowest SES and minority populations are at greater risk of injury. Up to 87% of individuals in prison may have a history of brain injury, and BI caused by violence may lead to more persistent symptoms and greater levels of disability.

Will findings from our studies have relevance for low SES groups? What could be done to improve BI outcomes for neglected individuals and populations?
Conclusion

It is unlikely that anyone living in the US – including all of us in this room – does not personally know someone living with brain injury.

Our society may never be able to provide long-term rehabilitation over the long-term for every brain-injured individual who needs it.

We can, however, rethink services and service delivery paradigms and challenge rehabilitation service limits.

Perhaps most important, we can take action to foster communities of brain health – emotional, social, physical, and cognitive – with potential benefits for all.
References


References cont


Thank you!

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