TBIoptions
ONLINE RESOURCES TO ENHANCE THE HEALTH AND WELL-BEING OF PEOPLE WHO EXPERIENCE TRAUMATIC BRAIN INJURY

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K-State Research & Extension

• Part of the nationwide land-grant system of universities with a mission of "extending" research to state citizens
• Partners the university and federal, state, and county government with offices in every county
• Extension agents provide educational programming within their local communities

Today’s Objectives
1. Describe the different aspects of TBIoptions (Connecting to Resources & Promoting Knowledge)
2. Identify 2-3 ways the online resources of TBIoptions may apply to your clinical practice
3. Discuss research that supports online public education about TBI

Overview of Presentation
• Background for development of TBIoptions
• TBIoptions: Connecting to Resources – online directory of agencies and organizations (community specific)
• TBIoptions: Promoting Knowledge – online educational program to promote awareness and understanding about TBI
• Discussion and questions

A TBI Results From External Impact
• Bump, blow or jolt to the head – Causes violent head motions that distribute injury throughout the brain
• Penetrating injury – Causes a pathway of destruction

Leading Causes of TBI

Faul, Xu, Wald, & Coronado, 2010
1.7 Million People Sustain a TBI Each Year

- TBI: 1,700,000
- Heart attack: 935,000
- Stroke: 795,000

Faul, Xu, Wald, & Coronado, 2010; Centers for Disease Control and Prevention, 2010

Hospitalization Rate (per 100,000 people)

- California: 72.5
- Kansas: 90.3
- Nebraska: 44.6
- United States: 84.3

Johnson, Thomas, Thomas, & Sarmiento, 2009

TBI Impacts People Across the Lifespan

- Children (0-4 years)
- Adolescents (15-19 years)
- Adults (65 & older)

The overall burden of TBI in the US is underestimated...

- The numbers do not include:
  - Physician visits (est. 430,000)
  - Outpatient settings (est. 89,000)
  - Individuals who do not seek care
  - Military-related injury

Faul, Xu, Wald, & Coronado, 2010

The Military

About 20% of service members returning from deployment self-report probable TBI

Tanielian & Jaycox, 2008

“Trauma to the brain can change the core of a person’s being – their thinking, memory, personality, and behavior”

Chen & D’Esposito, 2010, p. 11
Traumatic Brain Injury

- Many individuals return to their communities with various needs and life-long challenges
- Successful community integration encompasses areas that relate to independent living, work, and social activities

Sander, Clark, & Pappadis, 2010

TBIoptions: Connecting to Resources

- Online directory of agencies and services within local communities to help address needs (primarily for adults with TBI)
- Useful for:
  - Survivors & family members
  - Care providers & health professionals
  - Interested community members

Financial support provided by the Kansas Department of Social and Rehabilitation Services and by grant H28MC06764 from the Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

www.TBIoptions.ksu.edu
TBloptions: Connecting to Resources

- Offers brief description of each resource and contact information
- Organizes community resources into 4 main areas (Community Supports, Financial, Health Related, Treatment & Rehabilitation)
Summary Findings: Extension Agents

- TBI represented new subject matter – 88% of extension agents reported no formal training or prior education about TBI
- Post-experience ratings reflected
  - improved confidence in their knowledge about TBI
  - Improved confidence in locating community resources important for TBI
- Learning more about TBI – Ranked as “top outcome” from participating in project

Connecting to Resources: Considerations for SLPs

- Help you and your patients find a specific resource in local community
- A tool to help build awareness about the types of resources that may be of potential benefit for survivors and families
- Additionally, it provides descriptions of main categories to help others learn about their focus and why related resources are important

Additional Considerations for SLPs

- Contribute to the map - suggest a resource
- Help your area become a TBIoptions community!

To Enhance the Health and Well-being of People who Experience Traumatic Brain Injury...

*It is essential to identify, locate, and provide individuals and families resources to help promote successful community participation*
Equally important...

• Is to acknowledge that a lack of public understanding about the physical, cognitive, behavioral, and psychosocial impacts of an injury may be an obstacle to successful community integration
• The “invisible” aspect of TBI may lead to misperceptions, e.g., attributing undesirable behavior to another reason such as a personality trait

Hue, Deuel-Schram, & Goeken, 2006; McClure, 2011

Survivors say that...

• The attitude of other people is one of the barriers that they encounter that affects them the most
• Community-wide education and awareness is important to help improve acceptance and become integrated members of a community

Whitener, Gerhart, & Cusick, 2004; Sander et al., 2010; Rotondi, Sinkule, Baker, Harris, & Moldoven, 2007

TBIoptions: Promoting Knowledge

• A health education program designed to increase public awareness and understanding of traumatic brain injury (TBI) through two modes of delivery:
  – In-person (classroom)
  – Computer-based (electronic)

Financial support provided by Rural Health and Safety Education Competitive Program of the USDA Cooperative State Research, Education and Extension Service, grant number 2010-46100-21790.

TBIoptions: Promoting Knowledge

• Three main areas of content:
  – Background knowledge about TBI, including impacts (physical, cognitive, emotional, behavioral)
  – Consequences of TBI to all aspects of living to emphasize the importance of individual/community support
  – Use of the online directory (Connecting to Resources)

Features of the Program

• Lecture content presented with multiple learning strategies (e.g., charts, graphs, photos, animations)
• Use of print materials to reinforce key messages
• Carefully constructed video vignettes from survivors of TBI who share first-hand experiences that complement main areas of content

Video Vignettes (of Kansans)

• Designed to complement lecture content (2-4 min. in length)
  – My Story (circumstances surrounding the injury)
  – Impact (comments about cognitive status, physical, emotional well-being, & changes in behavior)
  – Consequences (adjustments to relationships, activities of daily living, and/or work)
  – Community (importance of individual & community supports in each person’s continuing recovery)
...Features (continued)

• Interactive components
  – Choices regarding survivor videos (whose story to follow)

Let’s Meet...

• Mother of two
  Western Kansas

• Volunteer fire fighter
  North eastern Kansas

• Husband, father, service member
  North central Kansas

Whose Story Should We Follow?

• Mother of two
  Western Kansas

• Volunteer fire fighter
  North eastern Kansas

• Husband, father, service member
  North central Kansas

...Features (continued)

• Interactive components
  – Reflective questions that support application of knowledge to real-life scenarios within videos (help evaluate self-learning)

Example Reflective Questions
(to evaluate self-learning)

• Was there an impact that surprised you?

• How do you think impacts have changed or not changed over time?

...Features (continued)

• Two modes of delivery
  – In-person (currently offered as a program through Cooperative Extension in the State of Kansas)
  – Electronic (computer-based learning)
Accessibility Considerations...

Automated, Audio Narration

Navigation Panel

(>Script of Narration is Accessible)

Captioning for all Videos
Research Study

Designed to evaluate the overall program, and to compare the two modes of delivery (classroom & electronic)


To determine if...

• the educational program changed participants’ perceptions about TBI based on:
  – Quantitative results (comparison of pre- and post-program self-ratings of understanding)
  – Qualitative comments about program content
• there were differences in quantitative outcomes in comparing two modes of delivery (classroom & electronic conditions)

Methods

• 44 participants (20-78 years of age) randomly assigned to each condition
  – N=22 classroom
  – N=22 electronic
• Each group experienced the same educational program (primary difference was the use of individual computer & headphones to access automated version for electronic condition)

Methods

• Assessment measures included:
  – Pre and post-program ratings of understanding for 5 primary areas of program content
  – Written responses to 3 open-ended questions about major themes of the program

Self-Ratings of Understanding (N=44)

(1 = Very Low; 5 = Very High)

<table>
<thead>
<tr>
<th>Areas of Understanding</th>
<th>Classroom (N=22)</th>
<th>Electronic (N=22)</th>
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</thead>
<tbody>
<tr>
<td>Definition of TBI &amp; Possible Causes</td>
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<tr>
<td>Physical, Emotional, Cognitive, &amp; Behavioral Impacts of TBI</td>
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<tr>
<td>How TBI affects Relationships, Activities of Daily Living, &amp; Work</td>
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<td>Importance of Individuals/Community in Providing Support</td>
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<td>Use of TBIoptions: Connecting to Resources</td>
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No Differences between Delivery Modes

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<th>Areas of Understanding</th>
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</tr>
</thead>
<tbody>
<tr>
<td>The definition of traumatic brain injury and possible causes of a TBI</td>
<td>2.45 (0.67)</td>
<td>2.27 (0.58)</td>
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<tr>
<td>The physical, emotional, cognitive and behavioral impacts of TBI</td>
<td>2.36 (0.66)</td>
<td>2.41 (0.66)</td>
</tr>
<tr>
<td>How TBI can affect relationships, activities of daily living, and work</td>
<td>2.68 (0.78)</td>
<td>2.55 (0.63)</td>
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<tr>
<td>The importance of individuals /community in supporting survivors and families</td>
<td>2.95 (1.13)</td>
<td>2.77 (1.02)</td>
</tr>
<tr>
<td>The use of TBIoptions: Connecting to Resources website</td>
<td>1.50 (0.60)</td>
<td>1.32 (0.48)</td>
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Qualitative Analysis of Written Comments in Response to:

- Impact of TBI that would be most challenging or frustrating for you?
- Difficult changes or consequences to overcome after a traumatic brain injury?
- Ways you or your community could provide support to a survivor and his or her family?

Most challenging or frustrating impact?

Most Prominent Theme:

**Cognitive** - 39% of participants

“Cognitive, because not being able to think clearly and difficulty in reasoning would be very frustrating.”

“Cognitive – not being able to remember certain things, things I have done for years would make me very frustrated and want to give up everything. Memories are very important to a person and being able to do daily activities.”

Difficult changes or consequences to overcome?

Most Prominent Themes (41% of participants):

Relearning or Readjusting to a New Normal

“Knowing that things may never be the same again or that it may take a very long time to return to a more normal way of doing things like you’d done before.”

Social Consequences

“One’s change in personality, others might view the new you as fake.”

Ways you or your community can provide support?

Most Prominent Themes (39% of participants):

Responsiveness

“...Ask what they need help with. Call once in a while to see if they need or want anything that you can provide.”

Emotional Support

“Take time to treat them like a person, be their friend, listen and be patient.”

Summary Findings

- Written comments provided additional information about areas of content that especially impacted participants
  - Recognition of **Cognitive** & **Social** changes suggest that participants may have gained increased awareness about the “invisible” aspects of TBI
  - Absence of visible injury contributes to misconceptions about recovery and disability

Summary Findings (cont.)

- Participants provided consistently higher ratings of understanding (pre- to post-program experience)
- Results reflected a similar patterns of ratings across both modes of program delivery
- Findings are supportive of other studies showing the effectiveness of electronic learning for health education

Hux et al., 2006; Katz et al., 2007; McClure, 2011

Cason & Stiller, 2011; Laasko, Armstrong, & Usher, 2012
Promoting Knowledge: Considerations for SLPs

• Your own professional development (introductory content)
• Help staff in different disciplines learn about TBI
• Important information for survivors and/or families and friends of a survivor
• Print (handout) materials
• Personal accounts for survivors and families

Comments Supported Importance of First-Hand Accounts

“The people telling their stories is what really grabbed me. Charts and graphs are very impersonal but when ‘mothers’ tell her story you can feel her emotions and it really hits you.”

• Personal accounts provide a means to learn from others & benefit from personal insights

Marsh, 2000

Discussion & Questions

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### References