Creative approaches to Long Term Management of Aphasia and TBI

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**TBI**: Michael de Riesthal, Ph.D., CCC-SLP
Pi Beta Phi Rehabilitation Institute at Vanderbilt Bill Wilkerson Center
Vanderbilt University
Disclosure statement

• Candace Vickers
  – **Relevant Financial relationship:** Employee of St. Jude Medical Center which sponsors Communication Recovery Groups (CRG) in Fullerton, California
  – **Relevant Nonfinancial relationship:**
    • Author of the book *Communication Recovery: Group Activities for Adults,* (now out of print.)
    • Have spouse with aphasia who participates in program to be described
Topics for Today

• Characteristics of persons with aphasia at risk of social isolation/lack of access to services
• *Communication Recovery* program as a creative solution to long term intervention for PWA who are d/ced and need more help
• Collaboration
• Data about members
• Promoting satisfying social networks after aphasia
• Ways to gain support for creative programs
Social Networks are...

- "Personal communities that reflect life participation in various spheres + values/choices about meaningful involvement in culture and society” (Hirsch, 1981)
Early wisdom on the need for social connection

- **Emile Durkheim** - Found that rate of suicide varies by social contact
  
  - (Durkheim, 1897)

- **Lev Vygotsky on disability** - “All contact with people, all situations which define a person’s place in the social sphere, his role and fate as a participant in life, all the social functions of daily life are reordered”
  
  (Vygotsky, 1929)
Aphasia in social situations...

At family dinners—“I just sit there.”

“They just say, HUH?”
Long term management of aphasia: The Problem

- Reduced access to outpatient ST services for aphasia for 20+ years
- Persons with aphasia often discharged into a vacuum
  - Ongoing frustration with communication
  - Social isolation
  - No community resource locally to meet needs
  - Partners still in need of education/training/support

- Persons with stroke induced aphasia

  Post discharge:
  - Two possibilities:
    - Social isolation/communication skills stagnation
    - Or..
    - Social Connection with peers
    - Communication skills practice with others in natural environment
Creative response:
Communication Recovery Groups (CRG), est. 1994

- **Group program initiated 1994**
  - Vickers 1998; Vickers, 2004
- **PWA discharged from therapy**
  - Referred to CRG by SLP
  - Outside referrals, word of mouth, internet research
  - National Aphasia Association website/National Stroke Association website
- **2 hours of weekly conversation groups**
  - Meet at local church, 45 weeks per year

**Leadership:**
- Candace Vickers & Darla Hagge, Co Directors
- Terry Vickers, Expert at Living with Aphasia, Lead Volunteer
- Approximately 38 trained student volunteers
Communication Recovery Groups
Members & Volunteers in action
Group run by Person w/ aphasia

Communication Recovery
Participation based transitions from op therapy
Growth of Communication Recovery Groups

<table>
<thead>
<tr>
<th>Year</th>
<th>Members</th>
<th>Volunteers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1994</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2002</td>
<td></td>
<td></td>
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<tr>
<td>2008</td>
<td></td>
<td></td>
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<tr>
<td>2012</td>
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</table>
Collaborators

• **Sisters of St. Joseph**, St. Joseph Health System
  – “healthy communities”, “perfect care”

• **Ongoing influx student volunteers** local universities; local SLPA programs send interns

• Local NSSHLA chapters promote to students

• **Community members** donate needed materials
  – E.g. Movable room partitions, iPads, recycled paper, markers, laminated maps, calendars, pictures

• **First Presbyterian Church** of Fullerton
  – Very affordable rent, large space and welcoming atmosphere
Data

Communicative/Social participation
Social networks
Partner training
Social network impacts after aphasia

Participants (N=40) (Vickers, 2010)

• 21 male, 19 female
• Mean age=66.15 [12.25]
• All community dwelling
  – 39 of 40 able to give informed consent directly
• Married/partnered=78%
• Ethnicities:
  – 65%=White/Anglo
  – 5 other ethnicities in group
• Education
  – All completed high school
  – 78% with 2 years of college
• Occupational history
  – 85% were ‘white collar workers’ prior to study
Two groups compared within sample

Groups:
- “Aphasia group” participants:
  - 28 persons attending Communication Recovery aphasia groups
- “No aphasia group” participants:
  - 12 persons not attending any aphasia group

Aphasia severity:
- No significant difference in aphasia severity between the 2 groups
- No significant social network size differences for amount of contacts/frequency of interaction between groups for “before aphasia” condition
Self-rated communication participation after aphasia

• **Phone use:**
  – 68% report “rarely” or “never” use phone

• **Email use:**
  – 64% report “never” use email

• **Participating in communication situations**
  – Rating of “sometimes” used **most** often
    • “sometimes” for 1:1 interactions=43% of participants
    • “sometimes” for small group interactions=42% of participants
## Social Participation Variables After Aphasia  
(N=40) (Vickers, 2010)

<table>
<thead>
<tr>
<th>Variable</th>
<th>“Aphasia Group” (N=28)</th>
<th>“No aphasia group” (N=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attend movies, plays or concerts</td>
<td>M=3.46, SE=.227; t (38)= -3.81, p&lt;.001, r=.53</td>
<td>M=1.83, SE=.386</td>
</tr>
<tr>
<td>Attend religious services</td>
<td>M=3.07, SE=.325; t (38) =-3.38, p&lt;.012, r=.48</td>
<td>M=1.75, SE=.372</td>
</tr>
<tr>
<td>Made new friends in the community since my stroke or brain injury</td>
<td>M=1.71, SE=.124; t (38) =-2.20; p&lt;.032, r=.34</td>
<td>M=1.25, SE=.131</td>
</tr>
<tr>
<td>Socialize with new friends from community since stroke/brain injury</td>
<td>M=2.68, SE=.341; t (38)=-1.947, p&lt;.059.</td>
<td>M=1.58, SE=.313</td>
</tr>
</tbody>
</table>
## Social network analysis

### Social networks assessment
- *Social Networks Communication Inventory* (Blackstone & Berg, 2003)
- Numerical count of partners calculated for before/after aphasia conditions
- Frequency of contact for before/after aphasia conditions rated using 4 point Likert scale
  - Rated Circles 1-4 only

### Circle of Communication Partners
- Partners calculated across 5 domains:
  - Circle 1-Life partners
  - Circle 2-Good friends/close relatives
  - Circle 3-Neighbors/acquaintances
  - Circle 4-Paid worker partners
  - Circle 5-Unfamiliar partners
Significant shrinkage of social network after aphasia: 40 PWA (p<.01, 2 tailed) (Vickers, 2010)
Self rated social connection vs. isolation after aphasia

The Friendship Scale (FS)

Use of FS

• *The Friendship Scale (FS)* (Hawthorne, 2006) – measured perceived social support vs. social isolation to help describe social integration in social networks in context of life with aphasia.

Description of FS

• FS is a 6 item questionnaire validated with 829 older Australian adults including those with acquired disabilities.

• Data facilitating interpretation of the FS with PWA is available. (Hawthorne, 2008)
Overall results of FS (N=40)

- Mean score=14.95. (Range-0-24)
  - As a group=sense social isolation, low level of social support

- 52.5% sense some amount of social isolation

- 47.5% sense at least some social support
Positive impact for attending weekly aphasia program

- **1-CRG participants**: Perceived significantly more social support and less social isolation than comparison group participants.
  - \( M=16.12 \) versus \( 12.25; \) \( p<0.050 \)

- **Comparison group**: Scores similar to those reported for nursing home residents
  - (Isolation, low level of support) and over 2 points below scores for persons with depression in Hawthorne’s study
  - (Hawthorne, 2006)
Partner training: Long term management phase

• Train partners during 1:1 tx sessions
  • (Lyon, 1992; Boles, 1998; Garrett & Beukelman, 1992; Kagan et al, 2000)

• Train close family members & caregivers

• Train good friends
  – Partners learn new skills for communication
  – PWA empowered to comprehend/express; increases participation in conversation (Kagan et al 2000)
Communication Training Series
Partners of Persons with aphasia


• Learner-centered education/training model with 19 spouses/partners
  – Direct Instruction
  – Small and whole group discussions
  – Role-play
  – Reflection
  – Weekly home practice

• Aphasia Couples Therapy (ACT) Workbook (Boles, 2010)
• Universal themed activities
• Facilitator, Candace Vickers
• 4 CU CSD 1st Year Graduate Students
<table>
<thead>
<tr>
<th>Survey Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Today’s session was informative.</td>
<td>48%</td>
<td>50%</td>
<td>2%</td>
<td>0%</td>
</tr>
<tr>
<td>2. I enjoyed talking with other spouses/partners.</td>
<td>50%</td>
<td>46%</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>3. I learned a communication strategy to use with my partner with aphasia.</td>
<td>35%</td>
<td>45%</td>
<td>16%</td>
<td>4%</td>
</tr>
<tr>
<td>4. I experienced a new insight during today’s session.</td>
<td>44%</td>
<td>42%</td>
<td>12%</td>
<td>2%</td>
</tr>
<tr>
<td>5. I would recommend this session to other partners of persons with aphasia.</td>
<td>65%</td>
<td>34%</td>
<td>1%</td>
<td>0%</td>
</tr>
</tbody>
</table>
Promoting healthy social networks for PWA

- Facilitate development of new friendships/social contacts via
  - Group therapy
  - Volunteerism/Peer Visitation
  - Networking with peers
Group program as transition after discharge: Advantages

- Multiple conversation partners available
- Community reentry opportunity
- Continuous program available
- Reduces impact of limited access to treatment
- Reduces dependence on clinician as sole source of communication practice
- New social networks/community experience for members and their families
- Members gain chance to share lives, skills, enhance identity after aphasia
- Help for families – Caregiver Support group can run concurrently
Create an enduring community group program

• Clinician invests extra time initially
  – Group activity planning
  – Volunteer training/recruitment
  – Get buy in from managers and administrators

• Program is self-perpetuating once all the elements are in place
  – Provides an avenue for meeting communication needs of the underserved
  – Valuable volunteer experience for students
  – Valuable clinical hours for graduate interns
Gaining support for medical center based programs

• Establish use of conversation group as standard tool in your treatment protocol

• Give group program a positive name and identity which coincides with the missions statement of your facility

• St. Jude receives accolades from CARPF for CRG
  – Show administration how your group program coincides with its core values
  – Network with any existing volunteer program in your facility or community
Selected references


Multidisciplinary Follow-up Clinic for Individuals with TBI

Michael de Riesthal, Ph.D., CCC-SLP
Pi Beta Phi Rehabilitation Institute
Vanderbilt University
Disclosure

• Relevant financial relationship: Employee of Vanderbilt University Medical Center, which supports the clinical program described.

• Relevant non-financial relationship: The Multidisciplinary TBI Clinic received “Professionals of the Year” award from the Brain Injury Association of Tennessee (BIAT). BIAT is associated with the Clinic described in this presentation.
Special Thanks

• Amanda Hereford, MA, CCC-SLP
Objectives

• Identification of programmatic needs

• Collaboration with colleagues

• Gaining of institutional support

• Role of speech-language pathologist
Objectives

• Identification

• Collaboration

• Role of Speech-Language Pathologist

• Institutional support
TBI Data

• One of the leading causes of disability in US
• 1/3 of all injury-related deaths
• In US, at least 1.7 million new TBI cases
• Approximately 275,000 require hospitalization

Faul et al. (2010)
Middle Tennessee
Level I Trauma Center

- 4,000 annual traumas
- 3,200 admitted to integrated acute care and sub-acute care unit
Continuum of Care

- Pre-hospital services
  - EMS, Life Flight, other care facilities
- Emergency department
- Acute care medical services
  - Trauma service
  - Hospital ward
Total TBI Patients Admitted

Insured
- Death
- Home
- Nursing facility
- Other location
- Rehabilitation

Uninsured
- Rehabilitation
- Other location
- Nursing facility
- Home
- Death

No or Disconnected Follow-up
Post-acute care settings

• Home
  – With outpatient rehabilitation
  – Without outpatient rehabilitation

• Inpatient rehabilitation

• Skilled or extended nursing facilities
Disparity in post-acute services

• Insurance (Nirula et al., 2009)
  – d/c home ↑ for those without insurance
  – d/c SNF ↑ for those with Medicare
  – d/c inpatient rehab ↑ with commercial insurance

• Age (Thompson et al., 2012)
  – d/c home ↓ as age ↑
  – d/c nursing home ↑ as age ↑
The Problem

• Identification of patients with TBI
• Disjointed medical/rehabilitation services
• Inconsistent long-term follow-up
• No insurance = limited services
Ensuring Continuum of Care

“Who follows our patients with TBI?”

Oscar Guillamondegui, MD MPH
Trauma Surgeon
Vanderbilt Trauma Registry

• Data available for a variety of variables including
  – TBI severity
  – Insurance status
  – Discharge disposition
796 Total TBI Patients Admitted

626 Insured

- 14% Death
- 47% Home
- 9% Nursing facility
- 4% Other location
- 26% Rehabilitation

170 Uninsured

- 4% Rehabilitation
- 6% Other location
- 2% Nursing facility
- 71% Home
- 17% Death

No or Disconnected Follow-up
Objectives

• Identification

• Collaboration

• Role of Speech-Language Pathologist

• Institutional support
Collaborations

• Department level
• Institution level
• Community level
Guidance from Colleagues: Duke University Hospital

• Problem
  – Only 10% of patients that met TBI criteria were referred to SLPs for a cognitive-communicative evaluation

• Solution
  – Improve referral process from Trauma service

Jones & Foley (2009)
Duke TBI Program

• Collaboration
  – Speech-language pathology
  – Trauma service

• Improve education about TBI
  – Staff
  – Patients

• Examine outcomes
  – Increased referrals-nearly 100% of patients with TBI
Collaboration at Vanderbilt

• Inter-departmental collaboration
  – Acute care speech-language pathology service
  – Trauma service

• Identification/initial patient capture
  – Standing order for SLP services
  – Cognitive-communicative evaluation
  – Creation of “TBI Patient Panel”
Collaboration at Vanderbilt

• Departmental
  – Acute care speech-language pathology service
  – Pi Beta Phi Rehabilitation Institute
Collaboration at Vanderbilt

• Community
  – Trauma Survivors Network
  – Brain Injury Association of Tennessee
  – Project BRAIN
Objectives

• Identification

• Collaboration

• **Role of Speech-Language Pathologist**

• Institutional support
Role of SLP in Developing Innovative Programs

• Provide excellent care
• Develop relationships
• Educate about TBI
  – Patients and families
  – Physicians
  – Nurses
  – Other rehabilitation clinicians
The inspiration to move this project forward could not have been performed without the intellectual prowess and fortitude of Amanda Hereford, MA, CCC-SLP. Without her guidance and strength and being one of the many folks to educate me as to the need for the multi-disciplinary approach to medicine, it never would have happened. For that, I am deeply indebted. Many thanks.

Oscar Guillamondegui, MD, MPH
Objectives

• Identification

• Collaboration

• Role of Speech-Language Pathologist

• Institutional support
Institutional Support

• Section Chief-Trauma & Surgical Critical Care
• Chair-Hearing and Speech Sciences
• Agreed to make personnel and space available to create follow-up clinic for patients with TBI
• Agreed that clinic must include patients who are uninsured or under-insured
Total TBI Patients Admitted

- Insured
  - Death
  - Home
  - Nursing facility
  - Other location
  - Rehabilitation
  - Multidisciplinary TBI Clinic

- Uninsured
  - Rehabilitation
  - Other location
  - Nursing facility
  - Home
  - Death
Multidisciplinary TBI Clinic

- Clinic characteristics
  - Meets first Friday of month
  - No charge to patient
  - Appointments are 1 to 1.5 hours
  - Multidisciplinary evaluation of patients at 3 months post-injury
Multidisciplinary TBI Clinic

- Team Members
  - Trauma Surgeons
  - Nurse Practitioner
  - Social Worker
  - Speech-Language Pathologists
  - Director/Peer Visitors-Trauma Survivor Network
  - Director-Brain Injury Association of Tennessee

- Cognition-Communication
- Social-Emotional
- Physical
- Community Resources
- Case Management
# Cognitive Screening: 20-30 Minutes

<table>
<thead>
<tr>
<th>Domain</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orientation</td>
<td>Galveston Orientation and Amnesia Test</td>
</tr>
<tr>
<td>Working memory</td>
<td>Numbers Reversed-Woodcock Johnson Tests of Cognitive Abilities</td>
</tr>
<tr>
<td>Memory/New Learning</td>
<td>Story Retelling (Immediate/Delayed)-Arizona Battery for Communication Disorders in Dementia</td>
</tr>
<tr>
<td>Attention</td>
<td>Trail Making A&amp;B</td>
</tr>
<tr>
<td>Executive Functioning</td>
<td>Controlled Oral Word Association Test</td>
</tr>
<tr>
<td>Reasoning</td>
<td>Verbal Analogies-Woodcock Johnson Tests of Cognitive Abilities</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>Quality of Life After Brain Injury</td>
</tr>
</tbody>
</table>
Clinic Outcomes

• Over 1,000 patients referred to acute care SLP service
• Over 200 patients seen for follow-up in the Multidisciplinary TBI Clinic
• Referrals for medical follow-up, rehabilitation, driver evaluation/training, neuropsych evaluation, etc.
Limitations

• Clinic does not include
  – Neuropsychology
  – Neurology
  – Neurosurgery
  – Physiatry
  – Occupational Therapy
  – Physical Therapy

• Volume is greater than available appointment slots

• Fairly high no-show rate
Next Steps

• Increase attendance at clinic
  – Offer additional clinic days during month
  – Find space with more clinic rooms

• Funding
  – Secure extramural funding that would help support the mission of the clinic
Next Steps

• Research
  – Predictors of quality of life 3-months post-TBI
    • Quality of life after brain injury (QOLIBRI)
    • Age, Sex, Primary insurance status, GCS
  – RCT examining effect of combined sympathetic blockade using propranolol and clonidine on
    • Short-term physiology, behavior, and cognition
    • Long-term neuropsychological outcomes
In Summary

• Development of innovative programs requires
  – Identification of problem
  – Collaboration of motivated personnel
  – Institutional support and partnerships

