MAXIMIZING SERVICES TO OUTPATIENTS WITH APHASIA

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RELEVANT FINANCIAL RELATIONSHIP DISCLOSURE

- I am an invited speaker for this convention and receiving an honorarium for presenting today.
CONTEXT FOR TODAY
LONG TERM MANAGEMENT OF APHASIA:

- **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
FOCUS FOR TODAY:

• **Premise:**
  - Aphasia can cause major life altering changes for persons with aphasia and their communication partners; providing enough treatment to make a difference is challenging in today’s healthcare environment.

• How to work within a **person centered** framework

• How to **maximize service** for persons with aphasia

• How to be **strategic with resources** given constraints in outpatient rehabilitation arena
LEARNING OUTCOMES FOR TODAY

1) Describe three freely available useful tools that enhance the assessment process in a person centered care framework for persons with aphasia.

2) Describe three specific methods to allow person with aphasia and caregiver to maximize time in therapy through use of customized home programs involving partners as well as technology.

3) List steps to providing community programming to provide Communication Recovery Groups for persons with aphasia (Vickers, 1998).
What does Person Centered Care look like?
PERSON CENTERED CARE DEFINED

• "Putting the patient and the family at the heart of every decision and empowering them to be genuine partners in their care" –Institute for Health Care Improvement, 2019

• “…change in treatment focus from isolated impairments to overall change in life participation.” AND-

• “…individualize treatment to each patient’s unique needs and circumstances.”-Brown & Vickers, 2015
PERSON CENTERED GOALS DEFINED

- “Goals defined by the client, in partnership with the clinician and family, that allow participation in meaningful activities and roles.”
  - Brown & Vickers, 2015 (The ASHA Leader)

Why person centered goals?

- Maximize outcomes leading to functional improvements important to individual
- Optimize individual’s potential to participate in meaningful activities
- Facilitate partnership ensuring individual and family have voice in care received and outcomes achieved
- Demonstrate to payers value of skilled services
  - ASHA (2015), Person-Centered Focus on Function: Aphasia. Available at asha.org/slp/icf
ICF: BEGINNING POINT FOR PERSON CENTERED CARE (WHO, 2001)
PART OF ASHA SCOPE OF PRACTICE (ASHA, 2016)

ICF Concepts

Health Condition (disorder/disease)

Body Function & Structure (Impairment)
Activities (Limitation)
Participation (Restriction)

Environmental Factors
Personal Factors
MAXIMIZING SERVICE IN SEVERE APHASIA
THE WORK OF DR. JACQUELINE HINCKLEY (2014)

- In One to One therapy:
- Suggests novel paradigm for assessment and therapy when there is limited treatment time available
- Begin with interview to determine goals and priorities BEFORE actual testing
- Client/family/caregiver collaborate to identify highest priority activities that would lead to life participation in preferred contexts
CONTRIBUTIONS OF HINCKLEY, 2014

- Assessments that reveal life participation restrictions as well as needs
  - Use of WHO ICF Checklist, Life Interests and Values (LIV) cards, and formal assessment such as Communication Activities of Daily Living-2 or Boston Assessment of Severe Aphasia, Measure of Participation in Conversation

- Informal assessment of language modalities

- Treatment targets successful participation in a specific preferred activity involving communication and interaction with others
MORE IDEAS ON ASSESSMENT THAT MAXIMIZES SERVICE

• Identifying strengths in language for skill building to support communication exchanges

Explore communication opportunities, partners in social networks, community integration
DIAGNOSTIC PERSPECTIVE FOR SLP

• **Moderate to severe aphasia scenario**:
  • Use standardized test to document baseline/medical need (ie., Aphasia Diagnostic Profiles; WAB, BDAE)
    • **And/or** informal assessment of each language modality for strengths/challenges

• Consider use of functional scales such as ASHA FACS, goals in terms of Functional communication measures from NOMS

• Discover **residual language strengths** for skill building and for use in 2 way communication with significant other
FREELY AVAILABLE ASSESSMENT TOOLS TO IDENTIFY:

**BIO SKETCH:** KEY RELEVANT VOCAB, EXPERIENCES

**SOCIAL NETWORKS:**
- NUMBERS, TYPES OF COMMUNICATION PARTNERS,
- FREQUENCY OF SOCIAL CONTACT WITH PARTNERS

**COMMUNITY INTEGRATION**

Quickly gain diagnostic information about the social aspects of your client’s life to enhance a person centered approach
LOOKING BEYOND IMPAIRMENTS

• **Use of biographical sketch**
  - (Garrett & Beukelman, 1992)
  - Use at very first session (Try to get completed before if possible by the PWA or a family member)

• **Partner attitudinal survey** (Garrett & Beukelman, 1992)

• **Social Network Assessment tool** (Antonucci & Akiyama, 1987)

• **Community Integration Scale** (Willer & Ottenbacher, 1994)
SAMPLE OF BIO SKETCH
Garrett & Beukelman, 1992
My name is ______________________________________________

_____________________.

My nickname is ______________________________. I live in
________________________ in the

State of _____________. I was born in
________________________ in the year _____________.

I mostly grew up in the city, town, or area of
________________________. I had ______ brothers and

______ sisters. My maiden name was ____________. My
ancestry is ____________________.

Some of the things that happened to me in my childhood
included:

___________________________________________________

___________________________________________________

___________________________________________________

___________________________________________________
I started dating when I was _______ years old. I met my husband/wife at _______________

My husband/wife’s name is ______________________________. We got married on
_______________. We lived in __________________________ after we were

married. We moved to
____________________________________________________

We bought/rented our first house. We built our house in
________________________. We had

______ children. Some of the stories I remember from when they were little include:
CONSIDER SOCIAL NETWORKS
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)
HUMAN CONTACT, IN SOCIAL NETWORKS...

- “Personal communities that reflect life participation in various spheres + values/choices about meaningful involvement in culture and society” (Hirsch, 1981)
SOCIAL NETWORKS AFTER ONSET OF APHASIA: IMPACT OF APHASIA GROUP ATTENDANCE (VICKERS, 2010)

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
Social Network Analysis for PWA
Significant shrinkage of social network after aphasia: 40 PWA (p<.01, 2 tailed) (Vickers, 2010)
POSITIVE IMPACT FOR PWA ATTENDING WEEKLY APHASIA PROGRAM (VICKERS, 2010)

• **CRG participants**:
  - Responded to 6 question survey, The Friendship Scale (Hawthorne, 2006)
  - Perceived *significantly more social support* and *less social isolation* than comparison group participants.
    - \((M=16.12 \text{ versus } 12.25; p<0.050)\)

• **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)*
EASY TO USE SOCIAL NETWORK ASSESSMENT TOOL

- Easy gauge of social integration
  - Inner circle of partners
  - Middle circle of partners
  - Outer circle of partners
  - Total types of partners in each
  - Total network size

- Antonucci & Akiyama, 1987
  - Used by many researchers
    - E.g. Hilari & Northcott, 2006

- Mean for males – 8.62
- Mean for females – 9.90
HOW HEALTHY IS **YOUR** SOCIAL NETWORK? (NOT SOCIAL MEDIA CONTACTS!)

- **Inner circle** = “You” + Add Communication Partners most important & close to you
- **Middle circle** = not as close but still important
- **Outer circle** = additional important people in your life
- **Add up the total.**
  - (Antonucci & Akiyama, 1987)
COMMUNITY INTEGRATION ASSESSMENT TOOL

- Community Integration Questionnaire (CIQ)
  - 15 questions, score from 0-29, higher the score, the higher the community integration

- Designed for persons with head injury; studied in persons with aphasia too

- Sample questions: “Approximately how many times a month do you usually visit with your friends or relatives?” “go out to eat at a restaurant” etc.

- “Do you have a close friend with whom you confide?”
CUSTOMIZED HOME PROGRAMS

With partners/Use of technology
NEW RECOGNITION: IMPORTANCE OF COMMUNICATION PARTNER

"Better communication in daily life often has its roots in the changed behavior of the partner." (Visch-Brink, Hars Kamp, et al '93). **Examples:**

- Garrett & Beukelman '92 - written choice communication/partner trng
- Kagan ‘98, training conversation partners
- Lyon ‘98 - extensive training with PWA and spouse
- Boles, ‘98 conversational coaching; SFAT’00
**TREATMENT THAT INCLUDES PARTNERS**

**Partner training**: prepare PWA & partner for communication at home and with others

Conversation is context for therapy; train partner in sessions as often as possible

(Boles, 1998)

**Group therapy**: provide “access to conversation” for PWA by providing conversational support during interactions


- Trained conversation partners
- Interaction with peers
PARTNER TRAINING: WHY DO IT?

- **How Partners benefit**
  - Learn tools for optimal communication
  - Chance to practice use of tools with support from clinician during conversation
  - Ongoing contact with clinician to make needed modifications, learn new skills

- **How PWA benefits**
  - As partner behaviors change, PWA’s communication increases in terms of frequency of initiation and turns, types of communication acts
  - Trained conversation partners were able to bring about increased participation in the conversation for people with aphasia
KEY CONCEPTS IN PARTNER TRAINING . . .

• Different partner needs for different levels of aphasia

• Partner part of each session

• Goals for partner
  • As sender of info.
  • As receiver of info.

• Partner needs:
  • Education/training re: nature of aphasia; support

  • Guided conversation practice with PWA
TYPICAL ISSUES FOR PARTNERS

• You don’t seem like the same person to me... why can’t you say my name?

• How do I communicate with you? Did you forget everything you knew?

• How do I find out what you want or what you mean?

• How can we enjoy each other when communication is so difficult?

• What is still working? Can life ever be good again?
EXAMPLE OF SEVERE APHASIA: PARTNER ISSUES

• Often in crisis/shock over change in loved one

• Answers all questions directed to PWA

• May focus on accurate speech production as only criteria of success

• Unable determine what PWA wants/needs/thinks-frustrated,

• Not aware of how to provide/create communication opportunities
TYPICAL SCENARIO: INTERACTION

• PWA - passive role in communication exchange
  • PWA may be persistent in trying to express content when efforts are unsuccessful

• Discord, frustration, feelings of loss for both partners

• PWA/ spouse often leave tx with no tools unless SLP teaches specific behaviors to partner and PWA making an exchange possible
INITIAL FOCUS OF TREATMENT

• Combine impairment and participation approaches for good of the patient
• Begin skill building for any residual language/speech abilities

• Examples, Melodic Intonation therapy to improve speech production, use of automatic speech tasks with deblockers to improve verbal expression, reading/writing exercises to do at home
INITIAL FOCUS: MODELING / DEMONSTRATION

- Demonstrate patient’s ability use preserved language abilities in a 2 way exchange

- Demonstrate use of written choice communication

- Demonstrate use of multimodality cues, and augmented input to increase patient’s comprehension

- Have significant other practice techniques with PWA in a real exchange
UTILIZING RESIDUAL LANGUAGE ABILITIES

• Recognition of written words in context - teach family to offer written choices

• Repetition ability at any level - encourage response to verbal choices and or written choices

• Any gestural ability - teach family to model and encourage/reinforce use of gestures
UTILIZING RESIDUAL LANGUAGE ABILITIES

• Any spontaneous writing ability - teach family to encourage use of writing first letter, drawing, etc. to convey message

• Benefits from multimodality cues for comprehension - teach family to emphasize gestures, key written words in exchanges to alert to topic
IMPORTANT PARTNER SKILLS TO TEACH

• Creating communication opportunities—what they are, how and when to provide

• How/when to present verbal choices; written choices

• Balancing interaction and turns

• How to use augmented input (Garrett/Beukelman, ‘92)

• Difference between testing and authentic exchange

• Acknowledging competence (Kagan, ‘98)
WAYS TO ENHANCE PARTNER LEARNING

• Help partner realize he/she is in therapy too

• Acknowledge crisis and that concepts are new for partner

• Emphasize skill level of partner vs reduction of impairments for patient

• Explain “staircase of improvement” concept, logical sequence for improvement to occur with partner and PWA
CLINICIAN MODELS TECHNIQUES IN AN EXCHANGE WITH PWA

- Learning strategies for partner
  - Have partner check off behaviors observed to increase awareness
  - Have partner note which clinician behaviors were most effective for patient/discuss

- Set up role play with PWA and partner-observe/critique

- Set goals for partner, display goals on board
TYPICAL MISTAKES MADE BY PARTNERS DURING/AFTER TRAINING

• Talking too much, too fast to PWA; guessing prematurely

• Failing to allow time for responses; quick topic changes

• Writing full sentences vs key words for written choices

• Failing to display written choices in PWA’s visual field

• Gives too many options, verbal choices too long
SUMMARY OF DESIRED PARTNER SKILLS FOR SEVERE APHASIA

• Must be able to grasp concept of altering own behavior & carry out

• Interested, supportive, accepting of PWA

• Can demonstrate use of multimodality communication (ie., gestures, etc.)

• Provides clear verbal or written choices at appropriate pace

• Understand how to create/provide communication opportunities
# Examples of Home Programs to Maximize Service

<table>
<thead>
<tr>
<th>Partner/PWA practice</th>
<th>PWA practice alone or with partner/volunteer</th>
<th>Skill Building to Support Speech Efforts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Skills learned at tx</strong></td>
<td><strong>Bungalow Aphasia Software</strong></td>
<td><strong>PWA/selected family member, friend or volunteer</strong></td>
</tr>
<tr>
<td>Gain agreement from partner and PWA to practice together between appointments</td>
<td><strong>Tactus TherapyAPP</strong></td>
<td><strong>Practice MIt Stimuli Together</strong></td>
</tr>
<tr>
<td>Partner creates communication opportunity</td>
<td><strong>Constant Therapy,</strong></td>
<td><strong>Practice External Pacing Strategies to Assist With Apraxia of Speech for Relevant Phrases</strong></td>
</tr>
<tr>
<td>Practices skills in using verbal or written choices versus open ended questions or guessing</td>
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**USE OF TECHNOLOGY FOR ENHANCING INTERACTION IN HOME PROGRAMS, GROUPS**

(VICKERS & MEHTA, 2012) (NESS & VICKERS RESEARCH PROJECT ONGOING, CBU)

<table>
<thead>
<tr>
<th>Visual images during interaction</th>
<th>2 partners/1 PWA</th>
<th>Permanent references/enhance communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enhance conversation</td>
<td>One partner facilitates interaction</td>
<td>Enlist family and/or client to bring in selfie photos of activities; ipad or iphone</td>
</tr>
<tr>
<td>Partners team up/confirm topic of interest for member</td>
<td>Other partner quickly looks up information in real time/displays image or video embodying that topic</td>
<td>Display images in 1-1 interactions or in groups-enhance communication</td>
</tr>
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CONVERSATION GROUPS FOR PERSONS WITH APHASIA: A WAY TO EXTEND SERVICE

EXAMPLE FROM SOUTHERN CALIFORNIA: COMMUNICATION RECOVERY GROUPS (CRG)

WHY?

Getting in the conversation - as important as getting back on your feet!
RESEARCH EVIDENCE ON GROUPS

- Wertz et al. (1981) - VA Study found PWA seen in groups vs 1:1 also made significant language improvements.

- Elman & Bernstein-Ellis (1999) - Significant linguistic and functional communication improvement in treatment group vs deferred tx group.

- Vickers, 2010
  - Positive impact on persons with aphasia who attend weekly conversation groups for persons with aphasia.
  - Significantly less perceived social isolation as measured by the Friendship Scale.
    - Communication Recovery Group (CRG)
COMMUNICATION RECOVERY GROUPS (CRG)

- Group treatment with trained communication partners to increase participation in conversation and supportive social networks
  - Vickers, 1998; 2004
  - Inspired by Jon Lyon, 1992, Communication Partners
COMMUNICATION RECOVERY GROUP (CRG)

A WAY TO MAXIMIZE SERVICE AND INCREASE COMMUNICATION OPPORTUNITIES, REDUCE SOCIAL ISOLATION

- 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, Trained student volunteers lead groups
  - Works well in a university clinic site as well

- Meet in community location 45 weeks per year
COMMUNICATION RECOVERY GROUPS FOR PERSONS WITH APHASIA
COMMUNICATION RECOVERY GROUPS
MEMBERS & STUDENT VOLUNTEERS/GRAD INTERNS IN ACTION
CONVERSATION GROUPS - PART OF LONG TERM MANAGEMENT

• Communication is more than information transfer

• Experience social closeness through conversation (Garrett & Beukelman, 1992)

• Conversation allows access to social/community life (Kagan, 1998)

• Participants experience new sense of community (Kagan, 1998)
GROUP PROGRAM AS TRANSITION AFTER DISCHARGE: ADVANTAGES

- Multiple conversation partners available
- 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
- Rich educational experience for CSD student volunteers, clinical hours for grad interns
GROUPS PROMOTE HEALTHY SOCIAL NETWORKS FOR PWA AND THEIR FAMILIES AS WELL

• Facilitate development of improved communication, new friendships/social contacts via
  • Group therapy
  • Partner training
  • Volunteerism/Peer Visitation
  • Networking with peers
  • Technology
  • Advocacy
PEER SUPPORT GROUP FOR FAMILIES MEETS DURING GROUPS, CAREGIVER RESOURCE CENTER LEADER
2010- Research shows 28 CRG members reported significantly more social connection, less isolation than 12 non attendees.
START A GROUP PROGRAM USING VOLUNTEERS

- Start with 1 or 2 people in active therapy who need conversation practice
- Establish regular time and space
- Add people as appropriate
- Include peers to act as conversation partners for members
DEFINE ROLE AND VALUE OF COMMUNICATION PARTNER VOLUNTEERS

- Role is to interact and participate in activities at clinician direction
- Active listening, acceptance of all conversation efforts
- Use specialized techniques as instructed
- Not there to get own needs met
- Explain value of communication partner in enhancing AP’s recovery and wellbeing
INCLUDE DIFFERENT TYPES OF COMMUNICATION PARTNERS

- Peers with aphasia
  - People still in therapy
  - People who are out of visits and need ongoing conversation/interaction practice

- Interested family member(s) - encourage interaction with non-family members in group

- Volunteers trained as Communication Partner Volunteers
TYPES OF COMMUNICATION RECOVERY GROUPS
CLINICIAN-LED

- Clinician supplies topics and activities
- Members interact in dyads and regroup periodically or do small group interaction whole session
- Clinician utilizes volunteer communication partners in the session
- Clinician addresses functional goals for selected individuals in active therapy

TRAINED VOLUNTEER LED

- Trained Communication Partner Volunteers co-facilitate groups
- Clinician matches volunteers to appropriate group assignments
- Clinician provides volunteers with conversation activities and flexible plan for group
- Clinician may or may not be present in group
- Volunteers meet with/report directly to clinician on regular basis
GAINING SUPPORT FOR YOUR GROUP PROGRAM

• Establish use of conversation group as a standard tool in your treatment protocol within your site if you can

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

• Show administration how your group program coincides with its core values

• Network with any existing volunteer program in your facility or community

• Consider use of SLPAs, grad interns, trained communication partner volunteers
OUR INSPIRATION: BE A CATALYST FOR CHANGE IN A PERSON’S COMMUNICATION WORLD

• Include communication partners in treatment (Lyon, 1992)

• Become skilled communication partner yourself & train others (Garrett & Beukelman, 1992; Kagan, 1998)

• Recruit and use volunteers as communication partners and group co-facilitators (Kagan, 1998; Vickers, 1998)

• Conversational coaching (Boles, 1998)
SOCIAL APPROACH TO APHASIA

“The goal of a social approach is to promote membership in a communicating society and participation in personally relevant activities for those affected by aphasia.”

Nina Simmons Mackie, 2001, p. 246
CLOSING THOUGHT...

• “People with aphasia are our husbands and wives, sisters and brothers, parents, children and friends. The time to invite them back into the conversation is now….”
  (Vickers, 2008)


• ASHA. (2015). Person-Centered Focus on Function: Aphasia. Available at: https://www.asha.org/slp/icf/


SELECTED REFERENCES


