Aphasia Groups:
One Approach Does Not Fit All

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Rehabilitation:

- Regain function in order to participate in life as fully as possible
- ASHA SLP Scope of practice
  “The overall objective of speech-language pathology services is to optimize individuals’ ability to communicate and/or swallow in natural environments, and thus improve their quality of life. This objective is best achieved through the provision of integrated service in meaningful life contexts.”
  ASHA, 2001, p. 26

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World Health Organization
(ICF)

Framework consists of two parts:
- Functioning and Disability
  - Body Functions and Structures
  - Activities and Participation
- Contextual Factors
  - Personal Factors
  - Environmental Factors

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ICF (WHO, 2001)

Health Condition (disorder or disease)

- Body Functions and Structures
- Activities
- Participation

Environmental Factors

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LPAA (2001)

Five core components:
• The explicit goal is enhancement of life participation
• All those affected by aphasia are entitled to service
• Both personal and environmental factors are targets of assessment and intervention
• Success is measured via documented life enhancement changes
• Emphasis is placed on availability of services as needed at all stages of life with aphasia

Advocacy efforts should be targeted to those components not available in healthcare systems

Group Treatment Studies
(See Kearns & Elman, 2001, in press; Elman, 1999a,c; 2007)

- Wertz & colleagues (1981)
  - compared 1:1 with group tx
  - Acute aphasia
  - 8 hours a week for up to 44 weeks
  - Only measure showing difference is PICA
  - “Our results indicate that individual treatment may be slightly superior to group treatment. However, the improvement displayed by our group-treated patients and the cost-effective advantages of group therapy should prompt speech-language pathologists to consider it for at least part of an aphasia patient’s care.”

- Aten, Caligiuri & Holland (1982)
  - 7 chronic nonfluent PWA
  - Functional communication/real life tasks
  - 2 hours tx for 12 weeks
  - CADL improved, not PICA

- Bollinger, Musson & Holland (1993)
  - 10 chronic PWA
  - 3 hours tx over 44 weeks
  - tx and no tx periods
  - Real life situations vs. Structured TV viewing
  - CADL & PICA improved

Historical Overview and Efficacy of Group Treatment

- Published Efficacy & Effectiveness Data
  - Aphasia Group Treatment

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Some Possible Benefits of Conversation Groups

- Groups promote interaction and variety of communicative functions or speech acts
- Groups provide opportunity for wider array of partners = more generalization
- Groups promote language improvisation

Some Possible Benefits of Conversation Groups (con.)

- Groups improve psychosocial functioning – Benefit of Community
- Groups involve more complex language (CATE—Thompson et al.)
- Groups are cost effective
- Others?

CURATIVE FACTORS IN GROUPS

(See Yalom, 1985; Luterman, 1996; Elman, 2000, 2002):

- Instillation of Hope
- Universality
- Imparting of Information
- Altruism
- Interpersonal Learning

CURATIVE FACTORS IN GROUPS (con.)

- Group Cohesiveness
- Catharsis
- Existential Issues
- Humor!

CURATIVE FACTORS IN GROUPS

• Elman & Bernstein-Ellis (1999a,b)
• 24 chronic PWA
• Randomized Controlled Trial (RCT)
• Controlled for social contact
• Randomized to immediate and deferred treatment group
• 5 hours tx weekly for 4 months
• Focus on initiation of conversation and exchange of information
• Group communication tx was efficacious
• Deferred treatment participants did not change with social contact alone
• Participants receiving tx had sig. higher scores on communicative and linguistic measures
• After 2 months, 4 months, and follow-up

CURATIVE FACTORS IN GROUPS (con.)

• Van der Gaag et al, (2005)
• 28 PWA in community based program (Connect in London)
• Average of 1.7 hrs week of group treatment (conversation, skill building, advocacy)
• CETI had improvement as did qualitative interviews
Qualitative Data--Interviews
Elman & Bernstein-Ellis (1999b)

- After two and four months of group communication treatment
- Interviews with those having aphasia
- Interviews with caregivers

Individuals with Aphasia Reported:

- Liked being with others
- Liked support of others having aphasia
- Made friends
- Liked being able to help others
- Liked seeing others improve
- More confident
- Enjoyed conversations
- Talking more

Caregivers reported about their family member:

- More confident
- More social
- More independent
- More motivation
- Made friends
- Less angry/happier
- Nice they could help others
- More speech/improving language

Stroke Support Groups: Rebuilding Identity
Barbara B. Shadden
ASHA 2006

A rose by any other name…

- Mutual help groups
- Self-help groups
- Community groups
- Clubs
  - Support groups

18% of Americans participate at some point

For stroke and its consequences:

- The American Stroke Association lists @ 1900
- On-line presence (e.g., the Stroke Network [http://www.strokenetwork.org])
- National Aphasia Association identifies >400 groups addressing communication problems [http://www.aphasia.org/agc.php]
Support groups matter because…

- We find increased focus on psychosocial needs of person with aphasia and SO’s
- Activity, quality of life, life satisfaction, and *life participation* matter.
- Health care options are becoming more limited – should support groups be considered alternative treatment delivery mechanisms?

What do support groups offer?

- Narrative community
- Acknowledging and embracing unique experiences and identities, including living with aphasia
- Shared challenges and solutions
- Transitions from helplessness to empowerment
- A social space which allows reframing of private personal stories within the context of the public community narrative of successful moving on

Importance of the shared constructed story

- Social interaction
- Interactive responsibility
- Involvement obligations (Shotter, 2005)
- Search for meaning in the life story

STROKE SUPPORT GROUP OF NW ARKANSAS

- **ENTRY CRITERIA**
  - Self selection is critical
  - Entry = choice to affiliate with the community, for one session or 10 years
  - Open to all dealing with impact of stroke and other neurological impairment on life
  - Differences appreciated, not minimized
- **NO FORMAL OR INFORMAL ASSESSMENT**

GOALS

- Typical: dissemination of info, development of coping skills & strategies, identification of resources, social interaction, emotional support and release.
- Beyond these, target renegotiation of identity for managing chronicity of life consequences of stroke because we see…

Aphasia as identity theft
GOALS expanded:
1. Serve as antidote to previous experiences with treatment of disability in medical community
2. Provide affirmation of each persons version of stroke story
3. Allow focus on present and future identity, not some past self
4. Give members a sense of ‘agency’

DOCUMENTATION: The Inarticulateness of Progress
• No formal records
• Progress of self and others affirmed often in group
• Informal debriefing of process by facilitator and ‘lead’ spouse through debriefing
• Facilitator informal notes about:
  – Type and extent of participation of each participant
  – Issues emerging in full group or breakout group sessions
  – Individuals who may need more attention in subsequent sessions
  – Procedures that may need modification during the next session

Schedule, Structure and Size
• Schedule: once monthly for 2 hours
• Structure:
  – Open circle
  – No guest speakers
  – Two parts
    • Common sharing time
    • Group breakouts
• Size – ranges from 8 to 30, between 12 and 16 is optimal

Role of Facilitator
• Facilitate topic maintenance and shifting
• Monitor time and tone; maintain group rules & address boundary violations
• Validate and protect all participants
• Accept participants for who and what they are at any point in time, while addressing different and emerging needs of old and new members; promote self-efficacy
• Affirm the focus on interaction and participation and the fundamentally social nature of the process
• Encourage humor

Core Values
• Respect for the concerns and competence of each member
• Acceptance
• Affirmation and validation
• Actions speak louder than words
• Feelings are okay
• Reflection and problem solving are encouraged

Core values continued
• Flexible goals
• A clean slate
• Participant oriented
• Focus on the story
• Interaction oriented
• Celebration of change
Core values grounded in group process

Group Rules and Routines

• Sharing
• Stroke survivors first
• Focus on new members
• Group breakouts
• Communication rules
  – All must speak slowly, clearly, loudly, repeating as necessary.
  – Only one conversation should occur at any point in time.
  – Nonverbal cues about communication breakdown must be responded to immediately.
  – The person communicating receives focus from all participants.

Boundary Violations

• Breakdown in the group’s rules related to communication and other-focus
• Statements or implications of incompetence or negative evaluative response
• Persistent lack of responsiveness to others

CHALLENGES

• Are there discharge criteria?
• Is reimbursement possible?

BOTTOM LINE

Support groups, either for aphasia or for persons dealing with stroke sequelae, may provide a social space and community narrative that promote rebuilding of new identities post-stroke through the sharing and validation of personal stories.

Aphasia Groups: Aphasia Center of California

Roberta J. Elman
Aphasia Center of California
Oakland, CA
www.aphasiacenter.org
Information about the Aphasia Center of California’s programs available:

<www.aphasiacenter.org>

<www.pluralpublishing.com>

Aphasia Center of California

• Our Mission: To encourage and expand communication skills and maximize psychosocial well-being for those with aphasia

Aphasia Center Values:

• Choice
• Shared Leadership
• Age Appropriate Programs & Policies
• Building Community

GOALS

• Enhance Communication
• Maximize Psychosocial Well-Being

Aphasia Center of California

• We are a community based nonprofit 501(c) (3) organization providing individual and group speech-language treatment, reading and writing groups, recreational classes, and caregiver groups
• We incorporated and received tax exempt status in 1996
Our Current Programs include:

- 9 Conversation Treatment Groups
- Individual Speech-Language Treatment
- Couples training
- Book Connection™—3 groups a week
- News Forum (alternates with Book Club)
- Fitness & Relaxation Class
- Painting/Drawing Class
- Stroke Group—educational series
- Education & Training—organizations

Aphasia Center of California

- More than 120 individuals with aphasia and their families from throughout the Bay Area attend the Aphasia Center of California
- Speech-language treatment and caregiver groups are provided by licensed SLPs
- Recreational classes are taught by Adult Education instructors

Aphasia Center of California

- Aphasia Center participants choose from the classes to create their unique individual treatment program
- We try to find the “best fit” Communication Treatment group for each person

Why we started the ACC

- Our Group Treatment Efficacy Study
- People improved speech-language skills after 2 months of group communication treatment
- People had more confidence in their ability to communicate—in their real lives!!

Aphasia Center Therapists:

- Ellen Bernstein-Ellis, M.A., CCC
- Susan Ewing, M.A., CCC
- Roberta J. Elman, Ph.D., CCC

Group & Individual Visits

- 1996—491 Visits
- 1997—2229 Visits
- 1998—2646 Visits
- 1999—3881 Visits
- 2000—4072 Visits
- 2001—4,458 Visits
- 2002—~ 5,000 Visits
Aphasia Center of California

- Aphasia is often chronic
  - Treatment should be similar to other chronic conditions
    - Diabetes
    - Arthritis
- Like a health club but for communication

Clinical Beliefs that Direct ACC Group Treatment

- Improve the ability to convey a message using whatever strategy is most useful for that individual.
- Foster increased initiation in conversational exchanges.
- Maximize each person’s opportunity to direct the discussion.
- Promote a lot of "cross-talk" or exchanges among group members.

Clinical Beliefs that Direct ACC Group Treatment (con.)

- It is valuable to practice conversational skills within the context of "typical conversations."
- The clinical techniques used to promote conversational interaction and information exchange provide the framework for successful groups—specific topics or tasks are simply the conversational springboard.

Clinical Beliefs that Direct ACC Group Treatment (con.)

- Benefits of conversational practice cross all types and all severity levels of aphasia.
- Capitalize on natural motivation to share topics of mutual interest.

Videotape Examples

- Communication Treatment Group

Book Connection™ Groups

♫ Goal: Reconnect with Books for Enjoyment
♫ Provide an age-appropriate social model: Book Clubs
♫ Help our Aphasia Center members reconnect with books and with each other
Book Connection™ Reading Ramps:

Reading Ramps make literature accessible through modifications that accommodate reading impairments (Bernstein-Ellis & Elman, 2006) <www.aphasiacenter.org>

The Book Connection™

We published the Book Connection™ materials in January 2006 on our website <www.aphasiacenter.org> so that others with aphasia can participate and benefit.

What are the Book Connection™ Reading Ramps?

Some are “off the shelf”:

- Unabridged Audiotapes
- Large Print Book version
- Info from the Internet
- Maps

Reading Ramps created for the Book Connection™:

- Summaries and Worksheets created for each book
- Vocabulary Guides
- Character Guides
- Timelines
- Schematics

Book Connection™ Discussion Groups

- Three weekly discussion groups
- One hour sessions
- Four to eight members per group
- Divided by severity of aphasia

The Book Connection™ Weekly Discussions

- Emphasize group members’ reactions to the book content
- Emphasize personal connections to story
- Emphasize humor
- Clarify story themes
I have a sense that, after my stroke, I did not get better until I met with other people with the same problem. My colleagues and I believe that joining a group is the most important thing that a stroke survivor can do for himself or herself.

Roger Ross
### The Introductory Program

A 12 week program delivered through the Pat Arato Aphasia Centre (PAAC)

The PAAC is the service delivery arm of the Aphasia Institute

### The Aphasia Institute

- Since 1979
- Started by a lay person
- Grassroots – group based

### The Pat Arato Centre

- Referral
- Assessment
- **INTRODUCTORY PROGRAM**
- Community Aphasia Program (CAP)

### Why group

- Cost effective
- Benefits of “collective wisdom”
- Focus on content and process
- Small units in the creation of community
The Introductory Program: some numbers

- 12 years of programs
- 1043 people with aphasia served
- 391 “significant others”

Groups within Groups

- Big group
- Small/home groups
- Family group
- Volunteer group
- Staff group

Language of Loss | Language of Life
---|---
loneliness | reconnection
isolation | camaraderie
grief | joy
Loss of identity | Claiming the “I”
Dependency | Freedom
Stress | Self care
Realization of chronicity | resourcefulness

Big Group

- Beginnings
- Endings

Small/home group

- Grouped by level of ability
- All follow the same curriculum
- 4-5 clients per group
- Lead by two volunteers
Family Group

- Parallel Process
- Large group of ‘significant others’
- No paid caregivers
- Co -lead by SLP and SW

Volunteer Group

- Skilled users of SCA
- Skilled group facilitators
- Ability to enable conversations and emergence of collective wisdom

Staff Group

- Learning centre for staff development
- Formal component of program staff orientation

The curriculum (content)

Four main threads
1. Getting to know you/Building Trust
2. Communication
3. Goal setting and moving forward
4. Endings

Getting to know you

- Pre preparation
- Telling your story
- Group beginning to form
Communication

• 4-5 weeks according to group needs
• What is aphasia?
• Getting the message IN
• Getting the message OUT

For this reason, R and I go to a place called the Aphasia Institute here in Toronto once every week, and we have conversations, and we are taught how to use of gestures and finger pointing and paper and a marker pen help to communicate with each other. The last visit there, we were asked to give a goal that we would like to set, and I chose to use the Aphasia Book to let all my friends and family know what I am going through, and how they can help me communicate with them. So this is why I am writing to you all. The same evening, R and I drew up the above list of persons we would write to, to let you all know that I am alive and well and trying very, very hard to cope with life now. Russi has added a little bit of his own to this message, but everything else is correct.

Goal setting

• Barriers to participating
• Choice as a value
• Self assessment
Ending

• Reflection and consolidation

• Evaluation

Documentation

• Weekly documentation
  - individual clients
  - group as a whole

  Promoting communication
  - journaling

Outcomes

• Week 2 and Week 12 (M)PCA

• Satisfaction surveys

• Development of A-FROM

Aphasia Groups:
One Approach Does Not Fit All

* * * * * * *

Kathryn Garrett

Seminar #1033

ASHA 2006

Miami, Florida

The issues

• Therapy for people with aphasia may often occur in structured, decontextualized contexts and teach discrete language subskills

• People with aphasia need a meaningful context within which to use language
  – personally relevant communication contexts
  – interactive contexts
  – functional contexts

SCAFFOLDED DISCOURSE MODEL

APHASIA GROUP THERAPY

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### Premise

- People with aphasia and neurologically-fragmented processing systems are the least likely individuals to reconstitute individually practiced subskills
  - Find it difficult to use words, grammatical structures, and gestures (practiced in isolation) in everyday communication
- Evidence on limited generalization supports this observation

<table>
<thead>
<tr>
<th>People with aphasia benefit from contextual support</th>
<th>maximizes their linguistic, cognitive, and communicative functioning</th>
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</thead>
<tbody>
<tr>
<td>- Thematic/topical activities</td>
<td></td>
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<tr>
<td>- Props</td>
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<tr>
<td>- Graphic context</td>
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<td>- Written labels</td>
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<tr>
<td>- Role playing</td>
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<td>- character acting</td>
<td></td>
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<tr>
<td>- scripts</td>
<td></td>
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<tr>
<td>- dilemmas, goals, and routines</td>
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</tbody>
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### Evidence

- Wallace & Canter, 1985
  - Personally relevant materials improve comprehension and expression for people with severe aphasia
- Reuterskiold, 1990
  - Emotionality of a topic or message increases auditory comprehension

### And also need...

- Skillful application and manipulation of cues, activity sequences, antecedents, opportunities to practice, and communication goals
  - “Scaffolding”

### Language/Communication Intervention Group

- All severity levels
- Goal -- get better

### A brief history

- University of Nebraska-Lincoln 1993-1996: Garrett & Ellis
  - Graduate student SLP clinical instruction venue
  - Adults with a wide variety of aphasia types, ages, backgrounds
- Duquesne University (Pittsburgh) 1998-present: Garrett, Staltari, Moir, & Baft-Neff
  - Ever-increasing demand for services at the post-acute rehabilitation phase
  - 20 members plus a waiting list
  - Individual and group therapy
  - Graduate student (SLP) clinical instruction
Constituency of Groups (3)

- **Mild Aphasia Group**
  - Participants have difficulties with fluency, semantic flexibility and specificity, organization of discourse, timing, and integration of language with high level social-pragmatic skills.
  - Participants have generally good auditory comprehension, and primarily communicate by speaking.
  - Are back to most routine life activities (exception - working at professional jobs) but complain that they “just don’t feel the same.”

- **Moderate Aphasia Group**
  - Difficulties with fluency, semantic flexibility and specificity, grammaticality, phonologic retrieval, repair of online communication breakdowns, organization of discourse, and integration of language with high level social-pragmatic communication.
  - Some comprehension challenges.
  - May communicate by speaking or supplement speech with alternative communication strategies.

- **Severe Aphasia Group**
  - Participants have limited to no verbal communication.
  - Mild-to-severe auditory comprehension breakdowns; noticeably better in contextual conversations.
  - Have difficulties initiating communication acts; conveying novel, semantically specific information; referencing what they’re talking about; attending to relevant info/conversational partners; engaging in reciprocal exchanges.

- **Organizational Structure**
  - University-based clinic.
  - Weekly sessions/1.5 hours.
  - 4-8 members.
  - SLP graduate students facilitate sessions (with supervision/co-construction).
  - Minimum of $8 per session – max of $30.
  - Insurance and other 3rd party payers often cover group therapy for 12 week blocks.
    - Medical Insurance.
    - Workman’s comp or Office of Vocational Rehabilitation.
    - Service group scholarships for individual clients.
    - Private pay – reduced fee schedule option.

Purposes (4) of Therapy Groups

1) To improve linguistic and motor speech skills.
   - Semantic/Syntactic.
   - Discourse.
   - Speech Intelligibility.

2) To improve interactional skills in.
   - Conversational Contexts.
   - Transactional Contexts (Shopping, Requesting).
   - Narrative Contexts (Storytelling).

3) To improve communicators’ use of compensatory strategies when appropriate.
   - Gestural deblocking.
   - Use of gestures (referential, symbolic, pantomime).
   - Purposeful circumlocution.
   - Self-cuing.
   - Rate reduction.
   - Responding via partner-supported strategies.
   - Low and High Tech AAC symbol systems.

4) To assist clients and significant others to learn to live with aphasia (after Lyon, 1996).
Structure of the Model – 4 phases

- 1) Conversation (20 minutes)
- 2) Context-Building
- 3) Language Mediation
- 4) Discourse

THEMATIC ACTIVITY
(60 minutes)

How it works…

- Conversation
  - No planning
  - Build on current events, happenings in participants’ lives
  - 1 primary clinician facilitator
  - Others provide individual support as needed
  - Communication skills:
    - Asking questions of others
    - Answering
    - Sharing information
    - Commenting
    - Introducing self and others

How it works…

- Thematic Activities
  - 1 clinician serves as lead facilitator
  - Group brainstorming meeting
  - Flesh out a core thematic idea
    - Make sure it’s relevant
    - Appropriate in terms of complexity
    - Has adequate communication opportunities
    - Provides a communication role
    - Anticipate scaffolding
    - Targets the appropriate language subskills for each participant
  - Lead clinician prints a plan
  - Mild Discourse group - clients aid in planning

Sample Theme - Election

- Context Building
  - Pictorial materials presented
  - Simple questions presented
    - Are you familiar with???
    - Who/what/where? (open-ended/choices)
    - Republican/Democrat/Independent? (choices)
    - Have you voted since your stroke? (yes/no)
    - Which issues are most important to you? (choices)

Scaffolding Strategies

- Visual context
- Props
- Timelines/graphic materials
- Models
- Tagged yes/no questions
- Written or pictorial choices
- Augmented Input
At the end of context building,

- The communication goal is broached
  - “To help you decide who to vote for... Ed Rendell (point to client) and Lynn Swann (point to client) are going to give a speech about these issues. You can rate them on each issue. You can ask them questions. We'll help you practice. Then, if you aren't too shy, tell us who you voted for and why.”

Language Mediation

- Practice with individual clinicians
  - “Ed Rendell” and “Lynn Swann” rehearsed their speeches
  - Other participants practiced asking questions
  - All modalities incorporated into practice

Scaffolding strategies

- Traditional speech cues
- Language Expansion cues
  - Syntactic models
  - Cohesive ties (“and...”)
- Semantic cues
- Multiple modalities
- Whole speech act cues - with intonation
  - (Now, say it like you mean it!)
- Feedback about adequacy of the message/discourse
- Multiple opportunities to practice

Final Discourse

- The SPEECHES!
- The QUESTIONS!
- The VOTE
- The EXPLANATIONS
- FINAL WRAPUP - clinician-led discussion about voting NOW, following aphasia

Sample Activities

- Mild Discourse Group
  - Advocating/Informing others about aphasia
  - Book reviews
  - Debates over controversial issues
  - Writing a letter to a political figure
  - Critiquing a movie, TV show, etc.
  - Members often suggest activities
  - Newspaper published monthly for awhile

- Moderate-Severe Groups
  - Greeting trick-or-treaters
  - Simulated Thanksgiving dinner
  - Directing the beautician/barber
  - Going to the Movies (with clients acting out a movie)
  - Showing visitors around Pittsburgh
  - Asking spouses out on a date
COMMUNICATOR:

- Communication ability
- Poor communication
- None

6. How many communication functions (e.g., asking questions, arguing, giving advice, greeting, generating unsolicited comments, or expressing opinions) did the communicator use when trying to convey messages that were not understood (i.e., speaking, writing, AAC system, etc.)?

- Methods
- 1  2  3  4  5  6  7

5. How flexible and strategic was the communicator when trying to convey messages that were not understood (i.e., speaking, writing, AAC system, etc.)?

- Methods
- 1  2  3  4  5  6  7

4. How frequently did Communicator X use different ways of communicating when trying to get his or her message across?

- Frequency
- 1  2  3  4  5  6  7

3. How much of the time did Communicator X take an active role in the interaction by asking questions, generating unsolicited comments, or expressing opinions?

- Participation
- 1  2  3  4  5  6  7

2. How much of the time was Communicator X able to get his/her message across?

- Message delivery
- 1  2  3  4  5  6  7

1. How much did the communicator participate in the interaction?

- Participation
- 1  2  3  4  5  6  7

Conclusions

- Effective model
  - For instructing clinicians
  - Targeting key communication skills
  - Integrating skills into discourse
  - Integrating skills into functional activities
  - Building a support community
  - Improving communication
  - Enriching our understanding of the therapeutic process

Garrett References


Outcomes assessment

- Ratings
- New tool for each component of the session
- Impairment (test) scores

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