Measuring Changes in Life Participation Associated with Attending an Aphasia Group
Poster Handout
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Social Integration
For People with Aphasia (PWA)
Some key contributors prior to 2000
Schuell, Jenkins, & Jimenez Pabon, (1964) describe social benefits of groups for PWA; see group as adjunct therapy
• Lyon (1992) issued call for SLPs to address the “handicap of aphasia” and train/include communication partners/focus on activities of choice for people with aphasia
—See also Lyon et al., 1997.
• Kagan & Gailey (1993) – Trained conversation partners for groups to address “handicap of aphasia”
• Elman & Bernstein-Ellis (1999) prove groups are efficacious in bringing about improved communication

Background
• World Health Organization International Classification of Impairments, Disabilities and Handicaps (ICIDH) published in 1980
—Major terms of ICIDH – impairment, disability and handicap
• New classification system approved by WHO in 2001 —The International Classification of Functioning, Disability and Health (ICF)
—“Activity limitation/participation restriction” replaced terms “disability” and “handicap”; many other changes.

Background, cont.
• ASHA included WHO’s ICF framework in SLP scope of practice (2001)
• Life Participation Approach to Aphasia (LPAA) (Chapey, Duchan, Elman, Garcia, Kagan, Lyon & Simmons-Mackie, 2001)
—Comprehensive approach consistent with tenets of WHO to consider environmental and personal factors in the therapy process
—Include communication partners, expand communication opportunities and life participation

Background:
Investigators assisted with revisions of ICF
• Vickers was a participant in the beta-2 field testing of the ICF for the communication sections. She is also founder of Communication Recovery aphasia groups at St. Jude Medical Center in Fullerton, California and author of book by same name (Vickers, 1998).

• Threats is the ASHA representative liaison to the World Health Organization (WHO) for development of the communication and swallowing sections of the ICF. He is the Senior Consultant for the American Psychological Association and the WHO in the development of a clinical manual of the ICF entitled Procedural Manual and Guide for the Standardized Application of the ICF: A Manual for Health Professionals.
—(Threats has written extensively about the ICF: See for example, Threats, 2000, 2001, 2002 & 2004 and others listed on references)

The ICF (WHO, 2001)
• Designed to be useable classification system for all stakeholders in health care
• Includes operational definitions for all categories, complete coding system, neutral terminology, inclusion of environmental factors, biopsychosocial orientation
• Acknowledges crucial role of environment in considering how persons with disabilities live their lives. Factors can hinder or facilitate communication and can be systematically recorded using codes for both barriers and environmental facilitators.

Goal of Pilot Study
• To explore life participation in natural communication environments through assessments based on ICF codes.

Communication Recovery (Vickers, 1998) aphasia group participants identified as convenience sample.
• IRB approval from St. Jude Medical Center, in 2002 to conduct questionnaire surveys and structured interviews with family members of current group members.
• Consent obtained from 8 group members & their family members.

Study site: Communication Recovery Group (CRG)
• Weekly Communication Recovery conversation groups founded in 1994 by Vickers at Jude Medical Center, Fullerton, California.
• Purposeful use of environmental facilitators such as Written Choice Communication (Garrett & Beukelman, 1992) and Communication Partner Volunteers (Lyon, 1992) in group sessions.
• Peer interaction in a supportive environment promoting sense of community with both peers with aphasia and volunteers of all ages, including volunteers who are stroke survivors.

Participant Selection Criteria
• Diagnosis of stroke(s).
• No known dementia or degenerative neurological condition.
• Acquired neurogenic communication disorder, chronic for 6 months or more.
  – (7 participants with chronic aphasia; 1 with mild dysarthria)
• Discharged from 1:1 individual speech/language therapy prior to group entry.
• No additional one to one therapy at any time since attending conversation groups in Communication Recovery.
• Not attending any other communication group.
• Immediate family member willing/able to be surveyed and interviewed.

Summary of Participants
• 7 male, 1 female; Age range-63 to 85 yrs.
  – Mean age=76.75 years old.
• Race/ethnicity: White/Anglo=7; Asian=1
  – 7 spoke English as L1, 1 bilingual English/Japanese.
• Mobility impairment in 5 of 8 participants.
• Aphasia Severity Rating (Goodglass & Kaplan, 1984)
  • Scale ranges from 0 to 5.
  • (0=no usable speech or comprehension; 5=minimal discernable handicap)
  – 2 members= 1 (Severe)
  – 4 members= 2 (Moderately severe)
  – 1 member= 4 (Mild to moderate)
  *(There was also 1 non aphasic participant)
• Educational levels – 4 with high school diploma, 1 completed 10th grade, 1 with B.S. degree, 1 with M.A. degree, 1 with PhD.
• Amount of 1:1 therapy received prior to group entry:
  – Range= 0-12 mos. (Mean=13.3 wks)
• Amount of time in group prior to study:
  – Range=3 months-7 yrs, 8 mos. (Mean=28.13 mos.)
Methods
• 8 group members/significant others randomly assigned to 2 teams of graduate students unfamiliar with members and their families
• Students trained and provided with written testing protocols
• 2 separate face to face interviews set up with family members outside of group sessions at St. Jude Medical Center

Structure of study
• Retrospective portion
  – Written questionnaire & structured interview about family member’s perception of participant’s communication in the month preceding entry into Communication Recovery
• Current Situation
  – Written questionnaire & structured interview about family member’s perception of participant’s communication over the past month
  – *Order of interviews & questionnaires for retrospective and current situation randomized

Content of Written Questionnaires based on activity/participation and environmental factors from ICF
• Questions concerned communication modalities (gesture, use of speech, writing/drawing)
• Also discourse skills, social skills
• Questions written with 5 point Likert scale type responses

Results from Written Questionnaires:
Mean scores reported for all individuals comparing pre and post group attendance abilities for communication, discourse, and social skills demonstrated positive change for most members in all areas. (Two members showed slight decline in discourse skills and one in social skills, possibly due to medical setbacks during study.) Further analysis not undertaken due to small sample size and preliminary nature of study on assessments based on ICF framework.

Structured Interviews:
Recurring themes about changes since attending Communication Recovery (CRG)
• Benefits of exposure to peers undergoing similar communication struggles
• Decrease in frustration, increased willingness to interact
• Increased participation in social activities with families/friends
• Increased attempts to help others
• Increases in telephone usage

Discussion
• Limitations of study:
  – Pilot study with small sample
  – Retrospective comparison to current situation versus baseline and later comparison

Discussion
• Despite limitations, results show usefulness of the ICF in guiding assessments for the performance qualifier of the Activity/Participation construct.
• Changes captured in this pilot study:
  – Observable changes in nonverbal communication in natural environments
  – Observable changes in use of verbal communication and compensatory strategies
  – Observable changes in helping behaviors, increased social involvement
References:


