

A Caregiver Curriculum for Living with Partners with Aphasia



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The University of Michigan Aphasia Program's (UMAP) Approach to Caregiver Education and Support

- UMAP is one of the few clinical programs that offers intensive therapy to adults with aphasia.
- UMAP addresses total communication with verbal expression being a critical component of the treatment protocol.
- Adults attend one or more monthly 4 week sessions receiving individual, group and computer and technological based therapy, 5 days per week.
- Structured therapy sessions are supplemented by:
 - group music
 - recreational activities
 - weekly dinner club

The University of Michigan Aphasia Program (UMAP)'s Approach to Caregiver Education and Support

- The Caregiver Support Group was initially requested by a UMAP caregiver and has become a critical component of UMAP
- Caregivers are provided with opportunities to learn and adjust to living with family members with aphasia
- Caregivers participate in weekly educational seminars and a psychosocial group
- Recreational activities in the community offer respite and opportunities for caregivers to share experiences

Words of a Caregiver

- *“Stroke disrupt lives. Without warning this giant picks up your house, turns it over, and shakes it vigorously. Nothing is untouched, not even your children.”*

- A. Harlow, wife of stroke survivor and former UMAP participant

Caregiver Stress

- Aphasia is particularly stressful to caregivers and comparable to that found in dementia caregivers (Draper et.al.,2007)
- Caregivers experience financial, health and significant alterations in their social lives
- Greatest change is role reversals for family and assuming new responsibilities (Luterman, D. ,2008)
- Caregivers exhibit feelings of anger and guilt (Luterman, D., 2008) and greater marital difficulties (Draper et.al., 2007)
- Exhibit depression, loneliness and other emotional problems (Draper et.al.,2007)
- As caregivers' well being declines so does their ability to care for the survivors and this increases their risk for poor health (Ostwald et.al.,2009)

Caregiver Stress (Ostwald et. al., 2009)

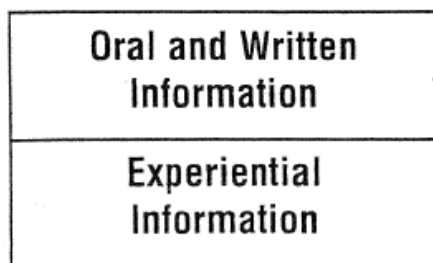
- Ostwald et.al., 2009 compared stress level experienced by couples first year home post-stroke
- The Perceived Stress Scale (PPS) and other measures used to assess health and well being of couples at 3, 6, 9 and 12 months
- Results indicated that PPS scores for caregivers and survivors were positively correlated
- -**Preparation** (knowledge, perception to care for physical and emotional needs and ability to arrange services) was a strong predictor of stress in caregivers
- - **Mutuality** (the degree of which the couple's relationship was characterized by love, shared activities and common values) was the strongest predictor for survivors
- Other predictors of higher stress in caregivers include: poor health, being younger, lack of preparation for care-giving duties and absence of social support

What is the role of the SLP?

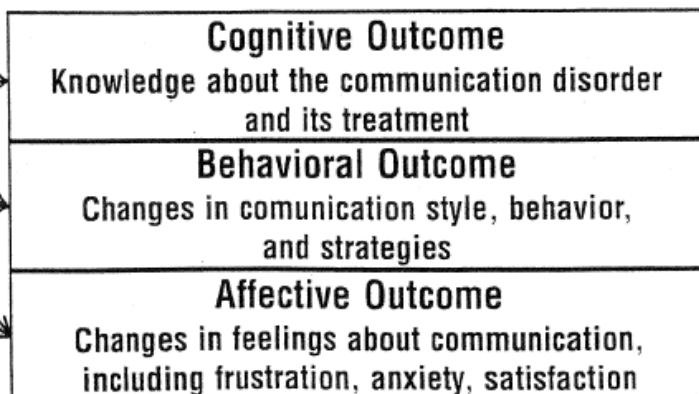
- Hinckley (2000) indicated that clinicians need to provide information in an effective manner that is ongoing, with at least three repetitions and combining oral, written and experiential information.

Figure. Possible relationships between form of family education and predicted outcomes. Verbal information affects cognitive, behavioral, and affective outcomes, and experiential information affects behavioral and affective outcomes.

Form of Family Education



Education Outcomes



- Possible relationships between form of family education and predicted outcomes (Hinckley).

What is the role of the SLP?

- Avent et.al (2005) study identified information needs of family members at different stages of aphasia: onset (hospitalization), initial speech-language intervention (rehabilitation) and return to home (chronic)
- Three recurrent informational needs noted during each stage: specific, time-based information, need for psychosocial support and counseling and positive expectations for the future
- Four additional topics included: complexity of aphasia, emotional impact of aphasia, lack of hope conveyed to family members and the numerous sources about aphasia
- The type of information was dependent on time post-onset
- Adjustment to aphasia is long-term for families
- SLPs play a key role in educating family members at all stages

SLP and Family Education

- Research has shown to maximize recovery in adults with aphasia, it is imperative that family education is initiated at onset and is ongoing throughout rehabilitation
- Speech-language pathologists play significant roles in fostering education and acceptance in clients and caregivers
- Speech-language pathologists must be good listeners to support caregivers
- Speech-language pathologists should seek mental health professionals when necessary

Caregiver Education Draper (2007)

- Draper studied stress in caregivers who participated in a four week program that targeted education, support and improving communication skills to determine if this would reduced caregiver stress and improve communication between couples
- Caregivers showed modest gains on measures of psychological function and benefited from a mix of education and emotional support to reduce stress
- Caregiver training does not change the burden of care, only the stress of the reaction
- Caregivers maintained gains by continual contact with other caregivers
- UMAP has created its own successful program that addresses these areas of concern
- UMAP caregivers also participate in ongoing recreational outings that offer respite care and time to develop friendships with others like themselves
- We continue to reassess our caregiver curriculum and hope to add new dimensions to the program

Yalom's 11 Curative Factors of Group Treatment (1995)

At UMAP, this approach has been utilized successfully with our UMAP caregivers.

- **Universality**: feeling of having similar problems to other; we are not alone
- **Altruism**: opportunity to rise out of one's self and help somebody else; feeling of usefulness
- **Instillation of Hope**: inspiration and encouragement from others who have overcome problems with which they are still struggling
- **Development of Socializing Techniques**: learning new ways to talk about feelings, observations, and concerns in a safe, supportive environment
- **Catharsis**: release of emotional tension; members sharing their stories to a supportive audience
- **Interpersonal Learning**: Finding out about themselves & others in the group

Yalom's Curative Factors of Group Treatment (1995) cont.

- **Imparting of Information:** teaching about problem and recovery
- **Direct Advice (Guidance):** receiving and giving suggestions for strategies for handling problems
- **Imitative Behavior:** taking on the manner of the group members who function more adequately
- **Corrective Recapitulation of Primary Family Group:** identifying and changing the dysfunctional patterns or roles one played in primary family
- **Existential Factors:** responsibility for their own actions

The UMAP Caregiver Curriculum

Educational Seminars

- Discussing aphasia and strokes
- Explaining other related disabilities
- Telling their stories
- Sharing and demonstrating communication strategies
- Teaching supportive conversation to caregivers with “hands on” training and watching DVDs
- Reviewing research on intensive therapy and UMAP outcomes
- Creating intensive therapy at home
- Sharing resources and experiences living with aphasia
- Being hopeful and realistic about progress your partner in therapy
- Being optimistic about their future together

Psychosocial Meetings

- Telling the narrative
- Exploring the emotional impact
- Connecting common themes between group members
- Normalizing feelings
- Exploring role changes
- Identifying needs and ways to meet them
- Helping that works, and helping that doesn't
- What are realistic expectations?
- Being hopeful about future

Nicki Wilson

Former UMAP caregiver tells her story



Picture of LE and CE



Case Discussion: LE

- 76 year old female
- Severe receptive and expressive aphasia secondary to a stroke incurred in March 2005
- Lived with her sister, CE, her primary caregiver
- Retired executive assistant
- Enjoyed reading novels, gardening, doing crossword puzzles and socializing with family and friends
- Engaged in household management and decision making tasks with encouragement from sister
- Attended UMAP for 2 sessions
- Attended weekly language group (LEG)

Response to Therapy

LE

Areas of Improvement

- **Reading Comprehension** at improved from 60% - 75% for matching sentences to pictures (field of 2)
- **Written Expression** improved for writing functional vocabulary, using letter slots for spelling completion

Areas of Weakness

- **Verbal Expression** limited to spontaneous production of 2/5 core vocabulary words-difficulty with initiation
- **Auditory Comprehension** unchanged on “Auditory Recognition of Words” on the **WAB** and inconsistent responses to “yes/no” questions
- **Supportive Conversation** LE and sister required maximum assistance to participate in these conversations.

Personality Traits LE

- **LE Pre Stroke:** Older sibling ,controlling and bullied CE, who was the follower
- **LE Post Stroke:** Reduced stamina, ongoing fatigued impacted ability to communicate, difficulty with initiating words but able to control situations nonverbally (refused to having pictures taken or to transfer into a chair)

Family Dynamics

LE and CE

- LE was historically the dominant sister and used to tell CE what to do and how to do it
- CE had been submissive for 60 years
- Post stroke this pattern was disrupted by necessity and LE became agitated as CE became more assertive
- Group became a place for CE to explore her new role and be supported

Success Story

LE and CE

A combination of therapy interventions enabled LE and CE to work through their emotional and communicative challenges to achieve fulfilling lives

- LE was more self-confident and hopeful about her recovery after ongoing encouragement from the clinicians at UMAP
- LE spontaneously used various communicative strategies (gestures and picture dictionary) learned in therapy to convey messages at home.
- LE was more accepting of CE's inability to not fully understand messages and would try again
- CE was able to anticipate the needs of her sister which reduced communication breakdowns
- CE was actively involved in the Caregiver Curriculum and observed therapy sessions
- CE had become more assertive and took charge of the relationship
- CE and LE both had learned to live a life with aphasia successfully

Picture of LS and LS



Case Discussion: LS

- 81 year old male
- Severe receptive and expressive aphasia, as well as apraxia, secondary to a stroke incurred in December 2005
- Lives with wife, LS, primary caregiver
- Has one adult son
- Jazz musician and retired music educator
- Enjoyed watching CNN, going to restaurants, attending concerts, traveling and visiting with friends
- Discharged from speech therapy at UMAP 4/11
- Continues music therapy twice at UMAP

Case Discussion: LS

Response to Therapy

Areas of Improvement

- **Multimodal Skills** improved for matching single object pictures to corresponding section (choice of 3) in picture dictionary and also scanning categorical tabs
- **Auditory Comprehension and Multimodal Skills** for responding to “wh” questions using picture dictionary increased by 30% accuracy
- **Reading Comprehension** from 60% to 75% accuracy for answering multiple choice questions related to biographical stories

Areas of Weakness

- **Multimodal Skills** were unchanged for selecting the corresponding pictures in the dictionary
- **Verbal Expression** is characterized by stereotypic syllables or phrases, imitates core phrases and successful with sentence completions

Personality

LS

- **LS Pre-Stroke:** Outgoing, friendly and loved to tell stories about musicians, made decisions together, became angry when wife pushed him to do something, not a dependent person
- **LS Post-Stroke:** Still outgoing talks to fellow musicians, displays a pleasant demeanor, enjoys when others introduce him, sometimes quiet, sad, and discouraged

Family Dynamics

LS and LS

- History of spouse being extroverted, sociable and a celebrity status having access to the International jazz music scene
- Wife made this happened with planning, resources and organizational skills
- After stroke, invitations stopped, there was a new less glamorous life with wife still planning everything, with few rewards

Success Story LS and LS

Numerous intervention approaches has aided LS and LS over the years to deal with the ongoing emotional and communicative challenges to have a meaningful life

- LS is a highly social and engaging individual who spontaneously gestures, and produces a few automatic words/phrases learned in therapy that helps convey messages at home
- LS 's ability to read words enhances his comprehension to follow limited conversations at home and in the world of music
- LS becomes mad over small issues that can't communicate, uses profanity with wife and apologizes for anger
- LS and LS, as a couple, continue to adjust to living with aphasia
- LS expresses that communication strategies are helpful at times but there are many communication breakdowns and both frustrated
- LS talks to him about selected topics and LS listens but responds with jargon
- LS can anticipate some of his needs and shares his love and knowledge of music
- LS is clinically depressed, tired of caring for LS and seeks their past life
- LS was involved in the Caregiver Curriculum in the past and continues to come to UMAP for social outings and to connect with other caregivers and clients

Caregiver Curriculum

Collaboration is essential!

Caregivers

- Establish realistic expectations if possible, based on the degree of aphasia and life experiences
- Be hopeful but balance with realism
- Listen rather than persuade
- Accept the family dynamics
- Create a hopeful environment

Professionals

- Working together based on mutual respect and trust creates success
- Sharing information about clients and caregivers has a significant impact on outcome
- Accept that it is a long and gradual process to see change in caregivers and clients
- Be flexible, go with the flow and don't give up!
- Be optimistic
- Be sensitive to the needs of the caregivers and clients

Activity: Developing a Caregiver Curriculum

- Create a caregiver curriculum for your clinical setting
- What would the critical elements of the program be?
- What barriers might you encounter?
- What other allied health or support staff would work with you?
- How would you get support from the other team members?

Summary

- Aphasia is a very isolating disorder and the caregiver groups offer a rare experience to connect, normalize and develop realistic expectations for the present and future.
- We encourage other professionals to bring together other family members who need the support and access to transformation in a group process.

Caregiver Resources – Websites

- American Speech Language Hearing Association
www.asha.org
- Aphasia Hope Foundation
www.aphasiahope.org
- Brain Injury Association
www.biausa.org
- National Aphasia Association
www.aphasia.org
- National Stroke Association
www.stroke.org
- American Heart Association
www.americanheart.org
- American Stroke Association (group locator)
www.strokeassociation.org
- University of Michigan Aphasia Program
www.aphasiahelp.com

Caregiver Resources – Books

- *Brain Attack, A Journey Back* by Liz Pearl (2005)
- *By His Side: Life and Love After a Stroke* by Eileen Stets Quinn (2002)
- *Care Packages* by Dana Reeve (1999)
- *Caregiving: Hospice Proven Technique* by Douglas Smith (1997)
- *Family Guide to Stroke: Treatment, Recovery and Prevention* by the American Health Association (1994)
- *Five Silent Years of Carrie TenBloom* by Pamela Roswell (1986)
- *God Isn't Finished With Me Yet* by Kathy Hughes (1990)
- *Helping Yourself Help Others* by Rosalyn Carter (1994)
- *Hiring Home Caregivers* by Helen Susik (1995)
- *I'll Carry the Fork* by Kara L. Swanson (2003)
- *I'll Take Care of You* by Joseph Illardo and Carole Rothman (1999)
- *Into the Blue: A Father's Flight and a Daughter's Return* by Susan Edsall

Caregiver Resources – Books cont.

- *Let me die laughing* by Megan Timothy
- *Like a Bolt: Tragedy to Triumph After Stroke* by Mary Morgan (2003)
- *Magic of Humor in Caregiving* by James Sherman (1995)
- *Minding the Body, Minding the Mind* by Joan Berysenko (1987)
- *My Year Off* by Robert McCrum
- *Rewire Your Brain, Rewire Your Life: A Handbook for Stroke Survivors & Their Caregivers* (2008) by Bob Guns
- *National Directory of Brain Injury Rehabilitation Services* (2005)
- *Patricia Neal: As I am – An Autobiography*
- *Ted's Stroke: The Caregiver Story* by Ellen Paullin (1988)
- *The Diving Bell and the Butterfly* by Jean Dominique Bauby (1998)
- *The After Stroke* by Evelyn Shirk (1991)
- *SPARRC (Supporting Partners of People with Aphasia in Relationships & Conversation)*

Caregiver Resources – Video/DVD

- **After Words:** A documentary Film featuring The Aphasia Community Group (DVD)
- **An Act of Love: The Patricia Neal Story**
- **Aphasia – A New Life:** York Durham Aphasia Centre
- **Care Packages:** Dana Reeve (Cambria Productions: 1999)
- **Caregiver: A video for caregivers of heart or stroke patients** (American Heart Association)
- **Communication: How to Communicate with Someone with Aphasia** (Healing Arts Communication)
- **Finding Their Voice** (The University of Michigan Residential Aphasia Program)
- **Stroke: When Minutes Matter** (American Stroke Association)
- **The Educated Caregiver: Coping Skills (3 part series)** (Life View Resources)

Caregiver Resources – Video/DVD cont.

- **Faces of Aphasia** (Boston University February 26,2000) DVD
- **After a Stroke** by Cleo Hutton (2005)
- **I Lose My Words** (Aphasia Support Group Session-Goshen, Indiana)
- **Pathways** (Susan Adair Ewing and Beth P. Pfalzgraf)
- **Speaking Out 2006:** Fifth National Conference (National Aphasia Association)
- **Supported Conversation for Aphasic Adults** (Aphasia Institute)
- **Using Coumadin Safely and Effectively** (DuPont Pharma)
- **What is Aphasia?** (Susan Adair Ewing and Beth P. Pfalzgraf)

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