

The Importance of Aphasia Group Treatment for Rebuilding Community and Health

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Recent interest in aphasia group treatment has been motivated by the potential benefits of working in a group environment. This article provides research evidence for the speech-language and psychosocial benefits of conversationally based aphasia groups. The history of aphasia groups and independent aphasia centers consistent with a social model of healthcare and the Life Participation Approach to Aphasia is traced. Research evidence is reviewed that demonstrates positive health benefits of building interpersonal relationships and community. It is argued that an important role for the speech-language pathologist is to help reconnect persons with aphasia to their family members, their friends, and their community. **Key words:** *aphasia, community, conversation, group treatment, positive health, social model, treatment*

We must stay focused on connecting people, not on fixing them.

Condoluci (1991)

APHASIA group treatment has been enjoying a renaissance since the 1990s (Elman, 2007). During World War II, too few speech-language pathologists were available to meet the growing number of soldiers who had sustained gunshot wounds to the brain. Group treatment became a practical solution to this lack of staff resources (Kearns & Elman, 2001, in press). World War II also spurred development of support groups at Veteran's hospitals for those living with aphasia (Kearns & Simmons, 1985). In addition, the Department of Veteran's Affairs contributed research on the effectiveness of group therapy with a cooperative study that compared individual treatment with group treatment in individuals who had acute aphasia. The results of this

study indicated that group treatment resulted in similar outcomes to individual treatment (Wertz et al., 1981).

Recent interest in aphasia group treatment has been motivated more by the potential benefits of working in a group environment rather than by a lack of personnel. Elman (1999a, 1999b, 2007) has suggested a number of potential speech-language and psychosocial benefits to aphasia groups that are conversationally based:

- Conversational aphasia groups promote interaction among members, which may encourage increased communicative initiation and turn-taking as well as an increased variety of communicative functions or speech acts (Davis, 1986; Wilcox, 1983).
- A conversation group provides an array of communicative partners and a more natural communicative task, which may increase the likelihood of transfer of treatment gains to home and community environments (Kearns & Elman, 2001, in press; Lyon, 1992). In addition, generalization may be more likely to occur with conversational practice than work on more basic linguistic tasks, given evidence that treating complex

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behaviors increases generalization when compared with treating simpler behaviors (Thompson, 2007).

- Groups may help to facilitate the improvisational nature of language as compared with reliance on rote learning of linguistic forms and specific utterances (Elman, 2004).
- Aphasia group treatment may directly or indirectly improve an individual's psychosocial functioning by providing a supportive environment with others who share similar issues and feelings (Elman & Bernstein-Ellis, 1999a).
- Conversational aphasia groups provide an opportunity for individuals with aphasia to affiliate with others at the same time as they are exchanging thoughts, opinions, and feelings (Elman, Kagan, & Cohen-Schneider, 2001).
- Conversationally based aphasia groups provide opportunities for both interactional and transactional uses of language (Brown & Yule, 1983; Elman, 2005; Simmons-Mackie, 2001).
- Group treatment can provide a vehicle for people with aphasia to work on establishing a new and positive identity (Elman, 2007; Pound, Parr, Lindsay, & Woolf, 2000; Shadden, 2007)
- Group treatment is a cost-effective way of providing treatment. This is becoming increasingly important as healthcare moves to a mature managed care model (Elman, 1998; Elman & Bernstein-Ellis, 1995).

HISTORY OF APHASIA CENTERS

Aphasia centers are a fairly recent addition to the continuum of services for people with aphasia. They are a logical extension of aphasia group programs. Although not created as an aphasia center, the Residential Aphasia Program (RAP) was established in 1947 at the University of Michigan in Ann Arbor to help World War II veterans. The RAP combined intensive individual and group treatment for people with aphasia, and began to serve non-veterans with aphasia after the war. RAP par-

ticipants received treatment for 6 weeks at a time, thereby creating a "short-term" aphasia center.

In 1979, Pat Arato founded the first independent, community-based aphasia center. Located in Toronto, Canada, and now called the Aphasia Institute, Arato desired services for her husband whose stroke had left him with aphasia. Inspired by actor and stroke survivor Patricia Neal, Arato and three other volunteers worked with a group of seven adults to reduce language barriers and enable communication. Today, the Aphasia Institute has 17 staff members and 100 volunteers, and provides direct services to more than 600 people with aphasia and their families annually. The institute serves as a local, provincial, national, and international resource for those affected by or working with aphasia (A. Kagan, personal communication). Information about the Aphasia Institute's programs, aphasia friendly resources, and training programs is available at its Web site (www.aphasia.ca).

The Aphasia Center of California (ACC) was the first independent, community-based aphasia center created in the United States. The present author's visit to the Aphasia Institute in 1989 served as a catalyst for the 1994 group treatment efficacy research that established the foundation for the ACC (Elman & Bernstein-Ellis, 1999a,b). The ACC currently provides more than 4,600 annual visits to 160 people with aphasia and their family members. In addition to the services provided in California, the aphasia center's Book ConnectionTM manual and materials have been used by other speech-language pathologists to start their own aphasia book clubs (Bernstein-Ellis & Elman, 2006, 2007). Additional information about the ACC's programs and the Book ConnectionTM is available on its Web site (www.aphasiacenter.org).

The 1990s and early 2000s saw a dramatic growth in the creation of independent, community-based aphasia centers. These centers were often inspired by the work of the Aphasia Institute and the ACC. Notable independent aphasia centers include the Connect program in the United

Kingdom (www.ukconnect.org), the Adler Aphasia Center in New Jersey (www.adleraphasiacenter.org), the York-Durham Aphasia Centre in Toronto (www.ydac.on.ca), and the West Texas Aphasia Center in Midland (www.wtx-aphasiacenter.org).

In addition to the growing number of independent, community-based aphasia centers, numerous aphasia programs are affiliated with universities, hospitals, and other outpatient settings. These programs provide a range of services. Some offer a single aphasia group, whereas others provide a more comprehensive array of services for those affected by aphasia.

MEDICAL MODEL VERSUS SOCIAL MODEL

Prior to the establishment of aphasia groups and aphasia centers, the vast majority of services for people with aphasia were provided in hospitals and rehabilitation settings. These settings typically followed a traditional or *medical model* of healthcare. The medical model typically views the individual as a “patient” with an ailment that needs to be fixed by an “expert.” This paradigm seems best suited to handle acute problems that result in a “cure” (Elman, 2005). Conditions such as aphasia, which are often chronic, can present a challenge for the medical model of healthcare, because a cure is often not possible. In contrast to the medical model, a *social model* of healthcare has evolved. This paradigm views the person as part of a collaborative team, along with healthcare professionals. Healthcare problems are seen as an interaction among personal, physical, environmental, and societal factors. The healthcare goal in the social model is to create positive change, even when a cure is not possible. A social model of healthcare may provide a better fit for chronic disorders, such as aphasia, than a medical model (Elman, 2005; Simmons-Mackie, 2001).

The World Health Organization (WHO) has created a multipurpose health classification system identified as the International Classi-

fication of Functioning, Disability, and Health (ICF), which attempts to integrate the medical and social models of healthcare. The ICF offers a framework for describing human functioning and disability. The first part of the framework includes two components: body structures and functions, and activities and participation. The second part of the framework refers to contextual factors that include two components: personal and environmental factors. The reader is referred to the WHO publication for a complete description of this framework (WHO, 2001).

Most aphasia centers have a philosophy of service delivery consistent with a social model of healthcare. Pioneers of social approaches to aphasia treatment included Sarno (1969) and Holland (1980), but it was not until the 1990s that a growing number of aphasiologists began to focus their attention on social approaches to aphasia assessment and intervention. The Life Participation Approach to Aphasia (LPAA Project Group, 2001), a social model framework proposed by Roberta Chapey, Judith Duchan, Roberta Elman, Linda Garcia, Aura Kagan, Jon Lyon, and Nina Simmons-Mackie, had its start during informal discussions and meetings in the early to mid 1990s, followed by a formalized working meeting in 1999. The LPAA was an independent effort, and, in part, a response to those in the United States who were stating that aphasia therapy was “dead.”

The LPAA attempts to unite various approaches to assessment, intervention, research, and advocacy. The LPAA framework includes five core components: (1) The explicit goal is enhancement of life participation; (2) all those affected by aphasia are entitled to service; (3) both personal and environmental factors are targets of assessment and intervention; (4) success is measured via documented life enhancement changes; and (5) emphasis is placed on availability of services as needed at all stages of life with aphasia (LPAA Project Group, 2001). The LPAA indicates that advocacy efforts should focus on those components that are not yet available in our current healthcare systems. As long as these five core components are

met, various types of aphasia assessments and interventions are consistent with the LPAA, including, but not limited to the following: aphasia group treatment (Elman, 2007), augmentative and alternative communication (AAC; Beukelman, Garrett, & Yorkston, 2007; Lasker, LaPointe, & Kodras, 2005), supported conversation for people with aphasia (SCATM; Kagan, 1998), self-advocacy training (Coles & Eales, 1999; Penman & Pound, 2007), and couples and family training (Boles, 1998; Lyon & Shadden, 2001). Although the LPAA Project Group (2000, 2001) was not the first to propose a social framework for aphasia research and services, it has been an important catalyst in changing and refocusing clinical, research, and advocacy efforts.

BENEFITS OF BUILDING COMMUNITY FOR PEOPLE WITH APHASIA

Aphasia can be a very isolating condition. When communication skills are lost or reduced, connecting with other people can be challenging at best. Sarno (2004) stated, "Aphasia not only disconnects the person from the community but invariably alters the person's identity and sense of self" (p. 22). Sarno (2004) went on to state,

A social model calls for a revision of intervention practices away from the traditional focus on static, noninteractive techniques intended to repair the language deficits manifest in aphasia, to approaches which acknowledge the social, interactive basis of human relationships. A high priority therapeutic goal is living with aphasia in the context of family and community (p. 26).

By nature, aphasia groups and aphasia centers provide something that individual treatment does not: groups connect people with aphasia to one another and are one way to build community. Yalom (1995) listed eight factors as the reasons why groups are "curative" or effective in psychotherapy: universality, instillation of hope, imparting of information, interpersonal learning, altruism, group cohesiveness, catharsis, and existential issues (Ewing, 2007; Luterman, 2001). Elman (1999b, 2000, 2007) added humor among rea-

sons why group treatment may result in positive outcomes.

Aphasia groups and aphasia centers provide places where people with aphasia can become part of a community that accepts and nurtures them. The dictionary definition of *community* includes three separate notions that all play a part in the community that groups and aphasia centers can offer (*Merriam-Webster's Collegiate Dictionary*, 2003). One definition is that a community is a unified body of individuals with common interests, a common location, common characteristics, a common policy, and/or a common history. This first notion of community is one reason that people are likely to join aphasia groups and aphasia centers—they have a common history of stroke or other acquired brain injury that results in similar interests and needs. A second dictionary definition of *community* includes the notion of society at large or the "bigger community." This bigger community often excludes people with aphasia when they are denied access to rights and services because of their communication disorder (Simmons-Mackie et al., 2007). Part of the role of speech-language pathologists, consistent with the American Speech-Language-Hearing Association's (ASHA's) scope of practice, is to enable people with aphasia to achieve fuller access to the community (ASHA, 2001). The third dictionary definition of *community* includes the notion of joint ownership or participation, common likeness, fellowship, or social state. Building fellowship with joint participation and leadership is a hallmark of effective aphasia groups and aphasia centers (Elman, 2000, 2007). These dictionary definitions are consistent with the various aspects of community that people with aphasia need to rejoin for functioning and participation.

SPEECH AND LANGUAGE BENEFITS OF APHASIA GROUPS: RESEARCH EVIDENCE

A growing number of studies provide evidence supporting the effectiveness and efficacy of aphasia treatment groups. As

mentioned earlier, Wertz et al. (1981) compared individual treatment with group treatment. By random assignment, participants received 8 hr weekly of either individual or group treatment. Group treatment focused on general conversation about current events and did not include direct manipulation of linguistic skills. This study found that overall performance on the *Porch Index of Communicative Ability* (PICA; Porch, 1973) was the only measure that showed significant differences between individual and group treatments. No significant differences were apparent on the *Token Test* (DeRenzi & Vignolo, 1962), *Word Fluency Measure* (Borkowski, Benton, & Sprren, 1967), *Coloured Progressive Matrices* (Raven, 1962), a *Conversational Rating* scale created for the study, and an *Informant's Rating* scale of functional language use adapted from Sarno (1969). Wertz et al. (1981) stated,

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 aphasic patient's care. (1981, p. 592)

Aten, Caliguiri, and Holland (1982) studied whether functional communication treatment was effective for seven, nonfluent patients with chronic aphasia who had reached a plateau on the PICA after "language-based" treatment. A control group was not utilized in this study. Participants received 2 hr of weekly treatment for a 12-week period. Treatment focused on improving functional communication in simulated situations such as shopping and reading labels. Results revealed significant improvement on the *Communicative Abilities of Daily Living* (CADL; Holland, 1980) but not on the PICA.

Bollinger, Musson, and Holland (1993) utilized a treatment/withdrawal design that provided participants with 3 hr of structured treatment weekly for 40 weeks. Ten individuals with chronic aphasia received "contemporary group treatment" and "structured television viewing group treatment" alternat-

ing with 10 weeks of no treatment. "Contemporary group treatment" consisted of real-life activities and socialization and some specific language tasks such as group repetition of words. "Structured television group treatment" consisted of watching specific television programs for later group discussion. This study found significant improvement on the CADL and the PICA. Results did not reveal that either treatment was superior to the other.

Elman and Bernstein-Ellis (1999a) investigated the efficacy of group communication treatment on the linguistic and communicative performance by adults with chronic aphasia using a randomized controlled trial. Participants were randomly assigned to either immediate or deferred treatment. Twenty-four participants completed 4 months of treatment. All participants received 5 hr of group communication treatment weekly, provided by a speech-language pathologist. Group communication treatment targeted increased initiation of conversation and exchanging information using whatever communicative means possible. While awaiting group communication treatment, participants in the deferred treatment groups served as the control group. Participants in the deferred treatment groups engaged in movement groups, church activities, and performance arts groups in order to control for the possible effects of social contact. Results revealed that group communication treatment was efficacious. Deferred treatment group participants did not change significantly with social contact alone. Participants receiving group communication treatment had significantly higher scores on communicative and linguistic measures than participants not receiving treatment. In addition, treatment effects continued over time. Significant improvement occurred following 2 and 4 months of treatment. In addition, no significant decline in linguistic or communicative performance was found 6 to 8 weeks after group treatment ended.

Van der Gaag et al. (2005) evaluated the impact of attending an aphasia center. People with chronic aphasia and their relatives received a variety of group therapies at the Connect Center in the United Kingdom.

Twenty-eight participants with aphasia received an average of 1.7 hr a week of therapy over 20 weeks. In addition, each participant received an average of 8 hr of counseling during the 6-month period. Outcome measures included quantitative ratings of quality of life as measured by the *EuroQoL* (EQ-5D; EuroQol Group, 1990) and the *Stroke and Aphasia Quality of Life Measure* (SAQoL-39; Hilari, Byng, Lamping, & Smith, 2003). Communication was measured with the *Communication Effectiveness Index* (CETI; Lomas et al., 1989). Qualitative outcomes included participants' perceptions of their quality of life and communication skills as measured by semistructured interviews. At the end of the 6-month period, there were statistically significant changes in the EQ-5D and CETI scores. There were no statistically significant changes on the SAQoL-39, though the direction of change was positive. The investigators reported that the qualitative interviews showed very similar patterns to the quantitative outcome measures.

PSYCHOSOCIAL BENEFITS OF APHASIA GROUPS: RESEARCH EVIDENCE

As part of a multimethod (Elman, 1995) randomized controlled trial that evaluated the efficacy of group communication treatment, Elman and Bernstein-Ellis (1999b) utilized semistructured qualitative interviews of participants and caregivers. Interviews of 12 individuals with aphasia and 12 relatives/caregivers were collected during the treatment phase of the efficacy study and transcribed verbatim. The interviews included queries about positive or negative aspects of participating in the communication treatment groups. Interview transcripts were coded and grouped. Common descriptors or themes were identified in order to provide the fewest number that still captured the information expressed in the interviews. Separate themes were identified for participant and caregiver interviews.

Themes were extremely similar for participants and caregivers. Nine positive psychosocial themes were reported by the participants

of group communication treatment: they liked being with others, they liked the support of others with aphasia, they liked making friends, they liked being able to help others, they liked seeing other improve, and they felt more confident. In addition, three positive speech-language themes were noted: they enjoyed the group conversations, their talking improved, and their reading/writing abilities improved. Eight positive psychosocial themes were reported by caregivers of participants in group communication treatment: their family member was more confident, more social, more independent, more motivated, liked making friends, was happier, and liked helping others. In addition, two positive speech-language themes were noted: their family member had improved in talking and had improved in reading/writing ability. Most participants and caregivers also provided specific examples of increased participation in community activities during and following aphasia group communication treatment, even though treatment had never been conducted in these environments. These qualitative data indicate that group communication treatment resulted in numerous positive psychosocial and speech-language changes as reported by the participants and the caregivers.

Participants identified only one negative aspect of group communication treatment: several individuals felt that 3-hr treatment sessions were too long. These participants indicated that they would have preferred treatment sessions lasting 60 to 90 minutes in length.

Taken together, the quantitative and qualitative data regarding aphasia group treatment provide support for both psychosocial and speech-language benefits of aphasia group participation. These data strongly argue for the addition of communication groups to a variety of rehabilitative and community settings.

HEALTH BENEFITS OF BUILDING RELATIONSHIPS AND COMMUNITY: RESEARCH EVIDENCE

Ryff and Singer (1998, 2000) have conducted a series of studies investigating the

core features of positive health. Ryff and colleagues have been interested in learning what people need to have in their lives in order to maintain good health. Their research revealed two main features of positive health and flourishing: having quality relationships with others, and having a life that is purposeful and meaningful. The presence or absence of these features impacts our biology, including neural circuitry, cardiovascular functioning, the neuroendocrine system, and the immunologic system. Increased *allostatic load* occurs when the body is at stress: "Allostatic load is a measure of the cumulative physiological burden expected on the body through attempts to adapt to life's demands" (Seeman, McEwen, Rowe, & Singer, 2001, p. 4770). Research has shown that high allostatic load is a predictor of increased cardiovascular disease, decreased cognitive function, decreased physical function, and mortality (Seeman et al., 2001).

Various studies have found that social interrelationship and social activity are associated with a higher rate of survival. Berkman and Syme (1979) found that people who lacked social and community ties were more likely to die in the 9 years of the study than did people who had more extensive contacts. It is possible that conditions such as aphasia, which often lead to increased isolation

and decreased social contact, may increase stress on the body and raise allostatic load. Therefore, the importance of reconnecting people with aphasia and building community may be critical for achieving and maintaining positive health. Ryff and Singer (2000) stated, "laughing, having fun, and enjoying the time spent with significant others may be vital ingredients of relational flourishing" (p. 39).

CONCLUSION

Participation in aphasia groups and aphasia centers may have more benefits than originally imagined. In addition to a number of speech-language and psychosocial benefits, reconnecting people through their participation in aphasia groups and aphasia centers may result in interpersonal flourishing and reduced stress, thereby improving a critical outcome for participants: positive health and longevity. One of the most important things speech-language pathologists can do is to reconnect people with aphasia to their family members, their friends, and their community. By helping to rebuild interpersonal connections and community, as well as establish new relationships, speech-language pathologists can help people affected by aphasia to live fuller and healthier lives.

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