

CHAPTER 5

Aphasia Group Communication Treatment: The Aphasia Center of California Approach

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Philosophy of Program

The Aphasia Center of California (ACC) opened its doors as a nonprofit organization in September 1996. Housed within a Senior Center in Oakland, California, the ACC was the first independent not-for-profit organization dedicated to providing direct services to individuals with aphasia in the United States. Our aphasia groups began in 1994 when the National Easter Seal Research Program funded our study to investigate the efficacy of group communication treatment for aphasia. As reviewed in Chapter 1, the results of the study were positive (Elman & Bernstein-Ellis, 1999a,b). Both statistical and anecdotal data told us that the establishment of the ACC would allow us to offer a greatly needed service to adults with aphasia and their caregivers.

The Center's mission statement is to encourage and expand communication and quality of life for all those affected by aphasia. Our philosophy and provision of service are consistent with a social model of health care (Elman, 2005). The following four core values guide the organization:

- Choice
- Shared leadership
- Age-appropriate services
- Community building

Currently, we offer nine communication groups. We also offer, on an as-needed basis, a caregiver support group and, on a rotating basis, the Book Connection™ program, which provides reading and writing practice in a book club format, and the News Forum, which focuses on the reading and discussion of current events. We also have offered a class on

using the Internet (Elman, 2001). Additionally, we offer a weekly exercise class and an art class co-facilitated by the Adult Education Department of the local school district. We are committed to providing a “treatment array” that our members feel best serves their interests and needs (Elman, 1998).

Several factors converged to forge the philosophical foundation of the ACC. First, we felt the urgent need to develop a viable, effective model for providing aphasia treatment in view of changes in health care provision and reimbursement. With the emergence of managed care, our treatment environment dramatically changed. The number of visits authorized by insurance carriers shrank. The nature of aphasia wasn't changing, but the time we had to treat communication deficits was, and this reduction had serious implications. It was becoming the norm that a patient who would have previously received a 3- to 6-month treatment authorization was now authorized for only 6 to 10 visits (Elman & Bernstein-Ellis, 1995). This forced a significant restructuring of our treatment goals and priorities (Elman, 1994, 1998, 1999a, 2005).

We struggled with many questions about the impact of managed care on our clinical approach. What type of communication goals could reasonably be met in the course of 10 sessions? Which goals would have the greatest impact on a client's quality of life at the conclusion of our brief clinical contact (Elman, 1994)? What treatment techniques and approaches, many of which were developed on the basis of lengthy treatment trials, would now be effective in a much-abbreviated clinical trial (Elman, 2006)? Individuals who recognized that they would benefit from additional treatment often did not have the financial resources

to pursue private-pay options. Although we still valued individual treatment for aphasia, we were forced to consider lower cost and efficacious options for meeting the needs of our clients.

Another primary factor that guided formation of the ACC reflected our conscious decision to consider aphasia as a chronic disorder (Elman, 1998, 2005; Lyon & Shadden, 2001; Sarno, 2004). Regardless of whether stroke survivors with aphasia received 10 therapy sessions or 50, many were left with residual deficits that had both significant and lasting impacts on their lives (Elman & Bernstein-Ellis, 1995, 1999b; Holland, 1992; Lyon, 1992, 1997; Parr, Byng, Gilpin, & Ireland, 1997; Pound, Parr, Lindsay, & Woolf, 2001; Sarno, 2004). Even our clients with mild aphasia told us that the onset of the disorder imposed lifelong changes in their communicative abilities (Elman & Bernstein-Ellis, 1995). We considered aphasia as any other chronic medical “condition” in which full recovery to premorbid status was unlikely (Elman, 1998, 2005). For instance, with the onset of diabetes, ongoing insulin treatment may be needed to manage the condition. It would be unethical to withdraw the insulin after an arbitrary amount of time without substituting another treatment. Is it not surprising that some stroke survivors become isolated and depressed after discharge from a speech-language therapy program? What should we do to replace the support and value that the therapeutic environment once provided? Patients with diabetes are not “discharged” from the treatment designed to best manage their chronic disorder. We concluded that people with chronic aphasia deserved the same conceptual approach of ongoing management to support their communication impairment.

A useful analogy for the sustained management of aphasia may be that of health club membership. People have many personal reasons for joining a health club, such as improving their level of fitness or attempting weight reduction. When the goal is achieved, patrons are not asked to leave the club. Rather, they are encouraged to continue their participation in order to sustain their accomplishment. The benefit of the exercise does not diminish once the goal is met. Some people continue to make improvements in their fitness level and actually exceed their original goal. Continued health club membership may enhance the chances that a person maintains the gains that he or she has made.

We suggest that health club membership and participation in an aphasia treatment group are remarkably similar. Each participating member has a persisting condition. Management of the condition may be enhanced by group treatment sessions that facilitate the use of strategies to optimize communication. Getting weekly “workouts” that promote successful communicative interactions may help sustain gains made in individual therapy. Some members make new gains over time because of the exposure to new strategies via peer modeling, the opportunity for practice and feedback, and the psychosocial support offered by the group environment.

This sustained management approach is consistent with the World Health Organization (WHO) framework, the International Classification of Impairments, Disabilities and Handicaps, ICF (WHO, 2001), and the Life Participation Approach to Aphasia (LPAA). Please see Chapter 1 for a brief description of the ICF and the LPAA. These frameworks indicate that speech-language pathologists should

address not only linguistic deficits of aphasia but also any resulting activity limitations, participation restrictions, and environmental barriers. We have learned that some valuable treatment goals may take much longer to achieve than our training taught us to expect. Moreover, we have learned that our members with aphasia make gains beyond standard periods for recovery (Elman & Bernstein-Ellis, 1999a, 1999b). ACC members and their families have told us about personal successes that significantly affect quality of life that they attribute, at least in part, to participation in our groups. Through their stories, we’ve learned that our members make changes and achieve goals that are not always captured by performance on standardized speech and language assessment tools but nonetheless are a vital contribution to their adjustment to living with aphasia. (Elman, 2005; LLPA Project Group, 2000, 2001; Pound et al., 2001).

A final factor was responsible for the creation of the ACC. A 1989 visit to the Aphasia Centre of North York (now the Aphasia Institute) in Toronto, Canada, greatly influenced our perspective on aphasia groups. The treatment model we saw was a source of clinical motivation and inspiration (Kagan, 1995, 1998; Kagan & Gailey, 1993; Kagan, Winckel, & Shumway, 1996). Its impact also has been cited by other clinical “visitors” (Hersh, 1998; Beeson & Holland, 1994; Jordan & Kaiser, 1996).

Entry Criteria

After the completion of our research study on the efficacy of group therapy for aphasia (Elman & Bernstein-Ellis,

1999a), we were able to open our program to the community at large. Currently, the ACC allows any adult with aphasia to attend. Our members travel to our groups from six counties in the Bay Area and some from more than 60 miles away. The primary etiology for our group members is either thromboembolic or hemorrhagic stroke. Some members have had only a single documented cerebrovascular incident. Others have a history of multiple strokes. We accept all levels of aphasia severity, from the most severe to only mild aphasia. We do have members with less common causes such as primary progressive aphasia, head injury, brain abscess, or chemotherapy-induced aphasia, and some with aphasia of unknown etiology. So long as the behavioral characteristics are “aphasic-like” in nature, and other behaviors do not detract from participation, an individual is welcome to join. Although we do not accept someone with a primary diagnosis of dementia, some of our members are coping with various degrees of cognitive decline.

There is no entry criterion for time post-onset. Our members range from 1 month post-stroke to more than 20 years post-stroke. A majority of our members are from 3 months to 10 years post-onset, with an age range of 28 to 95 years. We have a variety of referral sources. Some members locate us through the local newspaper, either from a feature story about the ACC or from a community bulletin board listing. Other members come via referral from local speech-language pathologists at hospitals, outpatient therapy clinics, or private practices. Still others hear about the ACC through a personal grapevine of information including friends, the ACC website or other websites, or our community outreach projects.

Assessment

During the research phase of our group program, we were able to complete a standard battery of both quantitative and qualitative measures of speech-language performance and psychosocial status on every member. Once we became a non-profit organization, we did not have the resources to complete these assessments as standard practice. We now gather relevant information at intake through several sources. There is typically a phone interview with either the potential member or with his or her caregiver. Frequently we are able to talk directly with the previous speech-language pathologist. These contacts allow us to obtain medical background, personal and social information, and treatment history, and to glean a sense of communicative functioning across the modalities. Sometimes we are able to obtain records with relevant assessment information. When we have the services of a student intern, we are able to arrange for a few supervised assessment sessions. We select members for whom we feel that the information from a standard aphasia battery would help us to understand better their communication profile.

Once an individual is interested in attending our program, we choose a group for that potential member to observe, based on which of our groups have an opening, as well as the person's schedule. In addition, we consider how a person's functioning and personality might interact with the current composition of the group. Sometimes, because of logistical constraints, there is simply no choice, but we have found that the groups are remarkable in their ability to adapt to the diversity of their member-

ship. The first observation session in the group allows us to assess informally each prospective participant's communicative and social style. Each member completes an emergency information form that provides personal contacts, pertinent medical history, and current medications. Group composition is addressed further in the Clinical Techniques section later in the chapter.

Treatment Goals

As we began to formulate the type of groups we wanted to promote, our experience in Toronto helped guide our treatment model at the ACC. Our primary treatment goals are to enhance communication skills and maximize psychosocial well-being and quality of life for individuals affected by aphasia. These primary goals are achieved by focusing on several well-defined factors, discussed next.

Member and Family Education

We believe that people with aphasia and those who care about them benefit from understanding the nature of the communication disorder. Most of our stroke survivors and their families tell us that they had never heard of the word "aphasia" until after their stroke. Very little or no patient education has been offered to a majority of our members before coming to the Center. Many of our members have never met anyone else living with aphasia until they attend our groups, and they report that they are grateful for the connection they feel. We try to offer materials that will enhance their understanding of aphasia. If this is appropriate,

we encourage new members and their families to watch videotapes about aphasia: *What Is Aphasia?* and *Pathways: Moving beyond Stroke and Aphasia* (Ewing & Pfaltzgraf, 1991a, 1991b). We also encourage a caregiver or family member to sit in on a session to observe how our groups function. We offer a quarterly stroke education support group for members and family members, as well as a caregivers' group. Another source of information and support is our biannual newsletter, which features topics related to aphasia, ACC members, and activities at the Center. Copies of the ACC newsletter are available on the Center's website (www.aphasiacenter.org).

Personal Goals

We try to promote an increased awareness of each members' personal goals and progress made toward those goals. We support attempts at communicative situations personally relevant to each member. We have found that many members find it difficult to acknowledge their gains and therefore benefit greatly from the recognition the group gives to them.

Conversational Practice: Expanding Participation

We firmly believe that both the desire to engage in adult conversation with peers and the benefits of conversational practice cross all severity levels of aphasia. Experience has taught us that it typically takes more effort to promote cross-talk and member-led discussions in groups composed of members with moderate to severe aphasia, but there remains a natural motivation to share topics of mutual

interest regardless of severity level (Elman, 2005; Kearns & Elman, 2001).

Capobianco and Mahli (1995) recognize the value of the group setting in that “patients congratulate each other, advise each other, and argue with each other—all of which are normal adult communication activities” (p. 2). When a group expresses an interest in a topic or theme, there is a communicative spark that can then be fanned by the clinical techniques chosen to promote interaction and information exchange. We view the topic or task as the springboard, rather than the vehicle, for sparking communicative intent. More times than not, an introduced topic has been cast aside to follow whatever unpredictable conversational path the group finds more interesting and thus more conversationally productive.

Sharing personally relevant topics promotes connections among the members. New friendships develop. Furthermore, members have the opportunity to assume or reclaim a variety of social roles. We have been influenced by research that shows strong relationships among variables such as positive health, social connectedness, and purpose in life (Ryff & Singer, 1998, 2000; Ryff, Singer, & Love, 2004). We work to help our members connect with one another, as well as to assist them in re-creating their own identities and future selves (Markus & Nurius, 1986).

For instance, one of our members, L.T., suffered a stroke in her late 40s that left her with severe physical and communication impairments. Even now, 8 years post-onset, she has no speech except for some vocalizations when crying or laughing. A former youth gospel choir director, L.T. had a busy social calendar that included many community events. After her stroke, she withdrew to her

home and refused to see friends or attend any church-related activities. After strong urging from her family, L.T. attended a communication group at the ACC. Over time, we worked to develop her expressive outputs of short graphic messages, typing short messages on a “low-tech” electronic device, communicative drawing, facial expressions, and gestures. With the support of her family, and after taking the Internet computer class, L.T. focused on developing her computer skills. She developed computer-generated lists to help us track birthdays. She then began developing personalized greetings for birthdays, thank you notes, get-well cards, and any other special occasion, that she circulated to get signatures. L.T., despite her profound post-stroke deficits, was admired and respected for her contributions to the Center. The staff relied on her to track upcoming birthdays. She became the “social manager” at the ACC, a role that played an important part of her life before her stroke. As another stroke survivor explained, the reason she likes being part of the group is that everyone is in “the same boat.” She observed that whereas her old friends mostly see what she can no longer do, her new ACC friends see her for what she can do.

Communicative Strategies

We focus on improving the ability to convey a message using whatever strategy is most useful for that individual. Typically, our focus is on content exchange instead of on linguistic accuracy. A variety of strategies to facilitate the successful exchange of information are modeled by the clinician and the group

members during discussions, including the use of natural gestures, personalized notebooks, environmental resources such as maps, newspapers, communicative drawing, and graphic supplementation. The specifics of these techniques are discussed later in this chapter.

Conversational Initiation

We focus on increasing initiation in conversational exchanges. Davis and Wilcox (1981, 1986) emphasize the importance of sharing the communicative burden in a conversation. Our clinical experience has revealed that it is typical for an individual with aphasia to assume a more passive, responder role, while the person without aphasia becomes the initiator. This was particularly true in our clients with moderate to severe aphasia. Our groups focus on both the initiator and the responder roles in conversations. We believe it is essential for the therapist to maximize the member's opportunity to direct the discussion. This is different from traditional didactic treatment models, which often place the primary responsibility for leading the group on the therapist (Elman, 2000).

Conversational Cross-Talk

We promote "cross-talk" or exchanges among group members. It is easy to fall into a "tea-party" or talk-show host pattern in which exchanges bounce back and forth between therapist and client—from the clinician to a member and then back to the clinician, who again initiates the exchange with the next member around the table. The goal of our groups, however, is to promote follow-up on

group member topics via questions and comments by other members in the group.

These treatment goals required that we embark into new clinical territory. The skills needed to facilitate participant-shared groups were markedly different from those used to direct individual therapy sessions. Making changes in our clinical style was much more difficult than anticipated. As one student intern aptly described, "It looks so easy when I observe the group, but when I try to do it, I'm surprised at how hard it is. It's like when you are skiing down hill and you see a rock straight ahead. You know you should avoid it, but for some reason you run straight into it. I know I need to change course with the group, but somehow I still head straight for that rock." We hope that our discussion in the Clinical Techniques section will help guide other clinicians around at least a few of the clinical obstacles that we experienced while learning to facilitate groups.

Documentation of Progress

The challenge of providing services as a nonprofit organization with limited resources has eliminated our ability to invest large amounts of time in formal reassessments. As previously mentioned, we occasionally are able to utilize the services of student interns to evaluate members who have not been recently assessed. Informal conversations with members and their families allow us to track reports of changes in communicative or psychosocial status. At staff meetings, we discuss changes that have been observed during group sessions. Informal logs have been helpful in tracking

anecdotal information. We also keep interesting samples of writing and communicative drawings to allow for comparison over time. We hope that with additional financial support, we will be able to invest more time in documenting progress. Part of the challenge lies in our interest to access tools that provide meaningful information, including quality of life changes. There are few tools available that are appropriate for use with people with aphasia, although effort and focus have increased in recent years to address this need (Blackstone & Berg, 2003; Elman, 2005; Frattali, 1996, 1998; Frattali, Thompson, Holland, Wohl, & Ferketic, 1995; Simmons-Mackie, 2001; Simmons-Mackie & Damico, 1996.) See Chapter 3 for an overview of various outcome measures.

Case Study

The following brief case study illustrates the outcomes of a rather typical ACC participant. J.B., a 48-year-old white female, suffered a hemorrhagic stroke that left her with a moderately severe nonfluent aphasia and right-sided paralysis. Unable to live independently, she resided with her parents. She started in an ACC communication group approximately 6 months after her stroke, subsequent to discharge from individual speech-language therapy. At entry, her performance score for the Aphasia Quotient (AQ) portion of the *Western Aphasia Battery* (WAB) was 65.2. Her interactions during group were slow and laborious. She needed constant coaching to use communicative strategies. Most notable was her poor eye contact. She spent most of the session looking down at the table. Initiation of communicative interactions was mark-

edly impaired. She expressed frustration and depression over the loss of her job as a school bus driver, her loss of independence, and her loss of an active social schedule.

J.B. attended group once weekly. The group encouraged her to utilize graphic attempts and communicative drawing as strategies to help convey content. The clinician asked the group members to cue J.B. regarding her eye contact. Discussions frequently addressed the psychosocial issues with which she was struggling, and group members offered support, perspective, and experience. She began to attempt some of the group's suggestions, starting with buying a wristwatch with large clear numbers and using a small notebook to track basic biographical and personal information. Over a 2-year period, her successful spoken communicative attempts increased in phrase length and content. There was a noticeable improvement in her eye contact and social skills. She moved back into her own home and began living independently. J.B. learned how to take public transportation, including giving instructions to the receptionist regarding her paratransit schedule. She started an exercise class at a local YMCA. She also participated in a reading and writing class and an art class at the ACC.

It has been remarkable to watch J.B. emerge as a mentor to other participants with aphasia in the communication groups. She began to take people under her wing and successfully hooked up several new members with the public transportation system for disabled citizens. She became pivotal in group discussions for initiating cross-talk. She introduced new topics and would ask follow-up questions without prompting. Periodic readministration of the WAB showed

steady gains in her AQ across time. Her WAB AQ after 4 years of participation at the ACC was 89.0. She was thrilled with the improvement it represented, yet it was a small aspect of the success she experienced.

J.B.'s WAB AQ has remained steady at 90.6 after 8 years of participation at the ACC. Her progress in the social-communicative arenas of her life continues to be impressive. Personal goals she has achieved during the last several years include independent travel to see her sister in another state, speaking at public forums to express her opinions on local issues such as building a casino in her neighborhood, organizing the invitations and reservations for a holiday breakfast, designing and selling her own line of greeting cards to family and friends, and rejoining her church choir. One remarkable achievement included leading more than 100 ACC members and guests for a sing-along at the Center's annual winter holiday party. We also appreciate and admire J.B.'s commitment to fund-raising efforts at the ACC. During the past several years, she has collected the most names on her sponsor list for our annual *Walk to Talk* event.

Despite her ongoing challenges with word finding, processing complex auditory input, reading, and writing, J.B. continues to inspire and support others through the encouragement she offers, as well as through the model she provides. She clearly embraces the philosophy of living fully with aphasia. Most notably, she has found an outlet for her deeply altruistic nature through her interactions with other group members. J.B.'s outcomes demonstrate what we've observed to varying degrees with many of our members. These observations have convinced us that "an individual with

aphasia should not be expected to discontinue activities or groups that enhance socialization, conversation and/or reintegration back into community activities, through the reduction of communicative barriers" (Elman, 1998, p. 230).

Clinical Techniques

ACC group sessions are 90 minutes long. Most groups range in size from 4 to 9 members, with 5 to 7 the preferred target number. Through experience, we've found that it may be more difficult to keep the conversational ball rolling with groups of fewer than 4 members. Likewise, with groups larger than 10 members, it is difficult to give everyone ample time to participate. We've learned that there are no hard and fast rules regarding group composition. Rather, the clinician's personal preference should be the primary guide. Two ACC clinicians prefer to form groups using severity as the lead attribute for placement. The tendency is to group members with mild to moderate aphasia together, and members with moderate to severe aphasia together. Thus, people with moderate aphasia often work well in either group. Grouping by severity seems to accommodate discussions about adjustment issues associated with the severity of the communication disorder. Our groups composed of people with milder aphasia seem to particularly appreciate the opportunity to have quicker-paced, philosophical discussions that members with a greater degree of aphasia may have trouble following. On the other hand, one clinician at the ACC prefers to have a mixture of aphasia severities in her groups. She feels that

this promotes modeling and coaching opportunities, while enriching the variety of interactions within the group. We are convinced that either approach to forming groups works exceedingly well.

We've been questioned if a person with Wernicke's aphasia can benefit from a group setting. We indeed advocate integrating our members with poor auditory comprehension into our groups. The need for these members to develop functional social conversation skills is just as relevant as it is for those members with nonfluent aphasia. Our members with Wernicke's aphasia typically need more time and practice than our members with nonfluent aphasia to successfully incorporate communication strategies such as the use of a communication book or communicative drawings. The groups provide an opportunity for consistent ongoing practice and reinforcement of progressive attempts at communication. We have found that members with Wernicke's aphasia benefit greatly from the peer modeling they receive. For a specific example of the benefits of group participation for individuals with Wernicke's aphasia, see the section on communication resources later in the chapter.

As group members enter the Center's primary therapy room, the first order of business is to locate the appropriate nametag from the wall hanger that boasts over 70 names. Members wear nametags at every session to promote the access of names during conversational exchanges. Our groups provide a warm welcome to participants. There is a deliberate effort to greet everyone who comes in the door. Coffee or other beverages are distributed by a group member who is willing to help with hospitality related tasks. Family members often are busy greeting one another and talking with the clinician

about relevant points of information. Once everyone is settled around the table, any guest for the day is introduced and handed a temporary nametag. We request that family members periodically observe, and we get a variety of other observers including potential members and their family members. Typically, we request that they join us around the table and participate as a group member. We prefer not to let visitors sit back in the corner and watch us interact. Inclusion of visitors in the group promotes a more natural conversation environment and provides novelty and variety in terms of conversational partners. Group members are responsible for introductions and for getting to know the guest.

When the group is ready to start, we try to follow up on a conversational element from the previous week and get a sense of any priority topic that the group is interested in discussing. Our groups have evolved over time from having preplanned "themes" to having "topical" discussions—whatever is most relevant to their interests that day. Looking back at our early philosophical discussions, we realized that relying on themes was a safety net. In the beginning, it felt too overwhelming to go into a group without some sort of structured clinical plan. As previously mentioned, our "best" interactive, participatory discussions typically ranged in topic far from the preplanned theme, so we learned that success did not rely on having a specific set of tasks or topics. Now, we rotate tasks or topics depending on the immediate context of the day. Some discussions are more structured than others, such as those addressing stroke education, role-playing communicative situations, interviewing guests, or sharing keepsakes or photos. Other discussions are less struc-

tured, such as those involving current events, personal activities, vacation/holiday plans, post-stroke adjustment discussions, and personal interests and hobbies. Our focus is directed to the techniques needed to promote conversational initiation and to facilitate the exchange of information regardless of whatever task or topic rotates across the conversational menu of the group.

Increasing Conversational Initiation

Increasing conversational control and initiation of our members with aphasia is a primary goal of our groups. There are a variety of techniques that we have found useful for addressing this goal.

Directing the Facilitator's Role to a Specific Group Member

This technique consists of asking a group member to lead the discussion about a specific topic. A peer facilitator can gather opinions about an upcoming election, survey each person's favorite type of pie, or inquire about everyone's weekend. This technique can be adapted across severity levels. Some members may need only a key word to help formulate a query, whereas others may benefit from a written script to prompt the question. Scripting, or conversational coaching, refers to writing out either a few words to a full sentence and handing it to the member, who either reads it directly or uses it as a springboard (Beeson & Holland, 1994; Hopper, Holland, & Rewega, 2002). Allowing a member to facilitate the discussion becomes particularly dynamic when the member in charge takes on an active role and goes

beyond the question at hand. The group is at its best when the follow-up questions and feedback come from their peer facilitator, rather than from the clinician.

"Passing the Question" or "Passing the Ball"

This time the facilitator's role is shared around the table. The group discusses a certain topic. As each person concludes a turn, he or she restates the question or topic for the next person. This method ensures that each member gets a turn to initiate and to respond. It helps to put the focus on the members, instead of allowing a clinical "tea party" between the clinician and the group members. This technique also lends itself to adaptation across severity levels. Members with mild aphasia may elaborate on the original question or theme, whereas non-verbal members may establish a communicative gesture to engage their partner.

Addressing a Member's Participation Level

We ask, "Who hasn't had a turn yet?" or "Who's been too quiet?" This works best when the group members begin to monitor one another's participation levels and try to ensure that everyone has had a turn.

Requesting That Members Generate a Topic

We ask members to bring in news articles, personal items, photos, or anything of interest. We ask the group, "What do you want to talk about?" This promotes novelty and humor—both essential elements for successful groups. Our best groups are ones that share laughter.

Frequently, it is a group member who first recognizes the humor in a situation or initiates a joke. The shared laughter crosses aphasia types and severity.

Peer “Scaffolding” or Cueing

This refers to the opportunity for one or more group members to help another group member around some sort of communicative block. Instead of the clinician’s providing a cue, the clinician asks, “Who can help Mrs. X get her message across?” This technique works well when multiple members offer help. By building on one another’s attempts, members are able to clarify the message. The group recognizes that the message has been directed by the group, rather than by the clinician.

Encouraging Peer Feedback

Frequently, it’s the other group members who won’t allow someone to “bail out” when faced with a communicative block. Instead, group members will display support by passing a pad of paper to encourage a drawing or writing attempt, or one member will offer his or her communication book for the “blocked” member to use, or will request that the member slow down or speak louder. Members directly tell one another, “Yes you can!” or “Try to do it,” and these exchanges seem to have more impact coming from a peer than from a clinician.

Peer Volunteers

We have asked members with mild aphasia to volunteer in our mild to moderate aphasia groups, and we’ve asked members with either mild or severe aphasia to volunteer in our moderate to severe aphasia groups. Volunteers are selected for their ability to model good commu-

nicative strategies or interactions. One of our most outstanding volunteers, L.I., had severely impaired auditory comprehension, with verbal output basically limited to “Hey, mom.” However, he could glean contextual information and use environmental resources in an extraordinary manner. L.I. could link a long string of functional gestures or combine multiple communicative elements in a drawing to convey complex information. He frequently initiated conversational topics using these strategies. The group as a whole benefited from his modeling of gestures and drawings.

“Personalizing” the Discussion

It is important to move from the key topic at hand to people’s personal experiences or opinions about that topic. For instance, if a member brings up a news item about France, there is opportunity for a series of related questions, such as “Who has been to France?” or “Who likes French cuisine?” or “What French movies have you seen?” Although the key topic often can hold the group’s interest, sometimes it is the related questions that spark the real conversation.

Increasing Exchange of Information

Another primary goal of our groups is to facilitate exchange of information, and we utilize several techniques for that purpose as well.

Supporting the Flow of Ideas with Graphic Attempts or Communicative Drawing

We frequently encourage members to draw or write to enhance their message.

Pads of paper and pens are standard items on the group's table. These are distributed to everyone in every group, regardless of severity. The clinician also uses drawing and graphics as a standard way to emphasize content or to confirm information. We prompt members: "Can you draw or write it?" or "How else can you show me what you mean?" Members often will exchange different ways of approaching a drawing and usually are delighted to offer a better version than the clinician's! Some members seem to have a natural affinity for drawing and, with support and guidance, use it very effectively. Others need a higher level of support, training, and modeling. It is beyond the scope of this chapter to review the skills needed for communicative drawing. Please refer to the work of Lyon (1995) for a detailed description of this useful technique.

Graphic Choices

As described by Garrett and Beukelman (1992), the clinician presents several viable responses to a member for him or her to indicate the preferred choice. For example, if we're discussing favorite cuisine, we might write "Mexican, French, Indian, Italian" in a clear column on a pad of paper and present it to members who are primarily nonverbal, or who have severely impaired auditory comprehension. When members are permitted to select the item themselves, they can take the lead in responding.

Natural Gestures

We frequently ask, within the context of a conversation, "How can you show me that?" Sometimes brief, simple gestures are sufficient, and other times more elaborate gestures help to convey the mes-

sage. Once again, it is sometimes the group members who generate a better way to show something compared with the clinician's model.

Communicative Resources

We make sure that maps, newspapers, number lines, visual scales, photos, an illustrated travel dictionary, and a calendar are always available. If members can't remember the name of the movie they saw, the movie section of the newspaper is available. If members can't recall the name of the place they plan to go on vacation, an appropriate map is within arm's reach. We have laminated several versions of maps, including our local region, the United States, and the world. When trying to hone in on how much a nonverbal member likes something, we use a laminated number line. There is a sad face over the number 1 and a happy face over the number 10. Our members carefully select where their response falls along this continuum. We also encourage members to grab matchbooks, take-out menus, or business cards when they go to a restaurant so they can share this information with other group members. The use of these items allows the members, instead of the clinician, to take the lead in providing the information.

Some of our members benefit from personalized notebooks. These have taken many forms, from adaptations of commercial products to family-generated versions. Size and complexity also have varied. Most include a section for weekly events, family, friends, pets, places, restaurants and food, photos, and basic information. We have found that some members quickly utilize the notebook, whereas others slowly gain facility.

One of our success stories involves a member with moderate Wernicke's

aphasia whose computer-savvy husband created both a purse-sized and larger binder-sized personal notebook. Because she is an accomplished artist, he scanned copies of her artwork into both of these versions. He also created a family tree diagram and imported photos for each member. Although her verbal output is severely limited, she quickly began using her notebooks to initiate topics and convey a wide range of information. A real success was that she was able to coach a newer member with moderate to severe Wernicke's aphasia to use his notebook more effectively. Initially, he seemed oblivious to the notebook. He then began to model her behavior of putting his communication binder on the table at the start of each group session. Eventually, he began to do this even without her visual model. If he was asked about his family, she would lean over and help him flip to the photo section of his notebook. Over time, he began to initiate using his communication book to provide information. Her peer modeling and cuing seemed to promote more progress than encouragement from his family or the clinician.

“Weekly Activity Highlights” Form

Families are coached to summarize highlights and routine items that occur each week in a special form (Figure 5-1). Information about a trip to the grocery store, a new outfit, or a weekly hair appointment can provide a tremendous amount of potential conversational material. Some members attempt to complete the information form themselves each week. For various members, the form acts like a script, and they take the lead in sharing the information with the group. For members who are nonverbal,

the form allows the clinician to gain some specific, personally relevant information that can be used to involve that particular member in the discussion. These forms provide a gateway to participation for members who are less able to initiate content, as well as for members with moderate to severe fluent aphasia.

Table 5-1 summarizes some of our “best bets” for sparking dynamic conversation in aphasia groups.

Management Issues

Along with the helpful techniques presented earlier, we've also learned some “management issues” inherent to the group setting that are important to address. One such issue involves handling one or two group members who become overly dominant. These members may occupy more than their fair share of the group's conversational time. In many cases, these members may not be sensitive to monitoring their own turn taking. One solution is to ask that member to be in charge of making sure that everyone participates. We ask him or her to “help us include each and every member of the group.” Sometimes we are even more directive and state that we need time for each person to respond.

The clinician is always at high risk for dominating the group. It can be hard for the clinician not to dominate by virtue of expertise. Although there is a definite tendency for the clinician to jump in immediately and provide needed cues, it's important to learn to involve the group members in problem solving any communicative obstacles. The clinician needs to ask, “What can Mary do to get her message across?” or “Could someone show another way to draw an airplane?”

Aphasia Center of California (ACC)

Weekly Activity Highlights

Name: _____ Date: _____

Please bring us up-to-date on events since the last ACC meeting. This information helps us to include more about each member in our group discussions. Both routine and special events are of interest to us.

Visitors:

| Name of visitor | Relationship to Aphasia Center member |
|------------------------|--|
| | |
| | |
| | |
| | |

Activities:

Anything else you'd like to add? (Upcoming events, other info . . .)

Figure 5–1. Aphasia Center of California Weekly Activity Highlights Form.

Table 5–1. “Best Bets” for Sparking Conversation with Aphasia Groups

| Capitalize on the Group’s Lead | Increase Member Participation |
|---------------------------------------|--------------------------------------|
| Beware of preset agendas or themes | Allow group members to facilitate |
| Allow the group to inform you | Novelty promotes interest |
| Follow the group’s interests | Resources assist participation |
| Encourage peer feedback | Humor enriches and motivates |

or “Who can show us a way to gesture driving?” These methods all support increasing the members’ participation while reducing the clinician’s dominance. It’s crucial for the clinician to learn the boundaries between being a “communication broker” and overfacilitating. Kagan (1995, 1998) refers to the high level of skill needed to unmask an aphasic member’s competency. Beeson and Holland (1994) refer to the clinician’s ability to be a “communication broker” by interpreting, facilitating, and guiding communicative exchanges among group members. The challenge lies in balancing these roles.

Group members often will offer strategies, support, and empathy. When a clinician gives up tight control of the discussion’s content, there is risk that awkward or uncomfortable issues may come up. Racial, religious, political, sexual, and gender-related topics frequently generate strong feelings. It is absolutely essential to establish ground rules for standards of behavior. ACC staff have agreed that individuals who openly promote bigoted racial or religious attitudes are not welcome in our groups. That is not to say that our members must agree on heated topics. One of the special attributes of the ACC is the wide diversity our group members possess with regard to cultural, economic, professional, and educational backgrounds. Part of the success of the groups comes from the common bond that forms from sharing life with aphasia. Differences make the discussions more interesting and dynamic, and our members share a deep respect and appreciation for one another.

A clinician must learn how to balance the techniques he or she chooses with the severity and size of the group. Some techniques are more labor intensive than others and may take too long in larger

groups, where it’s important to monitor the amount of time each person has to participate. It typically takes longer to communicate and confirm information with a partner who has aphasia, which can impair the conversational flow. This may result in side conversations that detract from the main conversational focus. Group members learn when a member needs extra time to convey a message, and we encourage patience. It is the facilitator’s role to bring the group back to a unified focus.

Facilitating participant-led groups provides additional challenges for the clinician. The clinician must understand the unique “flavor” of each group. Some groups are news oriented, whereas others prefer psychosocial issues or social topics. Groups flourish when the clinician can adjust to the preferences of each group. It’s also important for group members to understand that it takes time to form group bonds and cohesiveness. This facilitates the acclimation process and promotes realistic expectations for new group members.

Another challenge is to be sensitive to the appropriate yardstick of change for group members. A group composed of adults with chronic aphasia needs to progress beyond an emphasis on linguistic changes to adaptations that have a positive impact on the members’ quality of life. As discussed previously, it is important to understand issues of impairment, activity limitations, and participation restrictions in relation to aphasia (WHO, 2001).

Discharge Criteria

At the ACC, we do not believe in therapist-ordained discharge criteria. As discussed earlier, we consider aphasia to be a

chronic disorder that deserves continued communication and psychosocial support for as long as desired. ACC participants self-determine both the frequency and the duration of their attendance. As stated by Elman (1998), “rather than a therapist determining a discharge date, individuals with aphasia determine whether they desire discharge from the program. And using a market-based system, they vote with their feet” (p. 230).

Participants who attend one group weekly currently pay \$18 per session. For those participants who elect to attend twice a week, the cost for the second visit is \$12. Participants enroll in ACC groups by purchasing a \$180 session card (Figure 5-2). They “spend” down this card as the therapist crosses off the cost at each session attended. The session card is composed of circles, each representing \$6. This low-tech system allows the therapist to cross off sessions of either \$18 (3 circles) or \$12 (2 circles) on the same card. An additional advantage of this system is that there is no need to schedule “makeup” sessions if participants are ill or have medical appointments. When all sessions on the card have been attended, participants make a decision regarding reenrollment. If they decide to continue in the groups, they purchase a subsequent \$180 card. In addition to private payment directly from participants, several

Reimbursement

As discussed in articles by Elman (1998, 1999a), we have chosen to seek the major part of reimbursement for our groups outside of the traditional health care reimbursement system. We depend primarily on private fees for our speech-language pathologist-facilitated groups.

Aphasia Center of California Session Card

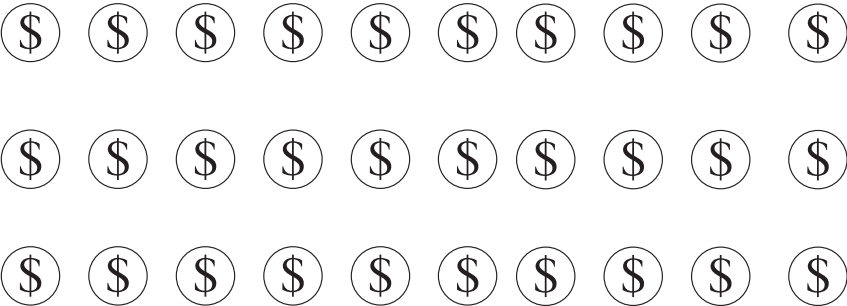
| | |
|--|-----------------|
| Participant Name | Date Purchased |
|  | |
| Date Expires | Staff Signature |

Figure 5-2. Aphasia Center of California Session Card.

third party payers authorize payment for our treatment groups.

Because the ACC is a charitable non-profit organization, its board of directors and staff members are committed to keeping program fees affordable. In addition, sliding fee reductions are available to those with low incomes. This approach permits all who can benefit to attend the Center. In addition, our recreational activities are co-facilitated by adult education instructors and are offered as a “value-added” service at no additional cost to current ACC participants.

Considerations for Specialized Groups

As we’ve described, our communication groups focus on the exchange of personal, educational, and social information, along with discussing relevant news, from personal to international. In other words, we talk about anything of interest going on in group members’ lives or in the world around them. We also offer several specialized groups. Although they are similar in their communicative-social goals to our communication groups, some additional considerations are warranted.

Book Connection™

The Book Connection™ is a weekly book club group that reads and discusses popular adult literature. Please see the manual by Bernstein-Ellis and Elman (2006) for an in-depth discussion of the Book Connection™ program. Consistent with reports in the literature (Parr, Byng, Gilpin, & Ireland, 1997), many of our

ACC members told us that losing the ability to read for pleasure significantly decreased their quality of life. We decided that a book club format could provide the opportunity for our members to connect with literature, as well as with one another. In order to make books accessible to members with mild to moderately severe reading deficits, we developed a series of “reading ramps.” Reading ramps are similar in purpose to the communication ramps discussed by Kagan and Gailey (1993)—both provide adaptations that allow an adult with aphasia to participate successfully in the social life of the community. Some of the reading ramps we use in the Book Connection™ program include large-print books, books on tapes, and a variety of materials found through multiple resources (e.g., Internet, library, video, newspaper, and so on) that serve to enrich the connection to the story. We also develop chapter summaries and highlights, vocabulary lists, character guides, and a series of worksheets that reinforce chapter content and help express personal reactions to the story. A sample of these materials is available on the ACC website (www.aphasia-center.org).

We offer two Book Connection™ groups: one for members with mild to moderate aphasia and one for members with moderate to moderately severe aphasia. However, other sites that have offered this program have reported success in mixing severity levels in their groups (Elman et al., 2005). We have found that severity of aphasia is not the most important parameter related to successful group participation. Instead, critical factors appear to be an interest in reading, a willingness to try adaptive strategies, and adequate auditory com-

prehension for social conversation. The weekly Book Connection™ meetings typically cover an hour's worth of audiotape, or about 20 to 30 pages of large-print reading. Members read and/or listen to the book on their own. Some members choose to read just the chapter summaries or highlights created to support the book. Most books span a 6- to 16-week period, depending on their length. The fee for the class is based on the group facilitator cost, multiplied by the number of weeks, plus the cost of the book, audiotapes, and copying.

The role of the clinician as a book club facilitator has both similarities to and differences from that of facilitator in communication groups. As in communication groups, the facilitator of a book club may need to function as a communication broker for members with more limited expressive output (Beeson & Holland, 1994; Kagan, 1998). Strategies to promote increased initiation, participation, and information exchange, as discussed earlier, are still relevant. In addition to these communication group techniques and strategies, the book club facilitator may need to summarize the general storyline to help reinforce story content. It also is important for the book club facilitator to keep in touch with the book club members to determine how they are juggling the "logistics" of the book club.

It is important for the clinician not to be the only "subject expert" when facilitating a book club group with members who have mild to moderate aphasia. These members asked us for a larger role. To help transfer the responsibility for leading the group, we encourage members to find and report on additional information related to the book. They also take turns in the role of discus-

sion leader. This can take the form of providing a brief synopsis of the chapter or developing a list of questions designed to spark group discussion. It can be challenging to guide a member in the role of facilitator while also being sensitive to the other dynamics of group process. We have found that some members become so enthusiastic about the book that it is challenging for them to maintain equal talking time.

Our group members tell us that the weekly book club discussions are the best part of this group. They enjoy the exchange of ideas and engaging discussion. One member described her perspective: "I gain a lot from others . . . group is wonderful . . . it's dynamic . . . everyone can operate at a certain level and feel success. Even if they can't speak, each person has ideas and energy and brings it to the class . . . you can be challenged at any level."

We have found that our Book Connection™ groups develop special bonds that come from sharing a common storyline as well as personal experiences related to that story. There is a sense of mutual accomplishment as members make their way through the book. We recognize this achievement with a variety of special events on the final session for the book. From viewing special videos, to having guest speakers, to eating food thematically related to the book, the members of the group celebrate together. For most members, it is the first time since their stroke that they have read a book for pleasure.

News Forum

When the Book Connection™ is on hiatus, we offer the News Forum groups.

The News Forum focuses on discussing current events. This program began when our members with mild to moderate aphasia expressed repeated frustration with the challenges of participating in discussions with families and friends, especially when the conversational focus turned to headline news. Although they were able to maintain participation for discussions regarding personal topics, they found it much harder to participate when they had to cite specific names, events, or content related to news stories. They felt relegated to a “nod and respond” role at dinner parties and other social gatherings. To meet this challenge, we formed a group that focuses on reading and presenting news stories.

As with the Book Connection™, we offer two News Forum groups. Members in both groups choose their own stories from the newspaper, magazines, or the Internet to share each week. The diversity of the topics brought in by Forum members is impressive and helps to keep the discussions novel and unique. Ranging in subject from travel, to human interest to sports to news at all levels, the stories that members bring in generate interest and adult discussion.

In our group with members who have moderate to severe aphasia, the facilitator must decide how to maximize each person’s participation. For some members, we’ve developed worksheets to help them create a script for their story. Members complete these worksheets at home and then use their scripts to describe the story to the group. Other members prefer to practice reading the headlines to the group. The News Forum facilitator can quickly skim the article, present the key facts, and foster a discussion around the topic. By generating short scripted questions related to the

story, the facilitator can engage members who need a springboard to participate. Sometimes the facilitator prepares two types of scripts: one that presents the facts of the story and a second that provides questions for other group members to ask about the story. Our News Forum groups support both scripted and nonscripted interactions. The goal is to promote the use of communicative strategies that best serve members in a variety of social interactions.

In our group with members who have mild to moderate aphasia, the participants take the lead in presenting their article. Many prefer to work from notes that they have prepared at home. Some highlight key content words and then glance at the story as they lead the discussion. Other group members are encouraged to jump in and ask questions. This simulates the challenge of “real” conversation for the presenter and allows all group members practice in getting into an ongoing conversation. The News Forum facilitator monitors the balance of group member participation and tracks conversational strategies being used. One of the main goals for the facilitator is to determine how to help each person utilize those strategies that allow for the most communicative independence and success.

Internet Classes

It is challenging for people with aphasia to learn from existing computer programs or attend Internet classes. Computer instructors typically do not have the needed skills to teach or communicate with people who have language impairments. The “digital divide” is great for all people with disabilities but is per-

haps largest for those with language disorders such as aphasia (Elman, 2001). Barriers must be overcome so that those with aphasia can achieve full participation in the ever-growing digital economy (Elman, 2001; Elman, Ogar, & Elman, 2000; Elman, Parr, & Moss, 2003).

Our ACC members told us repeatedly that they wanted to learn how to access the Internet. Because of the wide range of computer ability and interests, we decided to offer two Internet classes. One class focuses on basic computer skills needed for such activities as using a personal computer (PC), using a browser, and sending and receiving e-mail. The second class focuses on more advanced Internet skills, such as those needed to use search engines, evaluate website information, and shop at e-commerce sites.

We use a computer classroom at the Senior Center for our Internet groups. We created a small local area network (LAN) in the computer classroom and connected the machines together to a "digital subscriber line" (DSL) for fast access to the Internet. We also utilize an overhead teaching monitor that allows all members to view the instructor's computer. In this way, the instructor can demonstrate specific information and skills to all class members simultaneously.

Our Internet classes are more structured and didactic than our other groups, in keeping with their purpose and content. The instructor spends quite a bit of time interacting one on one with individuals in the class in order to demonstrate specific skills. However, even Internet classes provide opportunities for interaction among members. The class instructor can place specific members side by side so that they can instruct and learn from one another. For example, one of our class participants was quite facile at using the

keyboard one-handed to access her e-mail account. She then worked with another class member who was having much more difficulty in learning the necessary steps. With added practice and peer support, the second member achieved success, and both members were thrilled at being able to work together.

We determine the specific content for our Internet classes based on needs identified by the specific members who enroll. The instructor has a short interview with all enrolled members in order to determine their "wish list" for the class. In addition to creating this type of curriculum, it may be helpful for class instructors to read through the Internet training package prepared by The University of Queensland. Developed to train volunteers how to teach Internet skills to people with aphasia, it is available for download at the University's website (www.shrs.uq.edu.au/cdaru/aphasia_groups). See Chapter 8 for more information on The University of Queensland Internet program.

Conclusions

After a decade of experience, we find that the greatest rewards of the ACC still come from the stories that our group members and their families share with us about the impact the ACC has had on their adjustment to living with aphasia. These stories highlight new communicative successes and improvements in social adjustment. Most striking is that these changes continue no matter how many years members have participated in ACC programs. Our members continue to demonstrate that there is no ceiling to personal growth or learning. We

are fortunate to be able to create different learning environments, such as the Book Connection™, the News Forum, and Internet classes in response to their needs. Our members tell us that they feel connected to the ACC community and that this connection helps them to find greater meaning in their lives. As our group members help one another, they also help us achieve a better understanding of what quality of life means, especially for living with aphasia.

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