

Introduction

The need for meaningful engagement for people with chronic aphasia has received increasing attention in recent years with a gradual shift from medical to social models of disability for addressing those needs (Hewitt & Byng, 2003; Byng & Duchan, 2005; Simmons-Mackie, & Damico, 2007). In North America, a growing number of community-based and university-based aphasia centers are evidence of this shift in practice. Aphasia centres offer group programs that share a focus on quality of life, participation, and social support, with a variety of services ranging from conversation groups to drama classes (Simmons-Mackie, 2011; Simmons-Mackie & Holland, 2011). An important aspect of service delivery models within a social framework is that they emphasize involvement of participants as equal partners in program development and delivery, in contrast to models that situate professionals as experts.

Opportunities for meaningful engagement for people with aphasia can also be provided through the explicit acknowledgement of their expertise in living “*in the disorder*” (Holland, 2007, p.6). While such acknowledgement is implicit in many programs that seek to include people with aphasia in program development, it is more explicitly acknowledged in programs in which they have a key role in leading activities such as peer mentoring (Coles & Snow, 2011), advocacy (Fletcher & Ganzfried, 2011), and training students in health care professions, as, for example, in developing an education program about aphasia for nursing assistant students (Welsh & Szabo, 2011).

In our graduate speech-language pathology program, we recognized an opportunity to partner with people with chronic aphasia in the community to develop a university-based aphasia mentorship program that could be systematically incorporated into a two-year graduate-level speech-language pathology program as a means to educate students about aphasia. While many university programs offer campus-based aphasia group programs, descriptions of programs that explicitly position the person with aphasia as expert and teacher are relatively few (e.g., Avent, Patterson, Lu, & Small, 2009). In our university program, we developed an eight-month pilot project, working with twelve participants with chronic aphasia, to explore the feasibility of establishing a mentorship program on campus and to develop a design for such a program. Based on the findings of that project, we implemented an aphasia mentorship program, now in its first year, which has two primary goals: 1) to enhance quality of life for people with aphasia through engagement in meaningful activities associated with mentoring; and 2) to enrich education of speech-language pathology students as well as those in other health professions through their interactions with people with aphasia as mentors. The perspectives of participants with aphasia are routinely incorporated into activity planning and delivery. While some activities, such as presentations about aphasia to students in speech language pathology, audiology, or other health care professions, have explicit educational goals and format, others, such as a book club (Bernstein-Ellis & Elman, 2006), campus outings, or computer groups, involve speech-language pathology students and participants with aphasia exploring new topics together. In all activities, the participants with aphasia are viewed as experts in living in aphasia, drawing on their perspectives to guide students in gaining new insights about the impact of aphasia on social interaction and in finding ways to mitigate that impact.

The need for rigorous evaluation of outcomes of programs based on social models of disability for people with aphasia is well recognized (Kagan, 2011). This pilot research project explores the experiences of participants with aphasia in the mentorship program with the goal of identifying parameters that are meaningful to those participants. Identification of such

parameters is a critical step in developing appropriate outcome measures to be incorporated into a systematic evaluation of the program as it evolves.

Methodology

This project draws on the methodological approach of qualitative description, which is well suited to studies in which the goal is a clear description of events and experiences that privileges the perspectives of participants (Sandelowski, 2000). Descriptive and interpretive validity is increased through triangulation of multiple methods of data collection methods, described in procedures.

Participants

All fourteen participants with aphasia in the mentorship program (including nine from the original pilot project) agreed to participate in the research project. Time post onset ranges from 3 to 22 years, with a range also of aphasia type and severity, as determined by the Western Aphasia Battery Revised (Kertesz, 2007), completed with each participant upon joining the program.

Procedures

Semi-structured interviews, exploring experiences with aphasia as well as goals and expectations regarding the program, were conducted individually with all participants prior to their involvement in group activities. Participants also completed the Assessment for Living with Aphasia (see Simmons-Mackie et al., in submission). At the beginning of each academic term, participants met with the authors and at least one speech-language pathology student from each cohort to develop a weekly schedule of activities for the term. During the first academic term, fourteen weekly group sessions, each approximately two hours long, were attended by participants with aphasia and up to six speech-language pathology students. There was a major focus on public speaking, with support from a local Toastmaster's expert, as group members planned and practiced presentations in response to several invitations for presentations beyond the program. Other activities included a book club and development of a website for the program. A similar format for the second academic term is scheduled, although different activities are anticipated.

In addition to the initial interview data, other sources of data collected throughout the program include detailed notes from participant observation (Emerson, Fretz, & Shaw, 1995) during weekly sessions, as well as videorecordings of selected sessions. Finally, towards the end of the first academic year of the program, a speech-language pathologist with skills in supported conversation who is not affiliated with the project will conduct semi-structured individual interviews and a focus group with participants with aphasia regarding their experiences in the program. Thematic analysis of transcriptions of interviews and focus groups, together with participant observation notes (supported by videorecorded data) is ongoing.

Findings

While the majority of data have yet to be collected and/or analyzed, we have documented, first, a trend for some participants with aphasia to take on more responsibility over time for leading activities and, second, three themes emerging in preliminary analyses of data

collected to date. These include: “helping myself by helping others”, “feeling alive again”, and “learning about each other, ourselves, and aphasia.” We anticipate being able to expand on these and other themes that emerge as we continue our analysis.

Discussion

The explicit positioning of people with aphasia as mentors rather than as service recipients within a university speech-language pathology program is a novel approach that not only offers new strategies for educating students in speech-language pathology as well as other health professions about aphasia; it can also potentially enhance quality of life for participants with aphasia through meaningful engagement. It is anticipated that, in addition to guiding the development of specific outcome measures for a mentorship program, findings from this study will contribute to a growing literature on social approaches to interventions for people with chronic aphasia.

References

- Avent, J., Patterson, J., Lu, A., & Small, K. (2009). Reciprocal scaffolding treatment: A person with aphasia as clinical teacher. *Aphasiology, 23*, 110-119.
- Bernstein-Ellis, E., & Elman, R. (2006). The BookConnection™: A life participation book club for individuals with acquired reading impairment (computer software and manual). Accessed 2010, from <http://www.aphasiacenter.org>
- Byng, S., & Duchan, J. F. (2005). Social model philosophies and principles: their applications to therapies for aphasia. *Aphasiology, 19*, 906-922.
- Coles, J., & Snow, B. (2011). Applying the principles of peer mentorship in persons with aphasia. *Topics in Stroke Rehabilitation, 18*, 106-111.
- Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). *Writing ethnographic fieldnotes*. Chicago: University of Chicago Press.
- Fletcher, P., & Ganzfried, E. (2011). Aphasia advocacy and community education: Speaking Out! and beyond. *Topics in Stroke Rehabilitation, 18*, 92-100.
- Hewitt, C., & Byng, S. (2003). From doing to being: From participation to engagement. In S. Parr, J. Duchan & C. Pound (Eds.), *Aphasia inside out: Reflections on disability* (pp. 51-64). Berkshire, UK: Open University Press.
- Holland, A. (2007). *Counseling in communication disorders: A wellness perspective*. San Diego, CA: Plural.
- Kagan, A. (2011). A-FROM in action at the Aphasia Institute. *Seminars in Speech and Language, 32*, 216-228.
- Kertesz, A. (2007). *Western Aphasia Battery Revised*. San Antonio TX: Pearson.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health, 23*, 334-340.
- Simmons-Mackie, N. (2011). Aphasia centers: A growing trend in North America. *Seminars in Speech and Language, 32*, 199-202.
- Simmons-Mackie, N., & Damico, J. (2007). Access and social inclusion in aphasia: Interactional principles and applications. *Aphasiology, 21*, 81-97.
- Simmons-Mackie, N., & Holland, A. (2011). Aphasia centers in North America: A survey. *Seminars in Speech and Language, 32*, 203-215.
- Simmons-Mackie, N., Kagan, A., Victor, J.C., Carling-Rowland, A., Mok, A., Hoch, J., et al. (in submission). The assessment for Living with Aphasia: Psychometric evaluation.
- Welsh, D., & Szabo, G. (2011). Teaching nursing assistant students about aphasia and communication. *Seminars in Speech and Language, 32*, 243-255.