Assessing the long-term impact of aphasia center participation

Introduction

Comprehensive aphasia centers are a growing trend in North America and have begun to influence service delivery for individuals with aphasia and their families. Such centers are grounded in group interaction and are intensive in terms of participation time. Consistent with principles of Life Participation Approaches (LPAA, 2001), centers incorporate programming across a range of experiences and activities, including conversation groups, technology and interactive programming (e.g., Skyping across centers), as well as outreach initiatives. Early examples include The Aphasia Institute in Toronto, the Aphasia Center of California, and Connect in London (Elman, 2007a). Simmons-Mackie and Holland (2011) conducted a survey that identified 33 such centers, with the majority opening in the preceding 10 years. Since that date, these authors estimate that at least 8 new centers have been developed and staffed.

There are many obstacles to collecting effectiveness data in aphasia centers such as those described above. Heterogeneity of programming is an obvious one, compounded, in most cases, by limited professional staff and reliance on trained, but not necessarily equally talented volunteers for a substantial number of activities. Weather, transportation issues, self-selection of activities that are of interest to individual members, moving, illnesses and vacation schedules, as well as the very positive decision that members' lives have moved beyond the type of support provided by Center programming, also contributes to heterogeneity. Finally, time and resources for collection of pre- and post-involvement data are typically limited, and research participation in most aphasia centers is voluntary. Nevertheless, we believe that, in much the same ways that data can be gathered across public schools to demonstrate their effectiveness, consistent data can be gathered to support the value of aphasia centers.

It seems reasonable to assume that the relatively well-documented benefits of participating in an aphasia group would apply to aphasia centers (Avent, 1997; Elman, 2007a, b; Elman & Bernstein-Ellis, 1999). However, direct research on the impact of aphasia centers is limited (Hoen, Thelander, & Worsley, 1997; Van der Gaag et al., 2005). This presentation will describe the long-term impact of participation in programming at two well-established[1] community-based aphasia Centers, referred to here as Centers A and B. Both provide two full days of programming for 6-8 hours weekly, with additional time spent in socializing and operate on three fifteen week terms each calendar year. They share similar philosophies, and are of somewhat similar size in terms of participants and staff directly involved in their programs. A similar core assessment battery is used at both centers. This paper will present results of initial and one and two year follow-up data concerning the effects of involvement at both sites.

Methods

This presentation will focus primarily on the effects of participating at either Center A or B, as measured by the three evaluation tools described briefly below. Evaluations obtained prior to or within six weeks of beginning Center participation are reviewed against two time periods: 1) Follow-up evaluations obtained within roughly one year of involvement with the center (Year

[1] Center A is 10 years old, Center B is 6 years old.

1); and 2) follow-up evaluation completed roughly two years after beginning Center participation (Year 2). All participants were aphasic as a result of a stroke or head injury experienced at least 6 months before the first evaluation. They are more fully described in Table 1. Three evaluation tools are reported on here, as follows:

Communication Activities in Daily Living (CADL-2) (Holland, Frattali & Fromm, 1999), chosen because it is a standardized measure of everyday language usage.

Western Aphasia Battery-Revised (WAB-R) (Kertesz, 2007), chosen because it is widely-used to measure the extent of impairment in aphasia.

Communication Confidence Rating Scale for Aphasia (RIC-CCRSA) (Babbit & Cherney, 2010), chosen as a subjective customer satisfaction measure.

We examine here 61 persons with aphasia (PWAs) who agreed to be tested initially on at least one measure and who were available for reassessment one and/or two years later. The sample size varies across measures, largely as a result of the obstacles described earlier in this proposal. Table 1 more fully describes each sample. Test scores at the time of initial testing appear in Tables 2, 3, and 4.

Findings

Tables 2, 3, and 4 also provide paired sample t-test comparisons for initial versus Year 1 follow up data, as well as Year 2 follow up. Of interest is the observation that for all three measures, there are statistically significant changes. For the CADL-2 at Year 1, the small mean change is above the standard error of the mean (SEM) and it is maintained through Year 2. For the WAB, the small change at Year 1 is within the SEM; the change at Year 2 exceeds the SEM but does not reach significance. The RIC-CCRSA shows significant growth in confidence as measured by this tool. This gain is maintained through the second year.

Finally, we report on data from a one year follow-up of 26 PWAs who were tested over only one year using the recently-developed Assessment for Living with Aphasia (ALA) (Kagan et al., 2010; Simmons-Mackie et al., 2013). This newly-developed measure holds promise for measuring change following Center participation, as indicated by our data, and is currently included in our battery. See Table 5

Discussion

The discussion will focus on the following features: 1) The importance of collaborative efforts to provide effectiveness information if the Center Movement is to be taken seriously by third-party reimbursers and other interested parties; 2) The proposal of a core battery (including the ALA) to meet this goal; 3) An exploration of the pitfalls involved in research of this nature and the importance in pursuing it nonetheless.

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Table 1

Demographic Data

	Sample	Gender	Average Age (Current)	Average Age (Onset)	Aphasia Type
CADL-2	All participants N = 61	M = 46 F = 15	66.1	59.14	Anomic – 25 Broca's – 24 Conduction – 4 Global – 2 Mixed -2 Transcortical Motor – 1 Wernicke's – 2 Above Cutoff – 1
	Initial vs. Year 1 n = 42	M = 29 F = 13	66.7	59.8	Anomic – 18 Broca's – 15 Conduction – 4 Global – 2 Mixed -1 Transcortical Motor – 1 Wernicke's – 1
	Initial vs. Year 2 n = 25	M = 19 F = 6	66.1	58.7	Anomic – 12 Broca's – 7 Conduction – 3 Global – 2 Wernicke's – 1
	Year 1 vs. Year 2 n = 21	M = 15 F = 6	67.6	60.2	Anomic – 9 Broca's – 6 Conduction – 3 Global – 2 Wernicke's – 1

(table continues)

Table 1 (continued)

	Sample	Gender	Average Age (Current)	Average Age (Onset)	Aphasia Type
WAB-R	Initial vs. Year 1 n = 39	M = 29 F = 10	64.5	58.4	Anomic – 16 Broca's – 15 Conduction – 4 Global – 1 Mixed -1 Transcortical Motor – 1 Wernicke's – 1
	Initial vs. Year 2 n = 13	M = 10 F = 13	67.4	61.1	Anomic – 4 Broca's – 5 Conduction – 1 Global – 1 Wernicke's – 2
	Year 1 vs. Year 2 n = 9	M = 9 F = 0	65.4	59.7	Anomic – 3 Broca's – 5 Conduction – 1
RIC-CCRSA	Initial vs. Year 1 n = 33	M = 24 F = 9	64.3	58.6	Anomic – 13 Broca's – 13 Conduction – 4 Global – 1 Transcortical Motor – 1 Wernicke's – 1
	Initial vs. Year 2 n = 22	M = 18 F = 4	66.5	58.7	Anomic – 6 Broca's – 10 Conduction – 3 Global – 1 Wernicke's – 1 Above Cutoff – 1
	Year 1 vs. Year 2 n = 14	M = 11 F = 3	66.2	60.0	Anomic – 4 Broca's – 5 Conduction – 3 Global – 1 Wernicke's – 1

(table continues)

Table 1 (continued)

ALA	Initial vs. Year 1 n = 26	M = 18 F = 8	62.8	57.8	Anomic – 10 Broca's – 13 Conduction – 1 Transcortical Motor – 1 Above Cutoff – 1

Table 2

Paired Sample t-test for CADL-2

	Average Months Between Testing	n	Mean Initial	Mean Follow-up	Mean Difference	SD	t	df	p
Initial vs. Year 1	12.09 (range = 10-16)	42	73.50	78.43	4.93*	8.67	3.69	41	.001
Initial vs. Year 2	26.04 (range = 23-30)	25	72.48	78.76	6.28*	11.09	2.83	24	.009
Year 1 vs. Year 2	13.14 (range = 10-17)	21	76.67	77.19	1.00	6.44	0.71	20	.485

*Significant at $p < .05$, two tailed

Table 3

Paired Sample t-test for WAB-R

	Average Months Between Testing	n	Mean Initial	Mean Follow-up	Mean Difference	SD	t	df	p
Initial vs. Year 1	12.95 (range = 8-18)	39	63.76	65.31	1.55*	4.74	2.04	38	.048
Initial vs. Year 2	26.09 (range = 19-30)	13	59.64	65.39	5.85	10.55	2.00	12	.069
Year 1 vs. Year 2	13.89 (range = 12-17)	9	62.74	67.38	1.55	7.72	1.80	8	.109

*Significant at $p < .05$, two tailed

Table 4

Paired sample t-test for RIC-CCRSA

	Average months between testing	n	Mean Initial	Mean Follow-up	Mean Difference	SD	t	df	p
Initial vs. Year 1	12.94 (range = 9-18)	33`	67.00	72.63	5.64*	13.80	2.65	32	.025
Initial vs. Year 2	27.96 (range = 19-41)	22	65.41	74.43	9.02*	19.71	2.15	21	.044
Year 1 vs. Year 2	13.21 (range = 8-17)	14	73.68	78.75	5.07	14.55	1.30	13	.215

*Significant at $p < .05$, two tailed

Table 5
Paired sample t-test for ALA - Initial vs. Year 1

	n	Mean Initial	Mean Follow-up (1-year)	Mean Difference	SD	t	df	p
Aphasia Domain	26	1.63	1.88	0.25*	0.61	2.01	25	.046
Participation Domain	26	2.21	2.27	0.68	0.40	0.88	25	.386
Environment Domain	26	2.34	2.66	0.31*	0.66	2.43	25	.023
Personal Domain	26	2.61	2.69	0.08	0.40	1.07	25	.293
Wall Question	26	2.38	2.43	0.50	0.99	0.26	25	.800
Total	26	2.30	2.43	0.13*	0.29	2.35	25	.027

*Significant at $p < .05$, two tailed