

Knowledge of Aphasia: Results of a Survey

Most people understand stroke is a major cause of death and disability in the United States (Thom et al., 2003). However, public knowledge of aphasia, a major disability that affects many stroke survivors appears to be lacking as evidenced by two factors. First, funding for treatment of aphasia and aphasia research has remained stagnant for several years in spite of a dearth of positive aphasia treatment research (Rogers, Alarcon, & Olswang, 1999). Second, results from several surveys designed to assess public awareness of aphasia have shown many people have inadequate knowledge about the disorder, its causes, and its treatment (Code, Simmons-Mackie, Armstrong, Stiegler, Armstrong, & Bushby, 2001; Elman, Olgar, & Elman, 2000; Simmons-Mackie, Code, Armstrong, Stiegler, & Elman, 2002; Flynn, Cumberland, & Marshall, 2009). This has prompted clinicians, researchers, and patient advocates to call for actions to raise awareness, increase funding, and provide a broader array of services to individuals consigned to living a lifetime with aphasia (Elman et al., 2000; Hallowell & Chapey, 2008; Simmons-Mackie, 2008). The aim of the present study was to assess public knowledge of aphasia in hopes that this information would be useful in developing a subsequent plan of action to increase public awareness of this disorder.

Methods

Respondents

Two-hundred-twenty-three adults living in the stroke belt of the United States were administered an aphasia awareness survey (See Appendix A) used in a previous study by Simmons-Mackie and colleagues (2002). Surveys were conducted face-to-face in locations convenient to the respondent (shopping malls, churches, private homes) between September and December, 2010. Eighty-two males (37%) and 141 females (63%) between 18 and 82 ($M=31.4$; $SD = 14.84$) years of age responded to the survey. As shown in the Appendix A, the survey was terminated if the person indicated he/she had not heard of aphasia. One-hundred-ten respondents (49.3 %) indicated they had never heard of aphasia. Thus the investigators were able to assess knowledge of aphasia for 113 respondents (50.67%). Most of these respondents had obtained their information about aphasia at work ($n = 45$), from the media (newspaper, internet, television, $n = 19$), or knew of or about a person who had aphasia ($n = 25$).

Assessing Knowledge of Aphasia

The Aphasia Awareness Survey (See Appendix A) contained eight questions related to the symptoms of aphasia (See item 4) and five questions related to its causes (See item 6). Respondents answered these questions “yes,” “no,” or “not sure.” To assess respondents’ knowledge of aphasia, the questions were used to develop the 13-item “Aphasia Knowledge Quiz” shown in Table 1. Three certified speech-language pathologists with extensive experience with aphasia answered the 13 questions yes or no and unanimously agreed on the answers shown in Table 1. An apriori decision was made to consider any “not sure” answers from respondents as wrong answers. The reason for this was that a “not sure” response to a question such as “Do people with aphasia have mental health problems?” is the same as not knowing the answer.

Scoring

Respondents' answers to questions of the aphasia knowledge quiz were scored right or wrong. The number of correct responses was computed for each respondent. The percentage of correct responses were also calculated on a question by question basis.

Results

The number of correct responses on the aphasia knowledge quiz for the 113 respondents who had heard of aphasia ranged from 3-13. The mean number of correct responses was 9.17 (SD = 2.15). Table 1 gives the distribution of scores across the respondents. These data show that few respondents received perfect scores on the aphasia knowledge quiz.

Table 2 shows the percentage of correct responses for the respondents on a question by question basis. These data reflect three clear-cut findings. First, more than 80% of the respondents who were aware of aphasia know that it is a communication disorder (question 8), caused by brain damage (question 9) due to a stroke (question 9), and affects oral communication (questions 1 and 2). Second, most respondents did not realize aphasia is a general language deficit crossing all language modalities. Table 2 shows that only 38%, 42%, and 45% of the respondents were aware that aphasia impacted understanding, reading, and writing respectively. Finally, the mean percentage of correct responses to question 4, 5, 10, 11, and 12 was 72 %. This suggests that nearly 30% of the respondents considered people with aphasia to have problems related to thinking, intelligence, or mental health.

Discussion

This study assessed public knowledge of aphasia with a survey as a prerequisite step to developing an action plan to increase awareness of the disorder. It was encouraging that more than half (50.67%) of the 223 people taking the Aphasia Awareness Survey indicated they had heard of aphasia compared to only 13.9% in an earlier study by Simmons-Mackie et al. (2002). This may be due to the fact that this survey was conducted in a "stroke belt" state whereas the Simmons-Mackie et al. study was an International survey. It may also indicate public awareness of aphasia has increased in the last 10 years.

While encouraging that half the people surveyed had heard about aphasia, it appears that having heard about aphasia does not mean one knows anything about aphasia. Respondents' average score on the 13-item aphasia knowledge quiz was only 9.16. Table 2 shows most respondents answered 8 or more questions correctly, but there were also many lower scores. If a cutoff mark of 90% were used to assess knowledge of aphasia in people aware of the disorder, few of our respondents would receive passing marks. This suggests a need increase our efforts to inform the public what aphasia is and is not.

Examination of specific questions shown in Table 3 reflects most respondents consider aphasia a verbal problem first and foremost. Less than half the respondents were aware that aphasia impacts comprehension, reading, and writing. This may reflect the long lingering effects of the terms "expressive and receptive aphasia" coined by Weisenburg and McBride (1935) and used to this day by many physicians.

While answers to the aphasia knowledge quiz indicated many respondents associate aphasia with stroke and brain damage, it appears that some respondents consider aphasia to also impact cognition, thinking, and mental health. Written answers from the surveys, specifically to questions three (What is aphasia?) and five (What causes aphasia?) anecdotally corroborated this but respondents' written answers were not analyzable.

In sum, while this was a small survey, respondents' answers to the aphasia knowledge quiz suggest some clear trends. These were (a) an understanding of aphasia as a communication disorder caused by brain damage affecting speech (b) relatively lack of awareness of the effects of aphasia on understanding, reading, and writing, and (c) suspicions that aphasia impacts cognition, mental health, and thinking. Were the findings of this study to be replicated and supported by a larger survey, they could provide a framework for guiding efforts to educate the public about aphasia.

References

- Flynn, L. Cumberland, A., Marshall, J. (2009). Public knowledge about aphasia: A survey with comparative data. *Aphasiology*, 23, 393-401.
- Code, C. , Simmons-Mackie, N. et al. (2001). The public awareness of aphasia: An international survey. *The International Journal of Language and Communication Disorders*, 36, 1-5.
- Elman, R., Ogar, J., & Elman, S. (2000). Aphasia: Awareness, advocacy, and activism. *Aphasiology*, 14, 455-459.
- Hallowell, B. & Chapey, R. (2008). Delivering language intervention services to adults with neurogenic communication disorders. In R. Chapey (Ed.) *Language Intervention Strategies in Aphasia and Related Neurogenic Communication Disorders* (5th Ed.) (203-228). Baltimore: Lippincott Williams & Wilkins.
- Rogers, M., Alarcon, N., & Olswang, L. (1999). Aphasia management considered in the context of the World Health Organization model of disablements. *Physical Medicine and Rehabilitation Clinics of North America*, 10, 907-923.
- Simmons-Mackie, N. (2008). Social approaches to aphasia intervention. In R. Chapey (Ed.) *Language Intervention Strategies in Aphasia and Related Neurogenic Communication Disorders* (5th Ed.) (290-318). Baltimore: Lippincott Williams & Wilkins.
- Simmons-Mackie, N., Code, C., Armstrong, E., et al. (2002). *What is aphasia? Results of an international survey*. *Aphasiology*, 16, 837-848.
- Thom, T., Haase, N., Rosamond, W., et al. (2003). Heart disease and stroke-2006 update. *Circulation*, 105, 1-69.
- Weisenburg, T. H., & McBride, K. E. (1935) *Aphasia*. New York: Commonwealth Fund

Table 1.Aphasia Knowledge Quiz.

<i>Statement</i>	<i>Correct Answer</i>
1. PWA have trouble with pronunciation of speech	True
2. PWA have trouble with language or putting their ideas into words	True
3. PWA have problems understanding what people say to them	True
4. PWA have problems with thinking or general intelligence	False
5. PWA have “mental health” problems	False
6. PWA have reading problems	True
7. PWA have writing problems	True
8. PWA have communication problems	True
9. Aphasia is caused by brain damage	True
10. Aphasia is caused by emotional problems	False
11. Aphasia is caused by impaired intelligence	False
12. Aphasia is caused by mental problems	False
13. Aphasia is caused by stroke	True

Table 2. Distribution of Scores.

<i>Number of Correct Responses</i>	<i>Number of Respondents</i>
1	0
2	0
3	2
4	2
5	3
6	4
7	11
8	19
9	19
10	22
11	16
12	8
13	7

Table 3. Mean percentage of correct responses for participants on the Aphasia Knowledge Quiz.

<i>Statement</i>	<i>Percentage correct</i>
1. PWA have trouble with pronunciation of speech	81.14%
2. PWA have trouble with language or putting their ideas into words	83.19%
3. PWA have problems understanding what people say to them	38.05%
4. PWA have problems with thinking or general intelligence	69.91%
5. PWA have “mental health” problems	76.99%
6. PWA have reading problems	42.48%
7. PWA have writing problems	44.79%
8. PWA have communication problems	91.15%
9. Aphasia is caused by brain damage	84.07%
10. Aphasia is caused by emotional problems	71.68%
11. Aphasia is caused by impaired intelligence	71.68%
12. Aphasia is caused by mental problems	71.00%
13. Aphasia is caused by stroke	83.19%

Appendix A.

Awareness of Aphasia Survey

Date of Survey: _____

Place of Survey: _____

Time of Day: _____

1. Age of respondent _____ Gender _____ Occupation _____

2. Have you ever heard of aphasia? Yes _____ No _____ Not sure _____

If no stop here

3. What is aphasia? Tell me in your own words. (write verbatim)

4. Would you say that people with aphasia

- a. Have trouble with pronunciation of speech (yes, no, not sure)
- b. Have trouble with language or putting their ideas into words? (yes, no, not sure)
- c. Have problems understanding what people say to them? (yes, no, not sure)
- d. Have problems with thinking or general intelligence? (yes, no, not sure)
- e. Have "mental health" problems? (yes, no, not sure)
- f. Have reading problems? (yes, no, not sure)
- g. Have writing problems? (yes, no, not sure)
- h. Have communication problems? (yes, no, not sure)

5. What causes aphasia? Tell me in your own words. (Write verbatim)

6. Is aphasia caused by?

- a. Brain damage (yes, no, not sure)
- b. Emotional problems (yes, no, not sure)
- c. Impaired intelligence (yes, no, not sure)
- d. Mental problems (yes, no, not sure)
- e. Stroke (yes, no, not sure)

7. Where did you hear about aphasia? (In what context did you hear about aphasia?)

- a. Relative/friend has/had aphasia _____
- b. On TV/radio _____
- c. Newspapers/magazines _____
- d. Doctor _____
- e. Through my work _____
- f. Other (specify) _____

8. What do you think can be done to help people with aphasia? (write verbatim)

