

The persistent needs of people living with aphasia: Results of a national survey

Abstract

Our current knowledge about the information needs of people with aphasia comes primarily from small-scale qualitative studies. We distributed an electronic survey to consumers living with aphasia and professionals. There were 428 responses from across the United States. Both consumers and professionals rated information as “somewhat difficult to find”. The highest rated five topics were: how to keep improving; communication strategies; aphasia therapy techniques; coping strategies; and strategies for caregivers. There was an interest in receiving information through digital media such as webinars. The results have implications for national and regional efforts to provide information about living with aphasia.

Summary

Several small-scale, qualitative studies have explored the resource and information needs of individuals living with aphasia. In 1998, Denman reported the results of in-depth interviews with nine spouses of individuals with aphasia living at home in the UK. These spouses stated their need for social support, training, role change support, and respite care. They identified information needs for nature and course of aphasia, financial assistance, and local services. Similar findings came from another interview study of six spouses in Canada, who also identified the following needs: information, knowledge of communication strategies and techniques, social support, and respite care (Michellat, LeDorze, & Tetrault, 2001). Information about aphasia emerged as a critical need area, along with social support and hopefulness, in a study of 16 American family members who participated in focus groups (Avent et al, 2005).

Access to information can be achieved in a number of different ways. Individuals with aphasia do want to be provided with written information along with explanation about their stroke and aphasia in the early stages of hospitalization, and the readability and format of this information is important (Eames, McKenna, Worrall, & Read, 2003; Rose, Worrall, Hickson, & Hoffmann, 2010; Rose, Worrall, Hickson, & Hoffmann, 2011). When five people with aphasia and seven caregivers were asked about what information they would like to access on an aphasia website, they identified needs for information about stroke and its consequences, local services, and return to previous activities (Kerr, Hilari, & Litosseliti, 2010). In a three-year sample of individuals who attended a two-day aphasia conference, caregivers indicated needs for information about how to continue improving communication at home, understanding current research, coping, returning to activities, and understanding aphasia, and these themes were echoed by individuals with aphasia attending the conferences (Hinckley, Packard, & Bardach, 1995; Hinckley & Packard, 2001).

Across these studies, there is congruence on information need areas, specifically needs for information about aphasia, life participation, and coping. It is unknown how people living with aphasia would prefer to access this information over time. In addition, we do not know professionals’ perceptions about needed information or resources. The purpose of this paper is to report the results of a nationwide survey which asked consumers and professionals about the information that they need, the ease with which it can be accessed in their geographic region, and the method by which they prefer to be able to access the information.

Methods

Possible information needs were compiled across existing study results and included as options within a survey based on a previous needs assessment (National Aphasia Association, 1988). Aphasia-friendly language and graphics were provided. The text of the survey is shown in the Appendix. The survey was distributed electronically to 9,079 individuals on the email contact list of the NAA and was available for response from October 3–December 31, 2011. Professionals were encouraged to ask all members of their aphasia groups to respond to the survey. The survey was distributed and responses collected through *Constant Contact*[®].

Results

There were a total of 445 responses to the survey. Responses of individuals with an international residence were deleted, resulting in 428 total U.S. responses. 70.5% (302) of the remaining respondents were consumers, and 29.5% (126) were professionals. The consumer and professional responses were separated and results from each of these two respondent categories are reported.

Consumer Responses

The gender and age distribution of the consumer respondents is shown in Table 1. The geographic distribution of the consumer respondents is shown in Figure 1.

Consumer respondents rated the availability of resources nationally as 2 (median score on the four-point scale), signifying “somewhat difficult to find resources”. Ratings for availability of resources by state are shown in Figure 1.

The topics about which the respondents wanted to know more are shown in rank order in Table 2. Medians were calculated for preference ratings for method to receive the information. Consumer respondents’ first choice for receiving information was through written material, followed by webinars/teleseminars, and then by conferences.

42% of the consumer respondents had previously attended a conference about aphasia and aphasia resources, and 45% of consumers indicated a willingness to pay a fee to receive information and resource support.

Professional Responses

The gender and age distribution of the professional respondents is shown in Table 1. The geographic distribution of the professional respondents is shown in Figure 2.

Professional respondents rated the availability of resources nationally as 2 (median score on the four-point scale), signifying “somewhat difficult to find resources”. Ratings for availability of resources by state are shown in Figure 2.

The topics about which the respondents wanted to know more are shown in rank order in Table 2. Medians were calculated for preference ratings for method to receive the information. Professional respondents’ first choice for receiving information was through written material, followed by webinars/teleseminars, and then by conferences.

36% of the professional respondents had previously attended a conference about aphasia and aphasia resources, and 45% of professionals indicated a willingness to pay a fee to receive information and resource support.

Discussion

Overall, there was congruency between the responses for the consumers and professionals. Generally, respondents in both categories rated information “somewhat difficult to find”, although there were several states that earned a median rating of “somewhat easy to

find” (Arizona, North Dakota, Nebraska, Illinois, Indiana, Georgia, New York, Rhode Island, and Massachusetts).

The ratings of both the consumers and professionals for topics that they would like to have more information about were also in agreement. The top five topics for both groups were: how to keep improving after therapy ends; communication strategies for family and friends, aphasia therapy techniques, coping strategies/living successfully, and strategies for caregivers. These topics have been consistently shown to be need areas in previous studies.

Both consumers and professionals indicated that they prefer to receive written material about these topics, followed by the use of technology via webinar or teleseminar. This latter method of providing information and resources is currently little used and should be explored further. It should be noted that these respondents were to some degree technologically savvy since they responded to an electronic survey. Nearly half of all respondents had already attended a conference, and would be willing to pay some fee for resources.

The mission of the NAA is to promote universal awareness and understanding of aphasia and provide support to all persons with aphasia, their families and caregivers in the United States. Currently, this support and information is provided through several different avenues, including written materials, a website, a toll free resource line, and educational conferences. The rated methods for accessing information in this survey suggests that the NAA and all other professionals serving those with aphasia should consider using digital media more fully as an additional educational tool.

This national survey can help us understand geographic patterns in which more contact may be needed. Educational and support efforts can be focused on the most prevalent topic areas. The comments provided by participants offer insight into the development of future tools and programs for people with aphasia and their families. This is a large-scale survey and the results can inform both national and regional efforts to provide information and resources to those living with aphasia.

References

- Avent, J., Glista, S., Wallace, S., Jackson, J., Nishioka, J. & Yip, W. (2005). Family information needs about aphasia. *Aphasiology, 19*, 365-375.
- Denman, A. (1998). Determining the needs of spouses caring for aphasic partners. *Disability and Rehabilitation, 20*, 411-423.
- Eames, S., McKenna, K., Worrall, L., & Read, S. (2003). The suitability of written education material for stroke survivors and their carers. *Topics in Stroke Rehabilitation, 10*, 70-83.
- Hinckley, J. J., Packard, M. E. W., and Bardach, L. (1995). Alternative family education programming for adults with chronic aphasia. *Topics in Stroke Rehabilitation, 2*, 53-63.
- Hinckley, J. J. & Packard, M. E. W. (2001). Family education seminars and social functioning of adults with chronic aphasia. *Journal of Communication Disorders, 34*, 241-254.
- Kerr, J., Hilari, K., & Litosseliti, L. (2010). Information needs after stroke: What to include and how to structure it on a website. A qualitative study using focus groups and card sorting. *Aphasiology, 24*, 1170-1196.
- Michallet, B., LeDorze, G., & Tetrault, S. (2001). The needs of spouses caring for severely aphasic persons. *Aphasiology, 15*, 731-747.

National Aphasia Association (1988). Impact of aphasia on patients and families: Results of a needs survey. Unpublished report.

Rose, T., Worrall, L., Hickson, L., & Hoffmann, T. (2010). Do people with aphasia want written stroke and aphasia information? A verbal survey exploring preferences for when and how to provide stroke and aphasia information. *Topics in Stroke Rehabilitation, 17*, 79-98.

Rose, T., Worrall, L., Hickson, L., & Hoffmann, T. (2011). Aphasia friendly written health information: Content and design characteristics. *International Journal of Speech-Language Pathology, 13*, 355-347.

Table 1. Gender and age distribution of the consumer and professional respondents.
 Response on age and gender items was not required, so total number of responses does not equal n.

	Consumers (n= 302)	Professionals (n= 126)
Men	32% (98)	29% (36)
Women	68% (199)	71% (90)
Below age 40 years	16% (48)	14% (18)
Between age 40-60 years	51% (153)	46% (58)
Above age 60 years	32% (97)	40% (51)

Table 2. Topics about which respondents wanted to know more. Rank order for the consumers and professionals are shown in bold; number of positive responses for each topic are shown in parentheses. Respondents could select any number of topics.

Topics	Consumers (n= 302)	Professionals (n=126)
How to keep improving after therapy ends	1 (195)	1 (92)
Communication strategies for family and friends	2 (174)	5 (74)
Aphasia therapy techniques	3 (165)	2 (82)
Coping strategies/living successfully	4 (163)	3 (80)
Strategies for caregivers	5 (152)	4 (78)
New research`	6 (124)	6 (68)
Community education/outreach	7 (112)	8 (53)
What to tell friends about aphasia	8 (106)	9 (49)
Aphasia advocacy	9 (99)	7 (57)
Legal issues	10 (94)	10 (44)
Personal experiences with aphasia	11 (89)	15 (32)
Starting an aphasia group	12 (84)	11 (42)
Driving	13 (80)	12 (39)
Insurance/disability payment	14 (73)	14 (33)
Medical questions about stroke	15 (70)	13 (33)
Returning to work	16 (68)	16 (30)
Being a parent with aphasia	17 (52)	17 (20)
Sexuality and intimacy	18 (50)	18 (19)

Figure 1. Geographic distribution of consumer respondents with resource availability ratings.

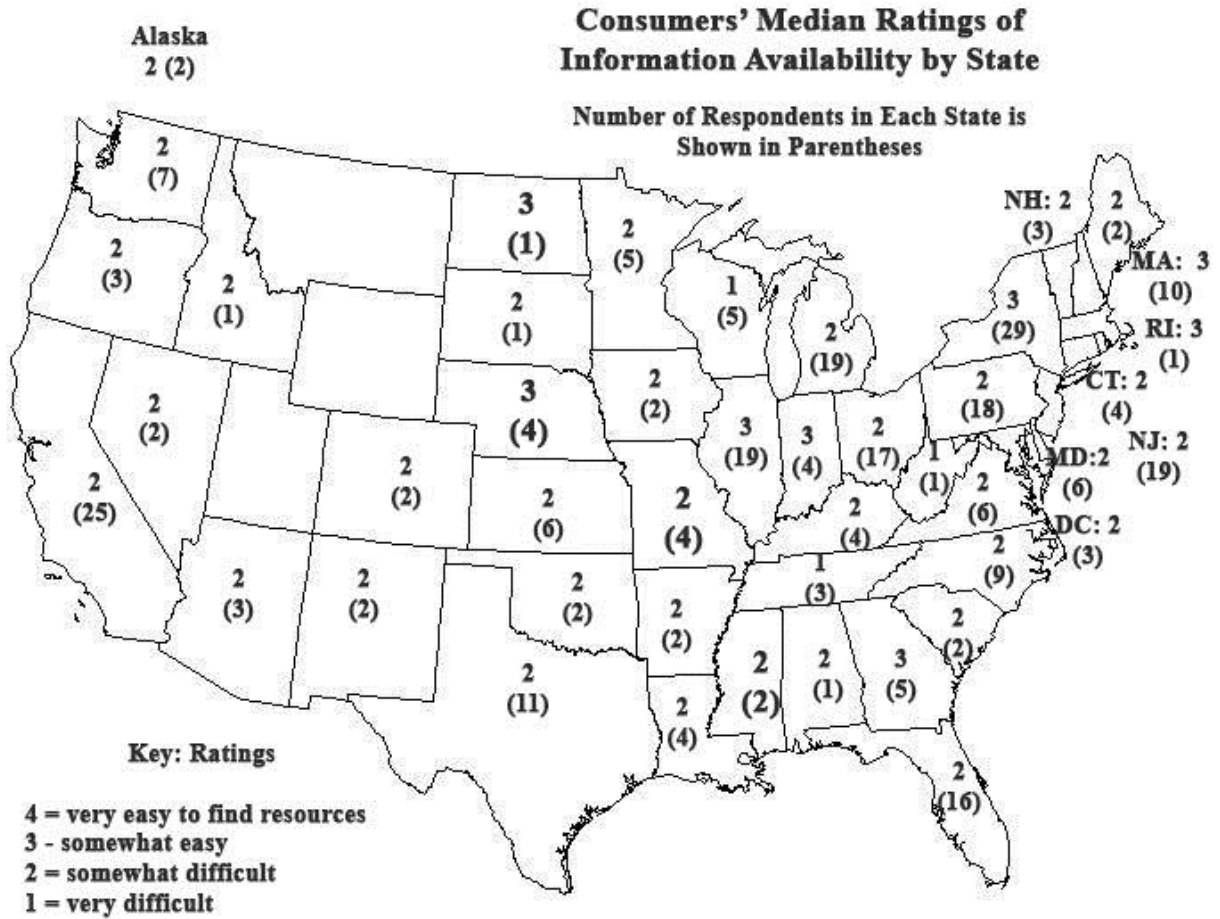
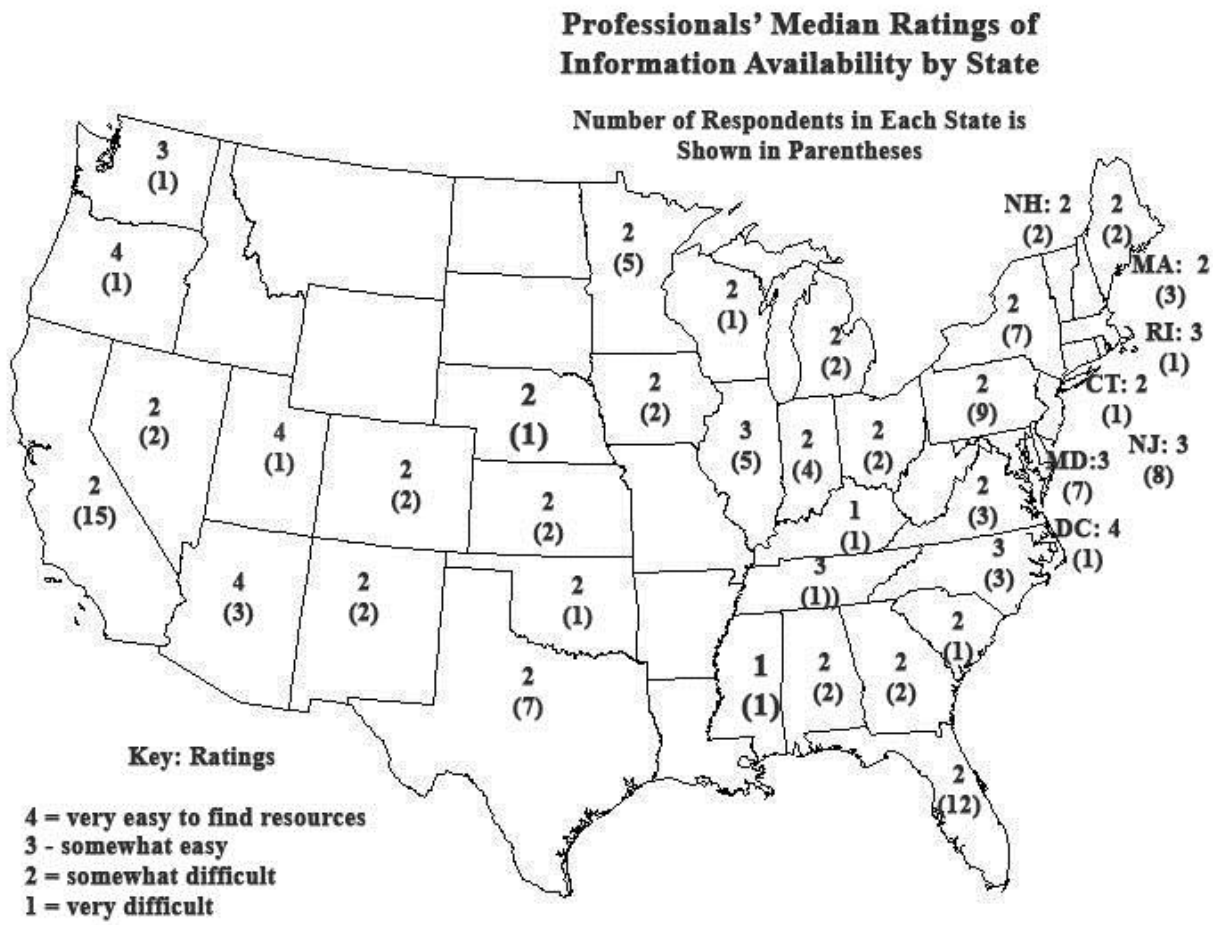


Figure 2. Geographic distribution of professional respondents with resource availability ratings.



Appendix. Text of survey questions. Open-ended comment boxes were also provided.

1. I am a...
 - 1) consumer (person with aphasia, caregiver, etc.)
 - 2) professional

2. What city and state do you live in?

3. Are you a male or a female?

4. Please select your age group.
 - 1) Below 40 years
 - 2) Between 40-60 years
 - 3) Over 60 years

5. Rate the availability of aphasia-related resources in the United States.
 - 1) Very easy to find resources
 - 2) Somewhat easy to find resources
 - 3) Somewhat difficult to find resources
 - 4) Very difficult to find resources

6. Rate the availability of aphasia-related resources in your state.
 - 1) Very easy to find resources
 - 2) Somewhat easy to find resources
 - 3) Somewhat difficult to find resources
 - 4) Very difficult to find resources

7. Rate the availability of aphasia-related resources in your city.
 - 1) Very easy to find resources
 - 2) Somewhat easy to find resources
 - 3) Somewhat difficult to find resources
 - 4) Very difficult to find resources


8. Select all of the topics you would like to learn more about.

√	
	Communication strategies for family and friends
	How to keep improving after therapy ends
	What to tell friends about aphasia
	How to cope/Living successfully
	Strategies for caregivers
	Returning to work
	Driving

	Being a parent with aphasia
	Legal issues such as guardianship, competency, power of attorney
	Medical questions about stroke
	Sexuality and intimacy
	Insurance/Disability Payment
	Starting an Aphasia Group/Center
	Aphasia Advocacy
	Aphasia Therapy Techniques
	Community education/outreach
	New Research
	Personal experiences with aphasia
	Other

9. What would help you locate or utilize resources for living with aphasia?

10. Have you ever attended a conference about aphasia?

Yes 

No 

11. How would you like to receive information and education? Rank order

_____ Attend a Conference

_____ Webinar/teleseminar (computer based/telephone based workshop)

_____ Receive written material