

Family members of individuals with aphasia clearly face different challenges at different points in time (Helm-Estabrooks & Albert, 2004; Lubinski, 2001; Sarno, 1993). Part of our role as speech-language pathologists is to educate families about aphasia but to do so in an effective manner. According to Luterman (2001), overwhelming individuals with information can undermine therapeutic effectiveness. He advocates a relationship building approach to information giving which implies empowering family members to seek information, as they need it. One approach to a relationship building exchange of information is to provide families with research-based, information-oriented guidelines that can be asked when family members are ready for the information.

Research is beginning to indicate that family members need different information at different points in time (Avent, Glista, Wallace, Jackson, Nishioka, & Yip, in press; Bloom & Slavin, 2003; Insalaco, Lubinski, & Sellers, 2004; Michallet, Le Dorze, & Tetreault, 2001; Pound, Parr, & Duchan, 2001). At onset of aphasia, family members report a need for information about recovery and prognosis, strategies to improve communication, community resources, aphasia and stroke, emotional support, finances and cost of treatment, and the impact of aphasia on cognition. Once speech-language treatment begins, family members report needing information about the purpose of testing and treatment, how to improve communicative interactions, ways the family can assist during treatment, co-existing sequelae and contacting more experienced family members to answer questions. Once formal treatment has ended, family members report needing information about alternative therapies and activities, adaptive travel guidelines, strategies for home treatment, support groups, and long-term planning resources.

The present study is a follow-up to the study by Avent et al. (in press). In the initial study, focus group interviews with family members were conducted to determine information needed at three different points in time: onset of aphasia, beginning of treatment, and chronic phase of aphasia. The purposes of the current study are to validate the information needs obtained in the initial study from a family member perspective, to compare the importance of information needs between families, experts (speech-language pathologists), and naïve individuals, and to determine whether the survey questions adequately cover information needs.

Method

Participants. Family members of individuals with aphasia, experts, and naïve adults participated in the survey study. The subject groups were: 30 adult family members, 39 experts, and 54 naïve adults.

Materials. A total of 216 surveys were distributed with 49 to family members, 83 to experts, and 84 to naïve adults. The overall return rate for the surveys was 55% for family members, 48% for experts, and 64% for naïve adults.

Procedures. The participants were asked to rank and rate informational questions regarding onset of aphasia, treatment, and chronic phases and provide additional information as necessary. A seven point Likert-type scale was used to rate the importance of each question (1=very important, 7=not important). Following the rating of each question, subjects were instructed to rank the importance of the questions. Additional space was provided on the survey for participants to add other relevant questions. Randomization and counterbalancing was used to present the questions for each of the three phases of aphasia (onset, treatment, chronic) in a varied sequence to subjects.

Experimental Design and Analysis. Results were analyzed using a multivariate analysis of variance (MANOVA) repeated measure within subject design with one between subject variable at three levels (family, expert, naïve) to compare responses across the three groups of participants during each phase. Rankings of the questions for most important, second most important and least important were used to compare relative importance of the questions for each group. Furthermore, questions added by the participants were qualitatively analyzed.

Results

Family member ratings. Mean ratings by family members for each stage of recovery (onset of aphasia, beginning of treatment and chronic stages) were used to determine the importance of each question. The mean ratings of 18/20 questions were *very important* with 2/20 rated as *moderately important*. No question was rated *not important*.

Family member, speech-language pathologist, and naïve adult ratings. The results of the MANOVA ($p=.000$) indicated significant results across the 20 questions, however, there was no interaction between groups and questions indicating general agreement about the importance of the questions. Since the group term was not significant ($p<0.201$), there was no difference in the question ratings for the three groups; however, a difference in level (means) was evident. It appears the families of individuals with aphasia, responded more favorably to the questions (had lower means) than the other two groups (expert and naïve).

Relationship between family, speech-language pathologist and naïve adult rankings. Participant responses to the portion of the survey requiring them to rank order the importance of the questions were tallied and a percentage of times participants ranked a question as “most important,” “second most important,” and “least important” were obtained. The results showed agreement on 1/9 questions between the rankings of family members and experts, 2/9 agreements between families and naïve adults, and 4/9 agreements between experts and naïve adults.

Information needs adequacy. Participants were asked to write-in suggestions for questions not covered by the survey. A total of 35 additional questions or comments were obtained from five family members, five experts, and three naïve adults. The content of the questions were qualitatively analyzed to determine unique questions not covered by the survey. Of the 35 additional questions, eight unique questions were not covered in the survey. Examples of additional questions included the following—during the onset stage: 1) How best to inform friends and family, 2) How to tell and prepare children prior to seeing loved one; during treatment: 1) What different types of rehabilitative centers are available, 2) How long will he/she need therapy; chronic stage: 1) Local transportation options, 2) What does accessibility really mean.

Discussion and Conclusions

Results of this study validate specific information needs of family members at three different points in time: onset of aphasia (hospitalization), during rehabilitation, and return to community living (chronic). Differences are evident, however, in the relative importance of information across the groups indicating a mismatch between family member information priorities and speech-language pathologist information-giving. Additional information-oriented questions obtained from this research indicate a need for future research to further define family-oriented information guidelines. From a clinical perspective, however, the information guidelines validated in this study can be used to improve *how* we educate families of individuals with

aphasia. Instead of “over helping” (Luterman, 2001) families with too much information, guidelines can be used to encourage families to ask questions, as information is needed.

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