Research Problem and Rationale

Survey data reveal that more than 90% of people with aphasia feel isolated (National Aphasia Association, 1988). One respondent said, "We need to feel welcome to visit people and we do not...We have no visitors...and lead very lonely lives." Negative outcomes associated with loneliness include physical illness (Alpass & Neville, 2003), depression (Alpass & Neville, 2003), and suicide (Wenz, 1977). Because chronic loneliness can interfere with psychological functioning, mental health, and physical health, clinicians might consider the alleviation and prevention of loneliness as a key focus of aphasia therapy (Heinrich & Gullone, 2006).

Loneliness is hypothesized to occur when a person's existing social relationships are discrepant from his or her expected or desired relationships (Rook, 1984). In people without aphasia, loneliness may be caused by emotional or social isolation (Weiss, 1973; 1974). Emotional loneliness is hypothesized to result from lack of a close, intimate attachment to another person. Such a relationship would otherwise provide feelings of affection and security. Social loneliness is hypothesized to result from lack of a network of social relationships in which the person is a part of a group of friends. Such a network would otherwise provide a sense of belonging based on shared concerns, work, or other activities (Russell, Cutrona, Rose, & Yurko, 1984). In people without aphasia, the underlying cause of loneliness determines treatment goals and methods by which they may be achieved. However, in people with aphasia, the cause(s) of loneliness, and thus the means by which it may be alleviated, have not been established.

In this study, our aims were to determine whether loneliness in people with aphasia differs significantly from loneliness in people without aphasia, and, if so, to identify treatable factors associated with increased loneliness in people with aphasia.

Methods of Data Acquisition

Twenty-six adults with aphasia and 21 normal controls completed the protocol. Participants with aphasia had a history of one or more strokes; brain damage confined to the left hemisphere, as confirmed by neuroradiological data; no history of other disease that would affect communicative ability; and, a diagnosis of aphasia, as determined by the principal investigator, using an operational definition provided by Rosenbek, LaPointe, and Wertz (1989). Normal controls had no history of brain injury or other disease that would affect communicative ability. Absence of brain damage in normal controls was based on history by self-report.

To compare overall loneliness between groups, all participants were administered the Revised UCLA Loneliness Scale (RULS, Russell, Peplau, & Cutrona, 1980). The RULS is the most frequently used measure of loneliness. Loneliness is conceptualized as a unidimensional emotional response to a discrepancy between desired and achieved levels of social contact (Peplau & Perlman, 1982). Ten positively-worded (i.e., nonlonely) and ten-negatively worded items comprise the scale.

To identify possible, treatable factors associated with loneliness within groups, the following data were collected:

<u>Demographic variables (all participants)</u>: age, gender, education, marital status, and work status

<u>Stroke-related variables (participants with aphasia)</u>: time post-stroke, language impairment (Porch Index of Communicative Ability-3rd Edition, PICA, Porch, 1981), and functional communication (Communication Activities of Daily Living-2nd Edition, CADL-2, Holland, Frattali, & Fromm, 1999)

<u>Interpersonal variables (all participants)</u>: perceived attachment (RULS questions 3, 7, and 13)*, sense of belonging (RULS questions 1, 5, and 6)*, and perceived frequency of social support (Inventory of Socially Supportive Behaviors, ISSB, Barrera, Sandler, & Ramsey, 1981)

*These six items from the RULS were found by the measure's authors to best differentiate between social and emotional loneliness, respectively. Emotional loneliness (lack of perceived attachment) is correlated with feeling that there is no one to turn to (Question 3), feeling no longer close to anyone (Question 7), and feeling that nobody really knows one well (Question 13). Social loneliness (lack of sense of belonging) is instead associated than emotional loneliness with not feeling "in tune" with others (Question 1), not feeling a part of a group of friends (Question 5), and not having a lot in common with other people (Question 6) (Russell, Cutrona, Rose, & Yurko, 1984).

To determine differences in continuous variables between groups, independent samples *t*-tests were used. To determine differences in discrete variables between groups, chi-square tests were used. To examine relationships between continuous variables and loneliness within groups, bivariate correlational analyses were performed. To examine relationships between discrete variables and loneliness within groups, analyses of variance were used. For this study, an alpha level of .05 was used to establish statistical significance.

Results and Analysis

Table 1 shows demographic information for all participants. Groups differed significantly in gender (more normal controls than participants with aphasia were female) and current work status (more normal controls than participants with aphasia were currently employed). Neither variable, however, was linked to loneliness in either of our groups (see Tables 5 and 6).

Table 2 shows stroke-related variables for participants with aphasia. Participants were, on average, three years post-stroke, with mild to moderate communicative disability.

Table 3 shows interpersonal variables for all participants. There were no differences in perceived attachment or frequency of social support between groups. However, participants with aphasia reported a significantly diminished sense of belonging as compared with normal controls.

Table 4 shows differences in loneliness between groups. Participants with aphasia were significantly lonelier than normal controls.

Table 5 shows that, within participants with aphasia, perceived attachment and sense of belonging were significantly related with overall loneliness. Perceived frequency of social support was not significantly related with loneliness in participants with aphasia. Moreover, no demographic or stroke-related variables were significantly related with loneliness in participants with aphasia.

Table 6 shows that, within normal controls, perceived attachment, sense of belonging, and perceived frequency of social support were significantly related with overall loneliness. No demographic variables were significantly related with loneliness in normal controls.

Conclusions

Loneliness in people with aphasia differs from loneliness in people without aphasia in that (a) participants with aphasia were significantly lonelier than normal controls; (b) perceived frequency of social support was significantly related with loneliness only in normal controls; and (c) participants with aphasia reported a significantly diminished sense of belonging as compared with normal controls. Thus, sense of belonging is a treatable factor associated with increased loneliness in people with aphasia.

Clinical Implications

Our results suggest that people with aphasia appear at risk for loneliness, regardless of severity of communication disorder or time post-stroke. Our results also suggest that people with aphasia may not feel "in tune" with others, part of a group of friends, or that they have a lot in common with others.

Validation of our results with samples large enough to permit causal modeling techniques may advocate a shift in focus of aphasia therapy. Traditional aphasia therapy targets external, behavioral components of interaction by improving patients' communication skills. However, in our sample of participants with aphasia, loneliness was not associated with language impairment or functional communication, but was linked instead with a perception of not feeling integrated within an interpersonal system (Hagerty & Patusky, 1999). Thus, nontraditional therapy directed at internal, psychological components of relationships – perhaps by improving aphasic patients' feelings of fitting with and being a valued part of a group or environment (Hagerty, Lynch-Sauer, Patusky, Bouwsema, & Collier, 1992) – may also be warranted.

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Demographic variables: All participants

Variable				
Age (Years)	Mean	Range	SD	Difference
Participants with aphasia	56.31	41-77	9.69	t(45) = 1.42, p =
				.164
Normal controls	52.67	42-76	7.46	
Education (Years)	Mean	Range	SD	
Participants with aphasia	14.46	10-18	2.20	t(45) = .58, p = .564
Normal controls	14.83	12-20	2.16	
Gender*	% Female			
Participants with aphasia	8			$\chi^2 = 11.60, p = .001$
Normal controls	52			
Marital Status	% Married			
Participants with aphasia	54			$\chi^2 = .01, p = .920$
Normal controls	52			
Work Status*	% Employed			
Participants with aphasia	4			$\chi^2 = 32.33, p = .000$
Normal controls	86			

*Differences in gender and work status between groups are statistically significant.

Stroke-related variables: Participants with aphasia

Variable	Mean	Range	SD
Months Post Stroke	38.08	1-120	35.52
Language Impairment (PICA, 1-16 scale)	11.88	8.78-	1.65
		14.25	
Functional Communication (CADL-2, 0-100 scale)	83.85	60-96	10.95

Interpersonal variables: All participants

Variable	Mean	Range	SD	Difference
Attachment				
(RULS questions, 1-4 scale)				
Q.3 (no one I can turn to)				
Participants with aphasia	2.19	1-4	1.02	t(45) = 1.40, p = .169
Normal controls	1.81	1-3	.81	
Q.7 (no longer close to anyone)				
Participants with aphasia	2.35	1-4	1.09	t(45) = 1.32, p = .195
Normal controls	1.95	1-4	.92	
Q.13 (no one knows me well)				
Participants with aphasia	2.65	1-4	1.13	t(45) = 0.04, p = .965
Normal controls	2.67	1-4	.80	
Sense of Belonging				
(RULS questions, 1-4 scale)				
Q.1 (feel in tune with others)*				
Participants with aphasia	2.08	1-3	.63	t(45) = 4.14, p = .000
Normal controls	1.38	1-2	.50	
Q.5 (feel part of a group of friends)*				
Participants with aphasia	2.23	1-4	1.07	t(45) = 2.44, p = .019
Normal controls	1.52	1-4	.87	
Q.6 (a lot in common with people)*				
Participants with aphasia	2.35	1-4	1.02	t(45) = 3.18, p = .003
Normal controls	1.57	1-2	.51	
Social Support				
(ISSB, 40-200 scale)				
Participants with aphasia	88.19	41-141	24.80	t(45) = 1.87, p = .069
Normal controls	76.52	59-112	15.92	

*Difference in sense of belonging (RULS Questions 1, 5, and 6) between groups is statistically significant.

Loneliness: All participants

Variable	Mean	Range	SD	Difference
Overall Loneliness				
(RULS total score, 20-80				
scale)*				
Participants with aphasia	45.27	23-67	13.57	t(45) = 2.34, p =
				.024
Normal controls	37.24	25-57	8.88	

*Difference in overall loneliness between groups is statistically significant.

Relationships among participant variables and loneliness: Participants with aphasia

Variable	Relationship with RULS Total Score
Demographic	
Age	r = .20, p = .325
Education	r = .17, p = .421
Gender	F(1,24) = 4.19, p = .052
Marital Status	F(1,24) = .05, p = .827
Work Status	F(1,24) = 1.34, p = .259
Stroke-Related	
Months Post Stroke	r = .37, p = .070
Language Impairment (PICA)	r = .09, p = .651
Functional Communication (CADL-2)	<i>r</i> =13, <i>p</i> = .515
Interpersonal	
Attachment (RULS questions)	
Q.3 (no one I can turn to)*	r = .68, p = .000
Q.7 (no longer close to anyone)*	r = .75, p = .000
Q.13 (no one knows me well)*	r = .85, p = .000
Sense of Belonging (RULS questions)	
Q.1 (feel in tune with others)*	r = .40, p = .042
Q.5 (feel part of a group of friends)*	r = .71, p = .000
Q.6 (a lot in common with people)*	r = .63, p = .001
Social Support (ISSB)	r =13, p = .514

*Correlations are statistically significant.

Relationships among participant variables and loneliness: Normal controls

Variable	Relationship with RULS Total Score
Demographic	
Age	r =23, p = .320
Education	r =29, p = .195
Gender	F(1,19) = 2.62, p = .122
Marital Status	F(1,19) = 1.93, p = .181
Work Status	F(1,19) = 1.59, p = .222
Interpersonal	
Attachment (RULS questions)	
Q.3 (no one I can turn to)*	r = .69, p = .001
Q.7 (no longer close to anyone)*	r = .80, p = .000
Q.13 (no one knows me well)*	r = .49, p = .023
Sense of Belonging (RULS questions)	
Q.1 (feel in tune with others)*	r = .66, p = .001
Q.5 (feel part of a group of friends)*	r = .65, p = .002
Q.6 (a lot in common with people)*	r = .51, p = .018
Social Support (ISSB)*	r =61, p = .004

*Correlations are statistically significant.