African American adults are conspicuously underrepresented among those who use clinical rehabilitative services and community-based supportive services for acquired neurogenic communication disorders. Low participation rates in clinical speech-language pathology are particularly troubling because African American adults disproportionately are at increased risk for communication disorders secondary to stroke, dementia, and related neurologic conditions affecting cognitive-communication processes. Lacking empirical evidence, professionals can only speculate about the causes of this widely agreed upon health-care disparity. The purpose of the present study was to assess the knowledge, beliefs, and attitudes regarding communication disorders in a sample of community-dwelling African American adults. Two assumptions guided the design of this study, namely that 1) human communication, whether intact or impaired, cannot be fully understood apart from its cultural context; and 2) that culturally resonant services are inherently more acceptable and, importantly, more effective.

Knowledge, beliefs, and attitudes about a range of communication phenomena, including acquired neurogenic disorders, may, in part, explain population disparities in access to speech-language rehabilitative, as well as to community-based supportive services. Further, increased understanding may better inform the design and development of population-specific treatments and services. The status of African Americans' knowledge, beliefs, and attitudes concerning communication processes and disorders in unknown, resulting in a significant scientific and practical information gap in communication sciences and disorders. This information void adversely affects researchers and clinicians, alike, and ultimately negatively affects health outcomes for many African American adults who could benefit from appropriate interventions. Without understanding the status of contemporary African Americans regarding communication phenomena, researchers likely will continue to under-serve this large segment of the population or continue to pose research questions that bear little or no relevance to this population's communicative needs. Thus, the unavailability of pertinent research-based evidence involving African American clients of all ages will impede the implementation of evidence-based clinical interventions with this population, as the "client preferences" component will not have been adequately considered. In an initial effort toward discerning African Americans' knowledge and attitudes surrounding acquired communication disorders the following questions were posed:

- 1. What is the extent of knowledge regarding the prevention and treatment of aphasia and dementia-related communication disorders?
- 2. What are attitudes toward seeking professional/supportive services regarding acquired communication disorders?
- 3. What is the relationship of demographic variables of age, acculturation, or educational level to knowledge, attitudes, and beliefs regarding aphasia and dementia-related communication disorders

## Method

<u>Participants</u>. Forty (N = 40) healthy African American adults (10 males), ages 19 to 77 years, participated in one of four focus groups lead by an experienced facilitator who used a scripted protocol aimed at uncovering the participants' knowledge and beliefs

about communication processes and disorders, as well as their prevention and treatment. Inclusion criteria were sufficient comprehension to understand and voluntarily provide informed consent; an ability to understand and to respond verbally to conversational-level (jargon-free) English; ability to write sufficiently to respond to a paper-and-pencil survey. Materials. A demographic information sheet, designed to characterize the participants was included in each packet. Four communication scenarios were developed to elicit written "Yes/No" responses to probes associated with situations commonly associated with aphasia and cognitive-communication issues associated with dementia.

# Sample Communication Scenario

You have a friend whose parents live out of town. She goes to visit them about every six months and usually talks to them every weekend. Well, actually she talks to her mother. Lately, her Dad is always "busy" when she calls. So, she hasn't talked to him in a couple of months. During her last visit, she noticed that her Dad was withdrawn and not particularly glad to see her. Shortly after she arrived, he went into his room, undressed, and went to bed. It was 11:00 A.M. When asked about his behavior, my friend's mother began to cry. She said that she doesn't know what's going on. She said, "Dad is not the same, lately. Either he is very agitated and angry or very quiet and withdrawn."

#### **Probes**

- 1. Would you suggest that your friend look for help in this situation?
- 2. What kind of help should she seek?
- 3. What else would you recommend?

In addition, participants were administered the African American Acculturation Scale (Klonoff & Landrine, 2000), a 47-item instrument with subscales in the areas of: Religion: Family: Preference for Things Black: Interracial Attitudes: Health: and Socialization. A "Communication Focus Group Protocol" was designed especially for this study. (All materials will be available to conference participants.) Procedures. All participants provided informed consent prior to participation in one of four procedurally-identical focus groups. Small groups of African American adults provided information regarding their knowledge, attitudes, and beliefs about communication processes and disorders. An experienced focus group facilitator guided the discussions, using a scripted protocol to insure consistency across groups. Online notes and audio-tape-recordings were used to capture the participants' responses. Transcripts were transcribed verbatim and given reliability checks by two speechlanguage pathology students blind to the study. Interjudge agreement was above 95%, and discrepancies were resolved by consensus. The transcripts were submitted to content analyses, with categories determined by emergent themes. The group facilitator's notes were used to supplement and support the transcribed data. Responses were analyzed additionally in relation to the respondents' age, educational level, and responses to items designed to determine the participants' acculturation level.

# Sample Quotations from Participants

- "That person may think he is okay. I'm all right. There's nothing wrong with me!"
- "...if you haven't had any issues ...you may not know there're resources available"
- "Sometimes they ... don't want to admit that they have a problem."
- "...this is not a disorder for me, whereas in mainstream settings, it might be viewed as a disorder."
- "Because they think someone might say they are not trusting God enough."

# Summary of Major Findings

- In response to the Communication Knowledge Scenarios, participants demonstrated awareness of the association of developmental delay, autism, dementia, and stroke with disorders of communication, as well as knowledge of professionals who should be sought for help. Despite low utilization of SLP services by African Americans, this population sample indicated that professional interventions were needed.
- Scores on the *African American Acculturation Scale* were comparable for younger and older adults, except for items in the Socialization subscale. Cohort effects are attributable to societal changes, rather than aging, per se. Other subscales trended in the expected direction toward African American cultural orientation.
- Focus group transcript analyses indicated knowledge of communication disorder; the benefits of professional interventions; and support for help-seeking when needed.
- Identified barriers to service utilization included: perceived stigma; denial of disorder; and lack of knowledge.
- Suggested ways to increase service utilization included: community-based services; promotion by a trusted community leader; and promotion of grass-roots outreach by members of the African American community.

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