

YOUNG AFRICAN AMERICAN ADULTS WITH APHASIA: A CASE SERIES

Charles Ellis, Ph.D., CCC-SLP

Department of Communication Sciences & Disorders,
East Carolina University, Greenville, NC, USA

Robert Mayo, Ph.D., CCC-SLP

Department of Communication Sciences & Disorders
University of North Carolina at Greensboro, Greensboro, NC, USA

ABSTRACT

Little is known about African Americans with aphasia. Virtually no studies have examined the impact of aphasia in young adult African Americans, even though stroke, the most common cause of aphasia, occurs far more frequently in African Americans at younger ages than other racial-ethnic groups. Aphasia occurring at younger non-traditional ages has substantial implications for survivors' quality of life, friendships and family-caregiver relationships. The objective of this case series report is to explore the impact of aphasia in African Americans with onset of aphasia before the age of 65. The observations of the cases will be discussed in the broader aphasia literature while also considering unique implications for African Americans.

KEY WORDS: Aphasia, African Americans, Stroke

Funding: This study is funded by the Agency for Healthcare Research and Quality Grant #: 1 R03 HS025043-01A1 awarded to the first author.

INTRODUCTION

Stroke in African Americans

Each year approximately 15 million individuals are diagnosed with strokes worldwide and 10 million of those will either die or be left with long term disability (World Health Organization, 2012). In the United States (US) an estimated 795,000 Americans experience strokes annually (Benjamin et al., 2018). There is evidence that stroke is on the decline in the US among Non-Hispanic Whites, however a corresponding decline has not been observed in African Americans (Kleindorfer, 2010). Studies have shown disparities in the risk of stroke between African Americans and Whites. White et al. (2005) found an age-adjusted risk of stroke of 191 per 100,000 in African Americans compared to 88 per 100,000 in Whites (White et al., 2005). Similarly, Howard et al. (2001) found the age-sex adjusted African American/White relative risk (RR) of stroke to be 1.51. Additionally, the age-sex African American/White adjusted relative risk of stroke at younger ages (ages 45-54) is substantially higher at a rate of 4.02 (Howard, Kleindorfer, Judd, McClure, Safford et al., 2011). Established factors associated with the disproportionate racial-ethnic risk of stroke at an earlier age include excess ratios of hypertension and diabetes, obesity, and socioeconomic factors (Howard, Cushman, Kissela, Kleindorfer et al. 2011; Huxley, Bell, Lutsey, Bushnell et al. 2014).

Aphasia in African Americans

Aphasia is a post-stroke condition that negatively impacts a stroke survivor's expressive and receptive language skills as well as overall communication ability (American Speech-Language-Hearing Association, 2018). A recent report indicated there are over 2.5 million Americans living with aphasia (Simmons-Mackie, 2018). Approximately 18% of all stroke survivors are discharged from US hospitals with aphasia (Ellis, Hardy, Lindrooth, & Peach, 2018). Similar to general stroke outcomes indicating higher risk of stroke among African Americans at younger ages, rates of aphasia were also higher among African Americans at younger ages. Ellis et al., (2018)

found the rate aphasia of stroke survivors age 19-44 was 7.7% in African Americans compared to 2.4% in Whites. Higher aphasia rates were also observed at ages 45-54 with a reported rate of 14.9% in African Americans and 5.8% in Whites.

Worse aphasia clinical outcomes have also been observed in African Americans. For example, in an early study using the Porch Index of Communicative Ability (PICA), a multidimensional test of aphasia designed to examine (comprehension, expression, reading, gesture, and writing), Wertz and colleagues (1997) found that following 48 weeks of language treatment, African Americans, who did not differ from Whites in initial severity of their aphasia, performed significantly worse than Whites on the Graphic and Gestural subtests of the PICA. Similarly, Ellis and Peach (2016) found worse aphasia outcomes among African Americans when compared to Whites in a study of 290 persons with aphasia (PWA). African Americans exhibited lower scores (4.8) on the 15- item Boston Naming Test compared to Whites (6.8) even after controlling for baseline differences in age, education, duration of aphasia and year of treatment ($p=.002$). In a second study, designed to comprehensively examine PWA language skills using the Western Aphasia Battery-Revised (WAB-R), Ellis & Peach (2017) also found lower word fluency (5.5 vs 7.6; $P=.015$), auditory word recognition (49.3 vs 53.3; $P=.02$), and comprehension of sequential commands (43.7 vs 53.2; $P=.017$) among African Americans when compared to Whites even after adjusting for age and years of education. Finally, Molrine & Pierce (2002) found racial differences in aphasia test subtest scores although they did not find differences in total scores of aphasia impairment.

Despite substantial evidence of African Americans having stroke and post-stroke aphasia at younger ages, higher aphasia rates and worse aphasia clinical outcomes, the study of aphasia in African Americans has been limited (Ellis, 2018). Even less attention has been given to young African Americans (<age 50) with stroke who are diagnosed with aphasia even though they are more likely to experience stroke and aphasia at younger ages (Ellis, Hardy,

Journal of the National Black Association for Speech-Language and Hearing

Lindrooth, & Peach, 2018). There is also evidence of differences in stroke subtypes that potentially contribute to differences in aphasia rates and aphasia outcomes. The findings of the Northern Manhattan Study indicated that African Americans had higher rates of all stroke subtypes when compared to Whites (White et al., 2005). Differences were also observed in a study by Song, Burgess & Kidwell (2012) who found racial-ethnic differences in cardioembolic stroke and small vessel disease in a comparison between African Americans and Whites. The impact of these differences on rates of aphasia and aphasia outcomes among African Americans is not clear.

Regardless, little is known about aphasia in African Americans and substantial study of this population is needed. Because African Americans are younger at stroke and aphasia onset, they are more likely to live longer with the negative impact of aphasia when compared to traditionally aged stroke survivors (\geq age 65). To date, there is little available data regarding the presence and impact of aphasia in young African Americans adults with stroke. Therefore, the aim of this paper is to profile aphasia in three young African American adult stroke survivors with aphasia. The paper will use a case series approach to highlight demographic characteristics and aphasia impairment observed on standardized assessments. The paper will conclude with a discussion of observations of the three cases and exploration of issues potentially unique to young African Americans adults living with aphasia.

METHODS

The case series approach utilized in this study was organized around the Living with Aphasia: Framework for Outcome Measurement (A-FROM). A-FROM was developed to account for the impact of aphasia on diverse life areas in PWA (Kagan et al. 2008). A-FROM explores the impact of aphasia from the perspective of the following domains: severity of aphasia, communication and language environment, participation in life situations, and personal identity, attitudes and feelings (Kagan et al., 2008; Kagan 2011). A-FROM was designed to consider the impact that aphasia has on life areas

important to PWA as well as their families (Kagan et al., 2008). Severity of aphasia was measured with the Western Aphasia Battery-Revised (Kertesz, 2006) and the National Outcomes Measurement System (NOMS) (American Speech-Language-Hearing Association, 2012). The WAB-R is a standardized aphasia assessment that derives an aphasia quotient (AQ) based on measures of expressive language, receptive language, and repetition. NOMS utilizes a series of seven-point assessment scales to obtain functional abilities and over multiple time points. A score of one indicates minimal or no ability whereas a score of seven indicates independence.

Information about the PWA's communication and language environment was obtained from semi-structured interviews of the PWA/caregiver who responded to semi-structured interview questions. Information about the PWA's participation in life situations and personal identity, attitudes and feelings was also examined using semi-structured client/caregiver interview questions and the ASHA Quality of Communication Life scale (ASHA-QCL) (Paul, Frattali, Holland, Thompson, Caperton, & Slater, 2005). The ASHA-QCL includes 18 questions designed to measure the PWA's perception of quality of communication. Each question uses a visual analog scale with five equally spaced hash marks for scores of 0-5. The word "yes" is located at the top of the five-point scale and the word "no" is at the bottom. A mean overall score is calculated based on the average of the first 17 questions. A separate score is calculated for question #18 "In general, my quality of life is good". In this study the mean total score and scores for select questions that provide information on participation in life situations and personal identity, attitudes and feelings are reported.

Case 1

Case 1 is a 33 y.o. male who was first admitted with a diagnosis of left frontal subdural empyema in October 2015. After a two-day complicated hospital stay, Case 1 received a left frontal craniotomy for evacuation of left frontal subdural empyema.

Journal of the National Black Association for Speech-Language and Hearing

Initial study visit: 32 months post-onset of illness.

Education/employment: High school education; food service worker

Severity of Aphasia: WAB AQ 54.2. Broca's aphasia with moderate apraxia of speech. NOMS verbal=3; NOMS comprehension=4.

Communication and Language Environment: Lives with mother but spends his days with his elderly grandmother. Caregiver/parent reports very limited attempts to communicate in any environment.

Participation in Life Situations: Romantic relationship and all friendships at the time of his hospitalization ended within months of injury. Case 1 is the father of a young child but is unable to actively participate in the child's care due to communication issues. Case 1 has right hemiplegia and is not able to drive. Transportation is provided by mother, grandmother or transportation service for rehabilitation needs. Case 1 and caregiver report no engagement in community-based events due to communication issues and hemiplegia. Select questions on the ASHA-QCL indicated very minimal participation in life events. Case 1 reported a score of 5/5 on telephone use but score of 0/5 on all other questions related to participation (See Table 1)

Personal identity, attitudes and feelings: Select questions on the ASHA-QCL indicated mixed ratings of personal identity, attitudes and feelings. Case 1 reported a score of 5/5 on questions related to "like myself", "see the funny things of life", "confident I can communicate" and "speaking for myself". In contrast, scores of 0/5 were reported on "role in family remaining the same" and "people understand me when I talk" (See Table 1).

Mean ASHA-QCL score and general rating of quality of life: Case 1 received a mean ASHA-QCL score of 1.6/5 and score of 5/5 on quality of life.

Table 1. Scores obtained on the WAB-R and NOMS.

Measures	Case #1	Case #2	Case #3
WAB-R AQ (Mean/SD)	54.2	26.2	13.6
• Information content	5	2	0
• Fluency, grammatical competence and paraphasias	4	2	0
Spontaneous Speech Total Score	9	4	0
• Yes/No	51	54	57
• Auditory word recognition	55	58	7
• Sequential commands	4	36	4
Auditory Verbal Comprehension Total Score	110	148	68
Repetition Total Score	52	3	0
• Object naming	57	6	0
• Word Fluency	5	0	0
• Sentence completion	8	2	0
• Responsive speech	4	6	0
Naming and Word Finding Total Score	74	14	0
NOMS Verbal	3	1	1
NOMS Comprehension	4	5	2

Case 2

Case 2 is a 43 y.o. male who was first admitted with a diagnosis of left middle cerebral artery stroke in May 2018. Case 2 received tPA and a thrombectomy to remove a middle cerebral artery thrombosis.

Initial study visit: 4 months post-stroke onset.

Education/employment: High school education; electrical helper.

Severity of Aphasia: WAB AQ 26.2. Broca’s aphasia with severe apraxia of speech. NOMS verbal=2; NOMS comprehension=5.

Communication and Language Environment: Lives with his parents and is the father of an adult child and a middle school child. He has

very limited communication due to severe apraxia of speech

Participation in Life Situations: Romantic relationship and all friendships at the time of his hospitalization ended shortly after his stroke. Case 2 is not able to drive due to his severe communication deficits. All transportation is provided by his parents for all needs. Case 2 and parent/caregiver report some engagement in local neighborhood events where he is known but does not communicate. Select questions on the ASHA-QCL indicated reduced participation in life events. Case 2 reported a score of 5/5 on “like to talk to people” and scores of ~5.0 on “stay in touch with people” and “get out of the house to do things”. Case 2 does not use the telephone and does not find it easy to communicate (scores=0). (See Table 1)

Journal of the National Black Association for Speech-Language and Hearing

Personal identity, attitudes and feelings: Select questions on the ASHA-QCL indicated mixed ratings of personal identity, attitudes and feelings. Case 2 reported a score of 5/5 on “like myself”, “see the funny things of life” and “confident I can communicate”. Lower scores were reported on all other select questions (See Table 1).

Mean ASHA-QCL score and general rating of quality of life: Case 3 received a mean ASHA-QCL score of 3/5 and score of 1.7/5 on quality of life.

Case 3

Case 3 is a 35 y.o. female who was first admitted with a diagnosis of left middle cerebral artery and left posterior cerebral artery stroke in May 2018. Case 3 received tPA and a thrombectomy after admission. A few days after admission, Case 3 underwent a comprehensive craniotomy to reduce brain edema and herniation.

Initial study visit: 6 months post-stroke onset

Education/employment: College education; nurse.

Severity of Aphasia: WAB AQ=13.6. Global aphasia with severe apraxia of speech. NOMS verbal=1; NOMS comprehension=2.

Communication and Language Environment: Case 3 lives with her husband and small children. She has very limited communication that consists of one perseverative word produced in different intonations. She spends time in her home and her mother’s home daily.

Participation in Life Situations: Case 3 was married at the time of evaluation. Case 3 is not able to drive due to an inability to ambulate and a right hemiplegia. All transportation is provided by her mother and husband. Case 3’s parent/caregiver reports some engagement in the community but she is unable to communicate in those settings where she is a passive bystander. Select questions on the ASHA-QCL indicated reduced participation in life events. Case 3

reported a score of 5/5 on “people include me in conversations” and “using the telephone”. In contrast, scores of 0/5 were reported on “meet the communication needs of job/school” and “getting out of the house to do things” (See Table 1).

Personal identity, attitudes and feelings: Select questions on the ASHA-QCL indicated mixed ratings of personal identity, attitudes and feelings. Case 3 reported a score of 5/5 on “like myself” and “confident I can communicate”. Scores of 4/5 were reported on “role in the family the same”, “see the funny things in life”. Lower scores were reported on all other select questions (See Table 1).

Mean ASHA-QCL score and general rating of quality of life: Case 3 received a mean ASHA-QCL score of 3.2/5 and score of 2.5/5 on quality of life.

Table 2. Mean score on the ASHA-QCL and scores for select questions.

Measures	Case #1	Case #2	Case #3
Mean Total ASHA-QCL score (Q1-Q17)	1.6	3.0	3.2
Selection question about participation in life situations			
Q1. I like to talk to people	0.0	5.0	5
Q2. It's easy for me to communicate	0.0	0.0	2.5
Q5. I meet the communication needs of my job/school	0.0	2.5	0.0
Q6. I stay in touch with family/friends	0.0	3.8	2.5
Q7. People include me in conversations	0.0	2.5	5.0
Q9. I use the telephone	5.0	0.0	5.0
Q15. I get out of the house and do things	0.0	3.8	0.0
Select questions about personal identity, attitudes and feelings			
Q3. My role in the family is the same	0.0	1.1	4.0
Q4. I like myself	5.0	5.0	5.0
Q10. I see the funny things in life	5.0	5.0	4.0
Q11. People understand me when I talk	0.0	1.7	3.5
Q14. I am confident I can communicate	5.0	5.0	5.0
Q17. I speak for myself	5.0	3.8	2.5
Q18. In general my quality of life is good	5.0	1.7	2.5

DISCUSSION

The findings of this case series highlight the complexity of issues for young African Americans adults with aphasia. Aphasia and its primary cause, stroke, is more common in older adults who are at very different life stages. Experiencing aphasia in the sixth decade of life and beyond is quite different than experiencing aphasia in one's third or fourth decade regardless of racial-ethnic background. However, there are some aspects of living with aphasia as a young African American that may require novel consideration for both clinical practice and future research directions.

Utilization of the A-FROM conceptual framework in this case series offers a more detailed examination and consideration of life issues that may be unique to young African Americans adults with significant disability. This discussion has been designed to explore several key issues while placing them in the context of the greater aphasia literature.

Long Lives with Communication Disability

The three cases reported in this paper all presented with significant communication disability. One PWA presented with very severe aphasia, one severe and one moderate aphasia

Journal of the National Black Association for Speech-Language and Hearing

based on WAB-R AQ scores (Kertesz, 2006). Significant communication disability occurring at a young age has the potential to substantially and negatively impact all areas of life. Many lose their ability to be gainfully employed resulting in reduced self-worth and self-identity (Ganzfried, 2018). At the same time, young adults who experience strokes frequently live long lives and therefore those with aphasia will live long lives with aphasia and the consequences of aphasia. Rutten-Jacobs and colleagues (2013) found the 20-year death rates of stroke survivors exceeded the general population. However, approximately 73% of those with ischemic stroke and 84% of those with intracranial hemorrhage were alive at 20 years. The long-term consequences of living many years with aphasia are social isolation and disconnection from society due to communication disability (Fotiadou, Northcott, Chatidaki & Hilari, 2014; Hilari & Northcott, 2017). Depression (which can occur in 30 to 50% of stroke survivors) and loneliness are additional consequences of aphasia that occur over time (Ayerbe, Ayis, Crichton, Wolfe, & Rudd, 2014; Ganzfried, 2018; Northcott, Moss, Harrison & Hilari, 2016). It is important to note that loneliness negatively influences neurological recovery and potentially aphasia recovery (Cacioppo, Capitanio, & Cacioppo, 2014).

Long-Term Aphasia Rehabilitation: Satisfaction and Care Concerns

Young PWA frequently have long-term aphasia rehabilitation needs. Consequently, they are likely to experience a succession of evaluations and discharges from therapy over a longer period as they try to improve their communication skills. Young adults with aphasia although not working and having work-related private health insurance, have options to receive rehabilitation services. Adults under the age of 65 with disabilities can benefit from Medicare and Medicaid services for their rehabilitation needs (Center for Medicare Advocacy, 2018). Moreover, rehabilitation services for young adults with disabilities for some conditions can be covered under Medicare and Medicaid even when they are only expected to maintain or slow deterioration (Center for

Medicare Advocacy, 2018). Obtaining such services can be difficult and require multiple appeals and can take up to two years, however these options outweigh the greater likelihood of working age African Americans being uninsured (Skolarus, Jones, Lisabeth, & Burke, 2014). To date, few studies have examined the impact of Medicare and Medicaid services for aphasia rehabilitation in young adults with aphasia and therefore, the benefit and impact of those programs are not entirely clear.

A secondary issue related to aphasia rehabilitation care is related to satisfaction with aphasia rehabilitation care. There is evidence that African Americans with aphasia report dissatisfaction with speech-language pathology (SLP) services due to limited frequency of visits even when they experience persisting communication difficulties (Mahendra & Spicer, 2014). Mahendra and Spicer (2014) found that African Americans experienced dissatisfaction and negative interactions with some clinicians. Some clients reported concern about a lack of effort and innovation during treatment as well as reduced visit frequency despite an urgent need to improve subtle communication deficits that precluded their return to employment. Others reported condescending attitudes and negative comments that were not encouraging or helpful. These findings have broader implications for young African Americans adults with aphasia who are likely to need long-term SLP services.

Reduced Life Participation and Changes in Personal Identity

Aphasia has been likened to “identify theft” in that the communication limitations imposed by the disorder frequently rob the PWA of their ability to participate in life as they once did and is associated with major disruptions in their sense of personal and social identity (Shadden, 2005). A substantial focus has recently emerged related to life participation among individuals with aphasia. The Life Participation Approach to Aphasia (LPAA) states that “regardless of the stage of management, LPAA emphasizes the attainment of re-engagement in life by strengthening daily participation in activities of choice” (p.1) (Chapey et al., 2000). In this case series of young adults with aphasia, life

Journal of the National Black Association for Speech-Language and Hearing

participation appears to have diminished greatly or become generally non-existent for the participants. Information from the ASHA-QCL indicated the most obvious contributors to reductions in participation were related to communication. Each participant reported very low scores on ease of communication, being unable to meet the communication needs of their previous job, being able to use the telephone and getting out of the house. Interestingly, Case #1 reported 5/5 (“yes”) on being able to use the telephone however his current skills likely only allow him to listen as he is not able to verbalize efficiently enough for telephone use. Information from the semi-structured interviews also indicated that each PWA either lived with or was supported by parents who were middle-aged employed individuals. Consequently, each stroke survivor was severely limited by their inability to drive and relied on parents for their transportation needs. The severity of the communication deficits also precluded involvement in activities common for young adults. In summary, each young adult described in this paper was mainly relegated to engagement in aphasia rehabilitation or their primary home setting.

The observations of limited participation are of great concern. PWA are less concerned about the number of social activities they are involved in as they are general engagement in social activities (Dalemans, Witte, Wade, & van den Heuvel, 2010). The PWA in this care series reported very little if any engagement in social activities most notably the result of severe communications deficits. Daleman et al. (2010) found that many PWA report strong social networks and contacts and engagement in social activities prior to the onset of aphasia. However, many of their pre-aphasia activities declined dramatically after the onset of aphasia due difficulties associated with needing to plan what they say and the general tempo of conversations. Consequently, their new communication problems cause many to feel they no longer belong in their pre-aphasia social groups and activities (Dalemans, Witte, Wade, & van den Heuvel, 2010). It is possible that the disengagement of pre-aphasia relationships has a different impact on reports of life satisfaction and quality of life in young adults with aphasia

than traditional aged stroke survivors with aphasia. Research designed to compare age-related differential impact of aphasia on participation is required to adequately test this hypothesis.

Disruption of Friendships

Most adults, whether young or old, value friendships. Friendships create a sense of acceptance and belonging to age-peers. Aphasia is a condition known to disrupt or eliminate friendships because many PWA are unable to express their thoughts in an efficient and timely manner or be able to follow conversations (Fotiadou, Northcott, Chatidaki & Hilari, 2014; Northcott & Hilari, 2011). Vickers (2010) noted that one year post-stroke, PWA living at home reported a 64 percent reduction in their contact with friends while Hilari and Northcott (2006) observed that 30 percent of PWA stated they had no friends. The loss of friendships can contribute to significant depression and loneliness (Northcott, Moss, Harrison & Hilari, 2016). In this case series, each PWA reported no significant friendships with age-peers. It is likely the dissolution of friendships that exists at the onset of aphasia was related to the severity of their communication disability. Some PWA report an unwillingness to participate in social relationships due to their communication issues which reduce their ability to receive emotional support (Fotidou et al., 2014). The observed impact of aphasia on maintaining or initiating friendships is likely the same regardless of race-ethnicity and the observations here are not unique to African Americans. It is more likely that the negative consequences are related to age given that post-stroke aphasia is primarily a condition of older adults. Consequently, there are fewer younger age-peers with aphasia than would be available for support and encouragement through aphasia support groups which consists of mostly older adults. Friendships are complicated regardless of age when communication issues are not present. The findings here show that aphasia-related communication issues disrupt and end friendships thereby leaving young PWA to live long lives absent of solid peer relationships.

Journal of the National Black Association for Speech-Language and Hearing

Caregivers Again

A common theme across cases was a high reliance on parents. According to Threats (2010), families of PWA experience “third party disability” or the impact of a disabling condition on the family members. Aphasia in young adults and in this case African Americans, frequently places a new burden on middle-age adults who are typically transitioning to becoming grandparents rather than reestablishing themselves as primary caregivers of adult children. In this study, two of the three individuals were unmarried and relied primarily on their mothers for transportation and other rehabilitative needs. The third case also had a high reliance on a parent even though married. According to Caswell (2014), the young stroke survivor with aphasia and his/her parent(s) would have established an “adult-to-adult relationship” prior to stroke onset. The traumatic event unfortunately causes individuals with disabilities such as aphasia to re-enter into a parent-PWA relationship that is like their childhood relationship. This is difficult for both the PWA and the parent(s) and has the potential to cause tension and frustration. This tension and frustration can exist in family members of PWA due to the burden associated with their communication issues and care needs (Ganzfried, 2018). The lack of age-based friendships excludes the young adult PWA from having an outlet for discussion, comfort, advisement and support. Many of the issues related to the absence of friendships resulting in greater social isolation and disconnection are intertwined with parents becoming caregivers again thereby compounding the impact of aphasia in young adults.

The Indirect Cost of Aphasia.

Although not specifically targeted in the data reported, the cost of aphasia in young adults is substantial. Young adults with aphasia have their lives disrupted during a critical life stage. Most are either approaching or are in their peak earning years and preparing/saving for typical

later life stages such as their children going to college and later becoming grandparents. The indirect cost of aphasia in young adults can be substantial but hard to measure (Ellis & Mauldin, 2013). Indirect costs include: lost wages due to disability or depression, reduced quality of life, caregiver lost wages due to work absences and caregiver burden. Indirect costs also include societal losses such as inability to engage in community service, inability to pay income taxes, and inability to make charitable contributions (Ellis & Mauldin, 2013). In a study examining the post-stroke goals of 50 PWA, Worrall et al. (2011) reported that younger persons with aphasia were particularly aware of the loss of work and career and often held deep, strong desires to return to some form of employment. Each of the PWA in this study had small school age children and their inability to regain their pre-aphasia parental roles is a substantial indirect cost of aphasia. Both the PWA and their children experience loss and some children can feel neglected when their parents have aphasia (Ganzfried, 2018). Young adult parents with aphasia experience dramatic changes in their parent-child relationship due to the inability to communicate effectively. Studies are urgently needed to examine the impact of aphasia in young adults on parenting and marital satisfaction.

CONCLUSIONS

Aphasia can have a devastating impact on any adult as result of the communication disability. Young adults with aphasia have unique experiences that are associated with the interaction between their life stage and their communication disability. A systematic and programmatic line of research is needed to adequately understand the unique needs of young African American adults with aphasia and strategies to achieve optimal outcomes. Future studies should specifically emphasize the negative impact of aphasia on marriages, parent-child relationships, employment/career re-integration and the emotional needs of PWA,

Journal of the National Black Association for Speech-Language and Hearing

REFERENCES

- American Speech-Language-Hearing Association. (2012). *National outcomes measurement system*. Rockville, MD: National Center for Evidence-Based Practice in Communication Disorders.
- American Speech-Language-Hearing Association. (2018). *Adult Speech and Language. Aphasia*. Retrieved from: <http://www.asha.org/public/speech/disorders/Aphasia/>.
- Ayerbe, L., Ayis, S., Crichton, S., Wolfe, C.D.A., & Rudd, A.G. (2014). The long-term outcomes of depression up to 10 years after stroke; The South London Stroke Register. *Journal of Neurology, Neurosurgery & Psychiatry, 85*(5), 514-521.
- Benjamin, E.J., Virani, S.S., Callaway, C.W., Chamberlain, A.M., Chang, A.R., Cheng, S. et al. (2018). Heart disease and stroke statistics-2018 Update: A report from the American Heart Association. *Circulation, 137*, e67-e492.
- Cacioppo, S., Capitanio, J.P. & Cacioppo, J.T. (2014). Toward a neurology of loneliness. *Psychological Bulletin, 140*, 1464-1504.
- Caswell J. (2014). Coming home: When adult stroke survivors depend on their parents for care. *Stroke Connection*. Fall, 8-10.
- Centers for Disease Control and Prevention. (2005). Differences in disability among black and white stroke survivors--United States, 2000-2001. *MMWR Morbidity Mortality Weekly Reports, 54*, 3-6.
- Center for Medicare Advocacy (2018). *Medicare Coverage for People with Disabilities*. Retrieved from: <http://www.medicareadvocacy.org/medicare-info/medicare-coverage-for-people-with-disabilities/#is%20available>.
- Chapey, R., Duchan, J., Elman, R. J., Garcia, L. J., Kagan, A., Lyon, J. G. & Simmons Mackie, N. (2000). *Life Participation Approach to Aphasia: A Statement of Values for the Future*. Retrieved from: <https://www.aphasiaaccess.org/assets/docs/lpaa%20paper.pdf>.
- Dalemans, R.J., de Witte, L., Wade, D., & van den Heuvel, W. (2010). Social participation through the eyes of people with aphasia. *International Journal of Language and Communication Disorders, 45*, 537-550.
- Ellis, C. & Mauldin, P.D. (2013). The real cost of communication disorders. *Asha Leader, 18*(3), 34-35.
- Ellis, C. & Peach, R.K. (2016). Racial-ethnic differences in the Boston Naming Test among persons with aphasia: Disparity or diagnostic inaccuracy. *Archives of Physical Medicine and Rehabilitation, 97*(10), e.108.
- Ellis, C. & Peach R.K. (2017). Racial-ethnic differences in word fluency and auditory comprehension among persons with post-stroke aphasia. *Archives of Physical Medicine and Rehabilitation, 98*(4), 681-686.
- Ellis, C. (2018). African Americans and aphasia: A 25 year review. *Journal of the National Black Association for Speech-Language and Hearing, 13*(1), 31-42.
- Ellis, C., Hardy, R.Y., Lindrooth, R.C., & Peach, R.K. (2018). Rate of aphasia among stroke patients discharged from hospitals in the United States. *Aphasiology, 32*, 1075-1086.
- Fotidadou, D., Northcott, S., Chatzidaki, A., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect a person's social relationships? *Aphasiology, 28*, 281-1300.
- Ganzfried, E. (2018). Living with aphasia: Realities, challenges and opportunities. *Perspectives of the ASHA Special Interest Groups, 3*, 68-79.
- Hilari, K. & Northcott, S. (2017). "Struggling to stay connected": Comparing the social relationship of health older people and people with stroke and aphasia. *Aphasiology, 31*, 674-687.
- Howard, G., Cushman, M., Kleindorfer, D.O., McClure, L.A., et al. (2011). Traditional risk factors as the underlying cause of racial disparities in stroke: Lessons from the half-full (empty?) glass. *Stroke, 42*(2), 3369-3375.

Journal of the National Black Association for Speech-Language and Hearing

- Howard, V.J., Kleindorfer, D.O., Judd, S.E., McClure, L.A., Safford, M.M. et al. (2011). Disparities in stroke incidence contributing to disparities in stroke mortality. *Annals of Neurology*, *69*, 619-27.
- Huxley, R.R., Bell, E.J., Lutsey, P.L., Bushnell, C., Shahar, E., Rosamond, W., Gottesman, R., & Folsom, A. (2014). A comparative analysis of risk factors for stroke in blacks and whites: The Atherosclerosis Risk in Communities study. *Ethnic Health*, *19*(6), 601-16.
- Kagan, A. (2011). A-FROM in action at the Aphasia Institute. *Seminars in Speech and Language*, *32*(3), 216-228.
- Kagan A, Simmons-Mackie N, Rowland A., Huijbregts, M. et al. (2008). Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology*, *22*, 258-280.
- Kertesz A. (2006). *The Western Aphasia Battery – Revised*. San Antonio, Texas: Harcourt Assessments.
- Kleindorfer D. (2009). Sociodemographic groups at risk: Race/ethnicity. *Stroke*, *40*, S75-8.
- Kleindorfer DO, Khoury J, Moomaw CJ, Alwell K, Woo D, Flaherty ML et al. (2010). Stroke incidence is decreasing in whites but not in blacks: A population-based estimate of temporal trends in stroke incidence from the Greater Cincinnati/Northern Kentucky Stroke Study. *Stroke*, *41*, 1326-31.
- Mahendra, N. & Spicer, J. (2014). Access to speech-language pathology services for African-American clients with aphasia: A qualitative study. *Perspectives on Communication Disorders and Sciences in Culturally and Linguistically Diverse Populations*, *21*, 53-62.
- Molrine, C. & Pierce, R.S. (2002). Black and White adults' expressive language performance on three tests of aphasia. *American Journal of Speech Language Pathology*, *11*, 139-150
- National Stroke Association. *African Americans and Stroke*. (2013). Retrieved from: <http://www.stroke.org/site/PageServer?pagename=AAMER>.
- Northcott, S. & Hilari, K. (2011). Why do people lose their friends after stroke? *International Journal of Language and Communication Disorders*, *46*, 524-534.
- Northcott, S., Moss, B., Harrison, K. & Hilari, K. (2016). A systematic review of the impact of stroke on social support and social networks: Associated factors and patterns of change. *Clinical Rehabilitation*, *30*, 811-831.
- Paul, D.R., C.M. Frattali, A. Holland, C.K. Thompson, C.J. Caperton, & Slater, S.C. (2005). *Quality of Communication Life Scale (ASHA QCL)*. American Speech Language Hearing Association: Rockville, MD.
- Rutten-Jacobs, L.C.A., Arntz, R.M., Maaijwee, N.A.M., Schoonderwaldt, H.C., Dorresteijn, L.D. van Dijk, E.J. et al. (2013). Long-term mortality after stroke among adults aged 18 to 50 Years. *Journal of the American Medical Association*, *309*, 1136-1144.
- Shadden, B. (2005). Aphasia as identity theft: Theory and practice. *Aphasiology*, *19*(3-5), 213-223.
- Simmons-Mackie N. (2018). *Aphasia in North America*. Retrieved from: <https://www.aphasiaaccess.org/white-paper>.
- Skolarus, L.E., Jones, D.K., Lisabeth, L.D., & Burke, J.F. (2014). The Affordable Care Act and stroke. (2014). *Stroke*, *45*, 2488-2492.
- Song, S., Burgess, R.E., Kidwell, C.S. (2012). Racial differences by ischemic stroke subtype: A comprehensive diagnostic approach. *Stroke Research and Treatment*. Article ID 735097, 6 pages, 2012. doi:10.1155/2012/735097.
- Threats, T. (2010). The ICF framework and third party disability: Application to the spouses of persons with aphasia. *Topics in Stroke Rehabilitation*, *17*, 451-457.
- Wertz, R.T., Auther, L.L., & Ross, K.B. (1997). Aphasia in African-Americans and Caucasians: Severity, improvement, and rate of improvement. *Aphasiology*, *11*, 533-542.

Journal of the National Black Association for Speech-Language and Hearing

White H, Boden-Albala B, Wang C, Elkind MS, Rundek T, Wright CB et al. (2015). Ischemic stroke subtype incidence among whites, blacks, and Hispanics: the Northern Manhattan Study. *Circulation*, *111*, 327-31.

World Health Organization. *Global Burden of Stroke*. (2012). Available at:

http://www.who.int/cardiovascular_diseases/en/cvd_atlas_15_burden_stroke.pdf

Worrall, L., Sheratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology*, *25*(3), 309-322.

ABOUT THE AUTHORS

Charles Ellis, Ph.D., CCC-SLP, is a Professor in the Department of Communication Sciences and Disorders and Director of the Communication Equity and Outcomes Laboratory at East Carolina University in Greenville, North Carolina. His research is designed to understand outcomes associated with adult neurologically based disorders of communication and factors that contribute to the lack of equity in service provision and outcome disparities that exist among some population groups. Email: ellisc14@ecu.edu.

Robert Mayo, Ph.D., CCC-SLP, is a Professor in the Department of Communication Sciences and Disorders, School of Health and Human Sciences at the University of North Carolina at Greensboro in Greensboro, North Carolina. His areas of research and professional interest include fluency disorders, disparities in communication healthcare services delivery, personnel preparation and professional ethics. E-mail: r_mayo@uncg.edu.