FORGING COMMUNITY PARTNERSHIPS TO REDUCE HEALTH DISPARITIES IN LOW-INCOME AFRICAN AMERICAN ELDERS OF NORTH ST. LOUIS AT RISK FOR DEMENTIA

Whitney Anne Postman
Department of Communication Sciences and Disorders, Saint Louis University, St. Louis, MO, USA

Sydney Rosenthal
Neuroscience Program and School of Medicine, Saint Louis University, St. Louis, MO, USA

Samantha Thompson **Laura Sankey**
Kailin Leisure **Rebecca Ferron**
Tayla Slay **Maureen Fischer**
Department of Communication Sciences and Disorders, Saint Louis University, St. Louis, MO, USA

— ABSTRACT —

Low-income African American elders experience disproportionately high prevalence of dementia, preventable hospitalizations, healthcare cost and caregiver burden. We describe our clinical program of group therapy services for low-income community-dwelling African American elders at risk for dementia, in partnership with two community health centers in the historic neighborhood of The Ville in North St. Louis. During our group sessions conducted in a revered setting at the heart of this neighborhood, our interventions incorporated culturally meaningful activities informed by input from participants and on-site staff. The program also promoted aging health literacy, leveraged local university and community resources for guest lectures and engaged in referrals to related health services as well as training on mobile technology devices. As a result of their involvement in our weekly group sessions, participants reported a) implementation of actionable new knowledge acquired during our activities and discussions; b) less stigma surrounding their perceived disabilities; increased utilization of local healthcare services; and c) enhanced confidence and independence with mobile technology. Preliminary data suggest that our provision of comprehensive, integrated and preventive services through our campus-community partnership can be a model for reducing health disparities that systematically affect African American elders at risk for dementia.

KEY WORDS: African Americans, Aging, Dementia, Health Disparities

I. INTRODUCTION

Population trends suggest that underserved elderly minorities, including African American and low-income communities, experience greater prevalence but inadequate or delayed detection of dementia, increased numbers of preventable hospitalizations, and higher healthcare cost burden (Al Hazzouri et al., 2017; Alzheimer's Association, 2019; Chin, Negash, & Hamilton, 2011; Glymour & Manly, 2008; Kaufman, Gallo & Fahs, 2018; Ouvrard et al., 2016; Reitz et al., 2010; Zhang et al., 2015). Statistics on dementia and mortality in the state of Missouri reflect these national trends (Glymour et al., 2011; Liu et al., 2015). To answer repeated calls to action for speech-language pathologists to address and correct health disparities experienced by aging minority populations at risk of dementia (Ellis et al., 2016; Fleming & Harris, 2017; Mayo & Mayo, 2016; Threats, 2010a), we developed the "Senior Social Group For Brain Health As We Age", a novel and unprecedented clinical program for economically disadvantaged African American elders of North St. Louis.

The ultimate aim of this community-based clinical service endeavor, continuously operating since its foundation in January 2017, was to create a model for reducing dementia-related health disparities that systematically and disproportionately affect populations of underserved and economically disadvantaged elderly African Americans in urban settings such as North St. Louis. This model met the cultural and linguistic needs of our participants by tailoring group sessions and performance assessments according to their specific characteristics. In this description of our clinical program, we first provide an overview, then we highlight each of the components identified as contributing factors to the success enjoyed by our group's stakeholders. These crucial contributing factors were: 1) the symbolic significance of the historic setting of our group sessions; 2) our attention to the cultural and linguistic backgrounds of each participant; 3) our efforts to enhance health literacy for matters related to aging; 4) our recruitment of representatives from local universities and other organizations for guest lectures; 5) our provision of hearing health services through our university's audiology clinic; and 6) our integration of mobile technology into our sessions. Our protocol was dynamically adapted to respond to repeatedly solicited feedback from participants and input from the staff of our community partners CareSTL Health and Northside Youth and Senior Service Center.

II. PROGRAM DESCRIPTION

Participants: From the launching of our program in January 2017 through 2020, over 20 elderly African American residents of North St. Louis who were long-standing clients of CareSTL Health and Northside Youth and Senior Service Center, Inc., were recruited to our "Senior Social Group For Brain Health As We Age" thanks to referrals by the CareSTL Health Medical and Behavioral Health staff. Participants' ages ranged from 62 to 92 years old. Upon recruitment to our group, participants were screened with the Saint Louis University Geriatric Workforce Enhancement Program's Rapid Geriatric Assessment, a screening tool to evaluate frailty, nutrition, loss of muscle mass (sarcopenia), and cognitive function (Morley & Adams, 2015). Moreover, all participants subjectively reported experiences of cognitive-communicative decline, such as decreased concentration, verbal memory and spatial orientation capacities. No specific diagnosis of mild cognitive impairment or dementia was required for entry into our group.

Leadership: The group was led by the first author (WP), whose background in cognitive neuroscience of language, linguistics with concentration on cross-linguistic comparison, and medical speech-language pathology allowed prioritization of cognitive-communicative impairments as therapeutic targets (see Figure 1). Assisting in preparation and leadership of group sessions were graduate-level students training in speech-language pathology, one undergraduate pre-medical student training in neuroscience, and another undergraduate student training in both speech-language pathology and sociology. Graduate students were supervised by WP as part of their clinical practicum experience. One member of our team was African American, and the other members identified as Caucasian, Semitic (Middle Eastern) or Asian.

Weekly Group Focus: An average of 10 to 12 participants attended our weekly group sessions; not all of the 20 recruited participants overlapped, as some left the group in 2018 for reasons of declining health while others joined our group more recently. Activities were constructed with an emphasis on age-related health topics relevant to dementia risk such as hearing and vision loss, nutrition, mnemonic strategies, stress management, and chronic renal and cardiac conditions (Bourgeois et al., 2016; Fortune et al., 2013; Lin & Albert, 2014). Weekly 2-hour-long sessions engaged members in activities that stimulated social interaction, communication, memory and executive functions. Inherent within our group leadership was the value of inclusion: the learning environment was optimized to promote socialization among members while simultaneously adapting group tasks to each individual's wants and needs.

An illustration of a popular collective initiative that resulted in a product of great pride was composition of a blog-post about our group for the Diverse Elders Coalition website (Postman, 2019). Each participant contributed to our blog-post entitled "Group sessions in St. Louis offer hope and help to African Americans at risk of cognitive decline". Also, each participant reviewed, edited and approved the final draft before publication on the Diverse Elders Coalition website and social media page. After publication, each participant received a printout of our blog-post, and instructions for accessing the website through their personal mobile devices.

Figure 1. *Dr. Whitney Postman, Ph.D./CCC-SLP served as team leader of our "Senior Social Group For Brain Health As We Age". This scene depicts our setting, in the auditorium of the historic Homer G. Phillips Hospital at the center of The Ville neighborhood of North St. Louis.*

III. SYMBOLIC SIGNIFICANCE OF OUR SETTING

Weekly group sessions were conducted in North St. Louis at CareSTL Health's site on the grounds of the former Homer G. Phillips Hospital (HGPH). HGPH has been a meaningful symbolic site for the St. Louis African American community since 1937, when HGPH opened its doors as a segregated facility that welcomed African American patients. Until its forcible closing in 1979, HGPH served as the premiere teaching hospital for African American physicians, nurses and allied health professionals (Fitzpatrick, Shackelford, & Robinson, 2018). The history of HGPH continues to serve as an emblem of black excellence in medicine and the persistent need to overcome racial health disparities.

Group leaders demonstrated respect for the cultural heritage of our participants by inviting them to engage in urgent debates relevant to the legendary HGPH setting and the surrounding African American community. For instance, in recent years racial conflicts in St. Louis and other cities in the state of Missouri have riveted the nation's attention. Notably, the killing of Michael Brown on August 9th, 2014 in Ferguson, a city in St. Louis County, and outcries against racism throughout 2015 at the University of Missouri's main campus in Columbia, have propelled Missouri onto the national stage as a focus of discourse on deeply rooted and persistent racial inequalities, in particular the intersections between race and poverty (Gordon, 2008). These events fostered topical discussions about racism that were channeled by the group leaders into deliberations about racial health disparities. Our team repeatedly underscored our group's goal of continuing the legacy of HGPH: our group strove to address and correct the accumulation of a lifetime of racial health disparities affecting aging populations, at the very site in the participants' community that was constructed to address and correct racial health disparities.

To illustrate, our team shared a provocative news article entitled "Black women are suffering from Alzheimer's disease and nobody's talking about it" (Meadows-Fernandez, 2017). Our participants took turns around our table to read this article in its entirety aloud, with assistance from our team members as needed. It sparked scintillating discussion about their own experiences with dementia in their families. One participant reported biweekly visits to a nursing home where her older sister was residing

and receiving care for Alzheimer's disease. Her confession to feelings of sadness and helplessness as she witnessed her sister's decline led to an outpouring of expressions of support from our group members, all of whom were then compelled to share similar family experiences.

Another participant insisted on expressing her dissatisfaction with the premise of this news article. She asked, "Why is the news always talking about black people as if we're sicker than everybody else?" Our team responded to this participant's poignant inquiry by validating her objections and elaborating upon them in a way that re-directed the entire group's attention to a positive development described in the news article. Group leader WP answered, "I'm so glad you said that, Ms. J———. You're absolutely right! Health disparities are totally offensive. That's one reason our group gets together every week. Check out what the article said about new organizations aimed at connecting with and educating African American elders, like the Purple Power Champions initiative in Colorado. Isn't that what we're doing together right here in St. Louis with our group? We're in this fight together, Ms. J———!" This response was deemed acceptable to this participant, because it restored power to her and the other participants through our collective action as a unified group with an expressed purpose to combat and overcome longstanding health inequities.

IV. INDIVIDUAL, CULTURAL AND LINGUISTIC DIVERSITY CONSIDERATIONS

Crucial to the success of our group sessions was person-centeredness. More specifically, participants were respected as unique individuals whose self-worth was reaffirmed through consideration of their specific histories, personalities and coping mechanisms. Choices of activities inspired by evidenced-based techniques including group games such as "Brain Health Jeopardy", word-search contests, and reminiscence tasks (Harris, 1997) were offered to cater to each participant's interests and capacities. Discourse was enhanced through pragmatic turn-taking cues, and reading and writing were supported with orthographic, phonemic and semantic assistance. We led conversations and activities that elicited participants' voluntary personal narratives about their individual backgrounds.

The interactive approach of our team with the participants was informed by foundational research on cultural and linguistic sensitivity in care for diverse populations (Harris & Fleming, 2009; Harris, Fleming & Harris, 2012; Mayo & Mayo, 2016; Payne, 2011, 2014; Wallace, 2014). Crucially, our team never entertained any preconceived notions or generalizations about the cultural and linguistic characteristics of our participants. With regard to language, we refrained from unfounded assumptions, such as the false premise that all of our participants spoke only an African American English dialect or a local St. Louisan dialect. To illustrate, the spontaneous exchange given below occurred between a subset of our participants (referred to as Participants 'A', 'B' and 'C' for convenience) during a group conversation on their childhood backgrounds. This exchange revealed that they were acutely aware of their distinctive speech patterns based on their places of origin, as well as how their speech patterns had evolved in response to the socio-political pressures of the communities that they encountered in St. Louis. Through these spirited exchanges, our participants and our team members demonstrated mutual respect for our inherent diversity.

Participant A: I came from Clarksdale, Mississippi. So I hold my chest up and be proud of myself. I used to hate it. Say I don't want that, right, all them country folks down there, right? And then when I come up here (…) it was starting to get where I would get that country talk outta me. But sometimes when I talk I feel it comin' back. You know, that accent.

Participant B: Southern drawl.

Participant A: Right, you know! But I mean, I used to be embarrassed by it.

Participant C: A lot of people were born in Mississippi, in St. Louis. 'Cause I ran into a lotta people…

Participant A: But then they be talkin' about way down yonder. Now I don't know what that means.

Participant C: Uh-huh!

Participant B: The Bayou girls!

Participant A: Is that what they said?

(Laughter around the table)

(November 28, 2018)

V. AGING HEALTH LITERACY

A secondary goal of the group was to provide them with comprehensive, integrated, and perhaps most crucially, *preventative* health services. The emphasis on prevention is now a dominant trend in the science of care for aging populations (Livingston et al., 2017; Vellas & Morley, 2018), especially those at highest

risk of dementia due to chronic health disparities (Dilworth-Anderson, Pierre & Hilliard, 2012; Mayo & Mayo, 2016). We introduced group participants to lay-friendly accessible literature on relevant issues related to our theme of "Brain Health As We Age", with the aim of enhancing participants' literacy for issues directly related to their health statuses (Qualls, 2014). We routinely distributed handouts, print-outs, brochures, pamphlets and booklets from authoritative sources such as the National Institute on Aging, the National Institute of Neurological Disorders and Stroke, the National Institute on Deafness and Other Communication Disorders, the Alzheimer's Association, the Centers for Disease Control and Prevention, the Mayo Clinic, the Cleveland Clinic, the American Heart Association and the American Diabetes Association.[1] Participants appreciated our distribution of visually appealing and highly informative materials to take home, review, and share with relatives, friends, and other healthcare professionals. They claimed that these materials deepened their understanding of aging health and improved their communication with their healthcare providers.

VI. RECRUITMENT OF LOCAL HEALTH RESOURCES

Among the most popular features of our "Senior Social Group For Brain Health As We Age" was our involvement of representatives from local universities as well as related advocacy and not-for-profit organizations such the Alzheimer's Association Greater Missouri Chapter. A list of our most well-received invited speakers is provided in Appendix A. Our invited speakers augmented the value of the information content of our group sessions by offering expert interactive lectures on relevant topics such as awareness and management of stroke risk and the relationship of stroke risk to dementia risk (see Figure 2); optimal nutrition and free social services for aging individuals; trauma recovery; insurance coverage for common prescriptions; opportunities for involvement in research studies; and care for the aging voice. CareSTL Health and Northside staffs were encouraged to attend these lectures, which were ideal opportunities for networking with local health experts and related service providers.

In addition to supplementing the subject matter of our group discussions, our recruitment of local experts from associated universities and organizations enhanced participants' awareness of the well-coordinated network of support for aging health in St. Louis. In this way, participation in our "Senior Social Group For Brain Health As We Age" involved much more than mere attendance at group sessions: it served as a launchpad for connection of our members to a wide array of local support services and sources of expertise.

Figure 2. *Dr. Alexandre Carter, M.D./Ph.D. from the Neurology Department at Washington University School of Medicine led an interactive presentation about the relationship between stroke prevention and reduction of dementia risk. In this scene, Dr. Carter explained to our participants how to complete the National Stroke Association's "Stroke Risk Scorecard" that was distributed to them as take-home handouts.*

VII. AUDIOLOGY SERVICES THROUGH OUR UNIVERSITY CLINIC

From its inception, our "Senior Social Group For Brain Health As We Age" was an ideal platform for directing participants to the no-fee audiology services led by author MF at Saint Louis University's Paul C. Reinert, S.J. Speech-Language and Hearing Clinic. Students were supervised on-site at CareSTL Health as they provided hearing screenings and counseling/education on age-related hearing loss for 100% of our group participants. For participants whose hearing screening results indicated further audiology services, appointments were arranged at MF's audiolo-

1 Readers interested in acquiring these publicly available materials are encouraged to contact the corresponding author.

gy clinic on Saint Louis University campus, with free transportation provided by Northside Youth and Senior Service Center, Inc.

These arrangements signified to our participants a rewarding reciprocal relationship between Saint Louis University and our community partners CareSTL Health and Northside; they were invited to benefit from free services at our university clinic in addition to our weekly gatherings at CareSTL Health's Homer G. Phillips Hospital location. This partnership helped us to eliminate barriers to hearing healthcare such as cost and lack of knowledge or access to services. Crucially, our participants who received treatment for hearing loss benefitted from intervention prior to reaching more severe levels of auditory disability. For involved students, these arrangements signified the rich rewards of interdisciplinary collaboration between speech-language pathology and audiology.

The coupling of our audiology services with our focus on brain health in our group sessions was an opportunity for us to concurrently treat hearing loss with cognitive-communicative decline in this vulnerable population. For participants with hearing impairment, we integrated aural rehabilitation goals into their cognitive-communicative goals, in a manner that respected the well-established links between presbycusis and dementia (Lin & Albert, 2014; Livingston et al., 2017). And for participants without hearing impairment, this coupling remained relevant to our principal theme of aging brain health. Lively group discussions of hearing loss as a risk factor for dementia emphasized how to protect and/or maintain hearing health, as means of reducing the potential impact of hearing loss on cognitive-communicative decline.

VIII. INTEGRATION OF MOBILE TECHNOLOGY INTO GROUP SESSIONS

Another innovative approach of our "Senior Social Group For Brain Health As We Age" was the integration of mobile technology into our sessions. Despite prevailing pre-conceptions of elderly individuals' aversion to new technological devices, aging populations— and especially minority elders— are among the most avid consumers of these devices (Kwan, 2012; Turner-Lee, Smedley & Miller, 2012). Our harnessing of mobile technology on behalf of our elderly African American participants was conducted in accordance with the biopsychosocial model of the World Health Organization's International Classification of Functioning, Disability, and Health (Atticks, 2012; Kong, 2015; Muñoz, Hoffman & Brimo, 2013; Postman, 2016; Threats, 2010b).

Figure 3. *Graduate students Rebecca Ferron and Kailin Leisure conducted hearing screenings for our participants on-site, in private offices adjacent to our group setting in the auditorium of the historic Homer G. Phillips Hospital.*

Figure 4. *Undergraduate student Tayla Slay trained our participants on implementation of basic apps with iPad devices from Dr. Postman's Neuro-Rehabilitation of Language Lab at Saint Louis University.*

After training on iPad interface fundamentals during our group sessions, 100% of our participants demonstrated intact learning of the iPad interface with multi-touch gestures (e.g., tap, swipe). And with minimal to no set-up assistance, they could also complete functional application tasks such as basic computation with calculator apps, temporal orientation with calendar apps, games involving orthography (e.g., word completion) and syntax/semantics (e.g., sentence completion), and photography/videog-

raphy apps (see Figure 4). They acknowledged the universal appeal of the artfully designed iPad interface, along with the wealth of apps and audio-visual stimuli that were accessible and amenable to their needs, norms and preferences. Because the majority of participants owned smart-phones, our training extended to their personal devices. As evidenced by their questionnaire responses shared in the next section, they reported increased confidence and independence with mobile technology, and keen interest in continuing tablet-mediated training.

IX. PARTICIPANT FEEDBACK

To maximize our responsiveness to participants' needs and wants from our group sessions, we solicited feedback through both informal and formal means. As an informal means of continuously soliciting feedback from our participants, either the team leader (WP) or a student conducted personal phone calls to the home phones or mobile phones of each of our participants on a weekly basis. These habitual calls were reminders of upcoming group sessions, but also opportunities for participants to privately contribute their feedback. Formally, participant-reported outcome measures were collected at least once per year from group members through participant satisfaction surveys.

Their comments revealed some underlying reasons for their enthusiasm for our group. They expressed appreciation for the fostering of respectful and responsive interactions within group sessions that generalized to improved socialization between group sessions. They also reported reduced stigma surrounding their perceived disabilities, increased confidence with mobile technology and with implementation of actionable new knowledge about healthy aging (e.g., management of blood pressure or diabetes), and enhanced awareness and utilization of healthcare services provided by community resources. Listed below are examples of their feedback, received either as written comments on our participant satisfaction surveys or as audio- or video-recorded oral interviews:

> *Participant (video-recorded oral interview): I'm so thankful to Doctor Sydney for showing me how to make a video on my phone, because I had made a video of my sister and I singing, "I Come to the Garden Alone". And yesterday I went to see her. She had a stroke. And, uh, she hadn't been able to talk for five days. And yesterday when I showed her the video of us singing, she tried to sing. And I was so happy, I mean, I couldda shouted all over! I'm just so thankful, and I thank Doctor Sydney for showing me how to make a vid— this was the first one I've ever made, besides the ones that she taught us, you know, when she was in class. (July 10, 2019)*
>
> *Participant (written comment): This group has had a very positive influence in my life and has helped me in understanding better the aging process and has also renewed my interest in life. Before joining I was somewhat depressed after losing my employment. It has renewed my interest in life and has been a catalyst to help me to encourage others. (December 12, 2018)*
>
> *Participant (written comment): You can learn about your health and you can follow up on your body and what's going on with you and your health. (December 12, 2018)*
>
> *Participant (written comment): The information that is given (topics) as far as health issues that we all have & are experienceing (sic) are great topics such as Nerology (sic), Cancer, Strokes, Heart Attack: All information is very informative. (December 12, 2018)*
>
> *Participant (written comment): I like coming to group, the leaders, and others in the group. We get help from the group. I am learning a lot from the group. Good students that read to us. Learning about my health and diabetes. Learned about dementia, brain health, and high cholesterol. The group answers my questions and what I want to learn. We learn about each other. I am no longer ashamed of my disability. I can also learn a lot from others in the group. (November 8, 2017)*
>
> *Participant (written comment): I have really benefited and enjoyed being a part of this group. Dr. Postman has a special loving personality that makes each of us feel comfortable ad welcome. I am trying to do better healthwise and make the "aging process" more tolerable. The information that is given (pamphlets as well) is very, very helpful. I have made new friends as well. (November 8, 2017)*
>
> *Participant (written comment): Talking about different things made me realize what I need to change in life. (May 17, 2017)*
>
> *Participant (written comment): This group helped me to feel free to communicate more. Dr. Postman makes everyone feel special, seem like she really care for real. (May 17, 2017)*
>
> *Participant (audio-recorded oral interview): Y'all wonderful peoples. Y'all know how to*

talk to us. (…) Y'all know how to respect us. We respect y'all. The-the games we do, we have fun doing the games, you know (...). 'Cause we learn a lot from y'all, you know. Y'all tell us about our ears, our eyes, our history of me being a diabetic, you know. And and that's something, that's com- that's something comfortable. You know you sit and think about things that y'all teach us and y'all show us, right? (…) And I think that's wonderful. Y'all not racist. You're not prejudiced. (April 12, 2017)

X. CONCLUSIONS

In this description of our "Senior Social Group For Brain Health As We Age" for low-income African American elders of North St. Louis, we have recounted the principal strategies that contributed to our group's successful operation since its inception in January 2017. These strategies followed the directives of the leaders in the field of culturally and linguistically competent clinical services to diverse populations. They included our demonstration of respect for our participants' heritage by situating our group sessions at a historically important site, integration of culturally meaningful activities as chosen by participants, promotion of aging health literacy, leveraging of local university and community resources, coordination of referrals to audiology services at our university clinic, training on mobile technology, and responsiveness to participants' actively solicited feedback.

To our knowledge, no such clinical program had been implemented for African American elders of North St. Louis prior to our establishment of this partnership with CareSTL Health and Northside Youth and Senior Service Center, Inc. Our comprehensive intervention and prevention approach overcame barriers to their care, thus helping them to maintain and maximize their cognitive-communicative capacities and overall health as they age. Our preliminary data suggest that our culturally and linguistic sensitive approach, enriched by interdisciplinary and local community collaborations, can inform best practices for reducing health disparities that systematically affect low-income urban-dwelling African American elders at risk of dementia.

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Appendix A

Invited Guest Speakers to our "Senior Social Group For Brain Health As We Age"

Guest Speaker	Affiliation	Lecture Content
Alexandre Carter, M.D./Ph.D.	Division of Stroke and Brain Injury, Department of Neurology, Washington University School of Medicine in St. Louis	Reduction of stroke risk & relationship to dementia risk
Melissa Ramel, Ph.D., M.P.H., R.D., L.D.	Nutrition and Dietetics Department, Saint Louis University	Optimal nutrition for aging individuals (e.g., reduce risk of sarcopenia & anemia)
Andrew Oberle, M.H.A./M.A.	Oberle Institute Development Director-Medical Center Development, Saint Louis University	Trauma recovery
Janese Prince, M.S.W. & Dahley Mensah, L.M.S.W./Q.M.H.P.	Alzheimer's Association Greater Missouri Chapter	Free services offered by the Alzheimer's Association for dementia prevention & care

Guest Speaker	Affiliation	Lecture Content
Kari Burch, OTD, OTR/L; Emily Townley, MSOT, OTR/L; Amy Sobrino, MSW, LCSW; Advancement Specialist Nick Clark	Memory Care Home Solutions (not-for-profit organization)	Free services offered by Memory Care Home Solutions for in-home support & caregiver training
Bridget George	BG Resource Insurance Agency	Insurance coverage for commonly prescribed medications
Kym Radford, Outreach Coordinator	Center for Community Health Partnership and Research, Washington University School of Medicine in St. Louis	Participation in research (participants' rights, ethical conduct of research)
Faith Stagge, Students Preparing for Academic-Research Careers (SPARC) award winner	Master's program, Communication Sciences & Disorders Department, Saint Louis University	Presbyphonia, care for the aging voice, anatomy/physiology of human vocal tract
Debra Blessing, Geriatric Workforce Enhancement Program Coordinator	A.T. Still University in Kirksville, Missouri	Nutritional support for elderly Missouri residents

Contact Information:
Dr. Whitney Anne Postman, Ph.D./CCC-SLP
Email: drwhitney.postman@health.slu.edu