

JOURNAL OF THE NATIONAL BLACK ASSOCIATION FOR SPEECH-LANGUAGE AND HEARING

VOLUME 15, NUMBER 1 SPRING 2020

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The Influence of Ethnicity and Residence on Presence of Stuttering in Children

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ABOUT THE EDITOR

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The following individuals served as reviewers, or otherwise contributed editorially, to this issue and/or another issue of *JNBASLH*. We thank them for their contributions to the journal. Any omissions were unintentional.

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ABOUT THE JOURNAL

The Journal of the National Black Association for Speech-Language and Hearing (JNBASLH) is a peer-reviewed, refereed journal that welcomes submissions concerning communication and communication disorders from practitioners, researchers or scholars that comprise diverse racial and ethnic backgrounds, as well as academic orientations.

JNBASLH editorial board welcomes submissions from professionals or scholars interested in communication breakdown and/or communication disorders in the context of the social, cultural and linguistic diversity within and among countries around the world.

JNBASLH is especially focused on those populations where diagnostic and intervention services are limited and/or are often provided services which are not culturally appropriate. It is expected that scholars in those areas could include, but not limited to, speech-language pathology, audiology, psychology, linguistics and so-ciology. Articles can cover any aspect of child or adult language communication and swallowing, including prevention, screening, assessment, intervention and environmental modifications. Special issues of *JNBASLH* concerning a specific topic may also be suggested by an author or through the initiation of the editors.

Aims & Scope

Topics accepted for publication in *JNBASLH* could include, but is not limited to, the following:

- Communication breakdowns among persons due to culture, age, race, background, education, or social status
- Use of the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) framework to describe communication use and disorders among the world's populations.
- Communication disorders in underserved or marginalized populations around the world
- Service delivery frameworks for countries' minority populations, including those who are minorities for a variety of reasons including race, religion, or primary language spoken.
- Dialectical differences and their effects on communication among populations
- Evidence base practice research with culturally and linguistic diverse populations
- Provision of communication services in low income/resource countries
- · Provision of communication services in middle income/resource countries
- Provision of communication services to immigrant and/or refuge populations
- Effects of poverty on communication development and the provision of services
- · Education/training issues in serving diverse populations
- Ethical issues in serving diverse populations
- · Role of religion in views of communication disability and its effect on service delivery

Submissions may include:

- Research papers using quantitative or qualitative methodology
- Description of clinical programs
- Theoretical discussion papers
- Scientifically conducted program evaluations demonstrating
- Clinical forums
- · Works using disability frameworks or model's effectiveness of clinical protocols
- Critical clinical literature reviews
- Case studies
- Tutorials
- Letters to the editor

Submission of Manuscripts

All manuscripts should be accompanied by a cover letter (e-mail) in which the corresponding author:

- Requests that the manuscript be considered for publication;
- Affirms that the manuscript has not been published previously, including in an electronic form;
- Affirms that the manuscript is not currently submitted elsewhere;
- Affirms that all applicable research adheres to the basic ethical considerations for the protection of human or animal participants in research;
- Notes the presence or absence of a dual commitment;
- Affirms that permission has been obtained to include any copyrighted material in the paper; and
- Supplies his or her business address, phone and fax numbers, and e-mail address.

All manuscripts must be submitted electronically and should follow the style and preparation presented in the *Publication Manual of the American Psychological Association* (Sixth Edition, 2010; see Journal for exceptions to APA style). Particular attention should be paid to the citing of references, both in the text and on the reference page. Manuscript submissions and inquiries should be addressed to: nbaslh@nbaslh.org.

Preparation of Manuscripts

Manuscripts must be written in English. Authors are referred to recent copies of the journal and are encouraged to copy the published format of papers therein.

Text should be supplied in a format compatible with Microsoft Word for Windows (PC). All manuscripts must be typed in 12pt font and in double-space with margins of at least 1-inch. Charts and tables are considered textual and should also be supplied in a format compatible with Word. All figures, including illustrations, diagrams, photographs, should be supplied in .jpg format.

Authors must write clearly and concisely, stating their objectives clearly, defining their terms, and substantiating their positions with well-reasoned, supporting evidence. In addition, they are encouraged to review articles in the area they are addressing which have been previously published in the journal and, where they feel appropriate, to reference them. This will enhance context, coherence, and continuity for readers.

All submissions are considered by the editorial board. A manuscript will be rejected if it does not fall within the scope of the journal or does not meet the submission requirements.

Manuscripts deemed acceptable will be sent to a minimum of two reviewers. This journal uses double-blind review, which means that both the reviewer and author identities are concealed from each other throughout the review process. The Editor and Associate Editor will consider the reviews and make a decision regarding a manuscript. Decisions are made on a case-by-case basis, typically within 6 weeks from submission, and the Editor's decision is final.

Disclaimer & Ethics Statement

The *JNBASLH* is not responsible for the claims and findings that researchers and others make, or imply, or the accuracy and authenticity of information that is released in the journal. Authors are expected to have research data that substantiates their claims. The editorial board reserves the right to refuse, reject, or cancel an article for any reason at any time without liability.

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ISSN

The JNBASLH's online ISSN is 1943-4316.

EDITOR'S NOTE

It is my privilege to publish Volume 15, Issue 1 of the *Journal of the National Black Association for Speech Language and Hearing (JNBASLH)*. This issue comes to you in the middle of the devasting effects of the COVID-19 pandemic. Many of our daily routines have been disrupted by the abrupt closure of many of our daily walks of life. We have all become familiar with the term "social distancing" as we attempt to reintegrate ourselves into mainstream society. We have also become aware of the significant disparity in mortality related to COVID-19. As Editor of *JNBASLH* I offer my deepest sympathies to the families that have been affected and my commitment to work tirelessly with other professions to find solutions for the many issues related to COVID-19.

Despite the challenges of COVID-19, you will find four interesting articles in this issue of *JNBASLH*. First, Green uses a qualitative approach to chronicle the experiences of a high-school Karenni student with a profound bilateral hearing loss who arrived in the United States from Burma (Myanmar). The study offers insights into the experiences of this student who is profoundly deaf as well as perspectives of their family as they have navigated the communication, educational, social, and cultural facets of life in the US. Next, Briley and Ellis explore ethnicity and residence differences in the presence of stuttering. They utilize data from the National Health Interview Survey, which showed that African American children were at greater odds of experiencing stuttering than White children and the odds of stuttering were greater for African American children in all regions of the US, with the exception of the Northeast. Then, Kimmons and Hobek examine the macrostructure characteristics of spoken narrative production from self-generated narratives of African American preschool children. They found higher narrative element scores and increased density of narrative elements as age increased. Finally, Ellis, Briley and Mayo offer a tutorial describing a telepractice approach for aphasia therapy. This article is timely given the drastic change in practice patterns in the field as clinicians move to a greater emphasis on telepractice vs face-to-face treatment during the COVID-10 Pandemic.

I sincerely thank all the contributors to this interesting issue of JNBASLH.

Charles Ellis, Jr. PhD CCC-SLP Editor



A CASE STUDY INVESTIGATION OF THE COMMUNICATION EXPERIENCES OF A DEAF KARENNI REFUGEE STUDENT AND FAMILY

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Understanding the experiences and perceptions of children and their families as they are served in school settings is of great importance. Families present with dynamic, moving parts which must be taken into consideration when weighing best practices for assessment and intervention. In instances of serving children and families from backgrounds vastly different from that of the clinician, context for these experiences and perceptions can provide valuable information which may offer direction for the implementation of services (Mindel & John, 2018). A clinician's reference for a family's cultural and linguistic background is of even more importance when hearing impairment is a factor. Even when language barriers are addressed between the family and clinician, issues in communication may continue to persist. It is not uncommon for child refugees who are deaf to have limited or even no exposure to spoken, written, and/or signed language, which further compromises communication efforts (Akamatsu & Cole, 2000; Sivunen, N., 2019). Lack of education on deaf issues and strategies for communication is also cited by Akamatsu and Cole (2000) as a limitation for most families of a refugee child who is deaf. The current qualitative case study examines the experiences of a high-school Karenni student with a profound bilateral hearing loss who arrived in the United States with their family as refugees from Burma (Myanmar). The current study provides insight into the experiences of this student who is profoundly deaf as well as perspectives of their family as they have navigated the communication, educational, social, and cultural facets of life in the United States. Aspects such as the role of the family in decision-making and modes of communication are also examined as the family tries to remain connected through Karenni language and culture, American Sign Language, and English.

KEY WORDS: Deaf, refugee, school-age, qualitative

INTRODUCTION

According to the United Nations Refugee Agency (UNRA, 2018), a refugee is defined as an individual who has been forced to leave their home country for fear of physical harm, in search of safety as the result of war or persecution. The UNRA (2018) estimates that there are more than 25.4 million refugees worldwide. Specific groups of people from the country of Burma (Myanmar) are among those who have experienced the hardship of persecution due to their political, social, religious, and ethnic expression or affiliation. Capped at the north by China and to the west by neighboring India and Bangladesh, Burma shares its eastern border with Thailand and Laos. Burma has one of the longest civil wars in modern history, spanning more than sixty years. Ethnic minority groups in the nation have been severely victimized over the years and have suffered violence and oppression at the hands of majority political groups (Saltzman, 2013). As a result, Burma is among the top five nations in the world with the largest number of refugees who have been resettled in other countries, including the United States (URNA, 2018).

Case Background

In 2012, among the more than 1450 initial resettlements in one southern state, was an eight-year-old child and their family (U.S. Department of Health and Human Services, 2013). The journey of the central participant of the study and their family began in Thailand where they lived on a refugee camp for several years. The Karenni family of ten fled their native country of Burma (Myanmar) and traveled by foot to Karenni Refugee Camp 1 in northern Thailand. Most of the children in the family were raised on the refugee camp as they awaited what they hoped would be permanent resettlement in the United States. The camp served as a safe haven for them after experiencing years of turmoil due to civil unrest and oppression of ethnic minorities, including the Karenni people.

Within Burma, the Karenni people are represented in the Karenni State located in the eastern portion of the country. . Many of the populations of Burma are marked by various differences in culture, including language and history. Despite having an ethnic state in Burma, in many cases the Karenni people may refer to themselves by their ethnic group as opposed to their nationality. A large reason for this is due to the Karenni nation being absorbed into Burma in 1947 (Duran, 2017). In part due to the ongoing conflict in the region, the Karenni State has been subject to challenges in health care and education (Karenni Social Development Center, n.d.). Consequently, many Karenni in Burma have limited literacy skills. Literature shows that many who identify as Karenni in Thai refugee camps have limited literacy not only in their native language, but in the language of their host country as well (Duran, 2017). For youth, fragmented learning and exposure to multiple languages may also result in varying proficiency levels in spoken and written forms of each language.

As native Karenni speakers, the family was faced with challenges and barriers in transition from Thailand to the United States. In addition to communication being a barrier, the extensive resettlement process was a challenge. Relocating a family of eight was no small feat. The process of resettlement from Thailand to the United States took over fourteen months from the time the family was identified as potential candidates for resettlement until they received approval. The family had never traveled using major transportation, including transport by car. Resettlement in the United States forced them to make the decision to leave behind almost everything and everyone they knew in Thailand with the understanding that they may never return.

Upon arrival, no one in the family of ten spoke or understood English at any level. What made their situation particularly unique was that their eight-yearold child had experienced hearing loss from birth. As a result, the child had no experience with deciphering or understanding spoken language. Now an eighteen-year old student, they are fully immersed as a high schooler in a school for deaf students, with American Sign Language (ASL) as the primary form of communication.

Prevalence of Hearing Loss

Cases of deafness and hearing loss within refugee populations across the United States are not necessarily rare; however, prevalence across refugee groups is not fully known. Currently, there is no accurate account for the number of refugees who experience deafness or hearing loss (Crock, Ernst, & McCallum, 2013). There is, on the other hand, documentation reflecting estimates of hearing loss in countries that may be points of origin for individuals from refugee backgrounds. For example, a report published by the World Health Organization (WHO) suggested the estimated prevalence of hearing loss for children between ages fifteen through nineteen is 3.82% in Burma and 5.40% in Thailand (Mathers, Smith, & Concha, 2000). The same study approximated adult onset of hearing loss between ages forty-one and sixty years of age is cited as 8.6% in Burma and 11.6% in Thailand.

Review of data on hearing loss throughout specific regions of the world may offer a glimpse of the prevalence of hearing loss within various groups, which may include individuals from refugee backgrounds. As reported by WHO (2018), global hearing loss throughout South Asia (which includes Burma and Thailand), is estimated to increase from 41 million in 2018, to approximately 49 million in 2030, and 133 million across the region by 2050. Per the same report, 7.37% of the population of South Asia and 6.85% of the East Asian population experience disabling hearing loss (WHO, 2018). Pediatric cases account for 2.4% of the population in South Asia, while 3.3% of the population who experience hearing impairment in East Asia are classified as pediatric.

In comparison, the U.S. Census Bureau (2018) reported hearing loss among Americans to be approximately 3.6%. Within the pediatric population, 0.6% of children between the ages of five and seventeen have a confirmed hearing loss. Similarly, about 0.9% of individuals in the United States between the ages of eighteen and thirty-four years of age are diagnosed with hearing loss.

In recent years, several grassroots organizations in the United States have developed efforts to engage, support, and provide advocacy for refugees who identify as deaf. Organizations such as Deaf Planet Soul (n.d.), based in Chicago, and the Deaf Refugee Advocacy (n.d.) group located in Rochester are just two examples of such efforts. Despite development of scattered programming throughout the United States designed to address the unique needs of refugees who are deaf, there is not as much scholarly information regarding the experiences of deaf refugees during and after resettlement. Studies which garner research-based insight into the background of refugees who are deaf in the United States could contribute to an increased understanding of how to best develop programming to address their needs.

Purpose of the Study

Given the limited documentation in this area, this study seeks to explore perspectives and experiences of a child and their family who arrived in the United States from Burma, by way of a refugee camp in Thailand. Specifically, the purpose of this study is to gain insight on the communicative, educational, social, and cultural experiences of a deaf refugee student and their family in the United States. A central theme and sub-themes were explored within this qualitative study through interviews with the student, their parents, and their adult siblings. This being a case study, the purpose is not to generate readily generalizable data, but rather to allow participants to reveal information that could potentially be useful in similar scenarios and/or development of professional resources.

Research Question

The key research question for the project was: "What are the communicative educational, social, and cultural experiences of a deaf refugee student and their family in the United States?" The proposed research question was not constructed in an effort to develop a priori hypothesis or create predetermined themes, but rather to examine trends in interview data as they arose through analysis. The research question was generated to explore experiences from a deaf refugee student and family unit that have not been previously largely captured in existing literature.

METHOD

Participants

All participants in the study were resettled in the United States from Karenni Refugee Camp 1, located in northern Thailand. The study involved one central participant and two sets of secondary participants. The central participant was an eighteen-year-old student who arrived in the United States at age eight. Secondary participants include the student's parents and older siblings. Interviews from the secondary participants were used to provide additional context for the student's background and family's experiences.

Central Participant

The central participant in this study was one eighteen-year-old student with profound hearing loss. After arriving in the United States at age eight, the student attended a public elementary school for a few months before transferring to a school specifically designed to educate deaf students. Per parent report, the limited hearing ability the student had upon arrival declined with time. At the time this study was conducted, the student's hearing was restricted to some environmental sounds with the use of bilateral hearing aids at maximum capacity. Upon arrival in the United States at age eight, the student was prescribed eyeglasses. At the time of the interview, the student wore glasses, which were self-reported to be needed "all the time." According to the student's older siblings, the student is currently able to see, but is progressively losing eyesight (characterized by decreased peripheral vision at the time of the interview). The student's participation in this project required use of an ASL interpreter for explanation of the study, consent, and communication during the course of data collection. The student demonstrated an ability to read and write in English during the course of the study.

Secondary participants (Parent and siblings)

This study also included the parents of the student. The parents' native language is Karenni, which is spoken daily at home. Both parents have limited English proficiency and required use of a Karenni interpreter for explanation of the study, consent, and communication during the course of data collection. The parents also have limited literacy skills in Karenni. Given the parents' limited literacy in Karenni and in order to accommodate, information related to consent was conveyed orally using a trained Karenni/ English interpreter. Additional participants included the central participant's three adult siblings. All three adult siblings are proficient speakers of both English and Karenni. Two of the siblings are trained Karenni/English interpreters. At the time of the interview, one sibling reported having attended community college, while a second was employed, and the third was enrolled at a four-year institution.

Data Collection Procedures

Semi-structured interviews

A total of four interviews were conducted. A semi-structured interview approach was used for each participant group. One interview was conducted with the student, one with the parents, another with the student's adult siblings, and the final interview was conducted with the family as a whole, totaling four sets of questions. The investigator conducted each interview separately in order to focus questions toward the target participant(s). Individualizing interviews also allowed the researcher to collect data that was more likely an authentic representation of each participants' perception.

All interviews took place in the participants' homes. The first interview was conducted with the deaf student and lasted approximately an hour and a half. This interview was conducted individually in effort to allow the student to provide responses based on their own experiences and perceptions without potential interference or interruption of others. The interview was conducted using a certified ASL interpreter.

The parent interview was conducted with the help of a trained Karenni/English language interpreter. The parent-focused interview lasted approximately an hour and a half, as did the separate interviews with the adult siblings. Neither the parents nor siblings are deaf and therefore did not require use of an ASL interpreter. All three adult siblings are bilingual and were observed to have a proficient level of English. A final interview was conducted with the family participants as a whole. One ASL interpreter was used for the family interview along with a Karenni/ English language interpreter. The ASL interpreter utilized simultaneous interpreting, while the Karenni/English language interpreter employed delayed interpreting. The purpose of the family interview was to allow them to answer and discuss questions as a unit, thus reflecting their collective perspectives and other family dynamics.

In effort to ensure integrity in the study, all interpreters received training from the author (KG) on the purpose and procedures of the project. Responses from all four interviews were documented using field notes and audio recording. Upon being given the option to include video recording, the deaf student participant declined. The investigator opted to avoid use of video recording for the study in order to respect the student's request and to maintain rapport with all participants.

Data Analysis

A qualitative, grounded theory approach was used to direct this study, as it lends itself to the collection of data that is a direct account of participants' experiences (Patton, 2015). Use of a qualitative design allows the researcher to capture rich, dense data through diverse methods that may reveal underlying phenomena which may not be readily gathered from quantitative data (Silverman, D., 2017). This approach was selected in part because it has the potential to capture experiences from participants in marginalized contexts and use less driven, preconceived research theories and literature (Stead et al., 2011). This is of particular importance given the limited literature on cases such as the one described in this study.

Each participant's audio recorded interview was uploaded to MaxQDA qualitative data analysis software. Once uploaded, the English production of each interview was transcribed verbatim within the MaxQDA software. Statements made in the family's native language were omitted, as the interpreter provided the responses in English. After the audio recordings were converted to text, the interview responses were organized using open coding (inductive coding) and arranged into theme groups. This analysis approach avoids use of a research hypothesis and predetermined variables (Patton, 2015). Open coding was used to decrease the potential for researcher assumptions and biases which could arise from deductive, hypothetical coding. Material from each interview were recategorized until it was determined that saturation had been achieved. Categories were created based on interview analysis and open coding. Broader themes were then developed and matched to the category with which they were most relevant.

RESULTS

Open coding of interview responses revealed a dominant theme centered on issues and challenges in communication. Further analysis of responses then yielded six initial categories, which were broadened to sub-themes related to issues in communication. Sub-themes included: 1) Impact of refugee and deaf status on education; 2) Impact of deafness and refugee background on student's social experiences; 3) Navigating cross-cultural experiences in education and healthcare; 4) Communication history and multimodal communication experiences; 5) Transition from specialized educational setting to family and community living; and 6) Family education regarding professional support. The central theme of communication issues and challenges and thus subthemes emerged as being closely connected with the central research question.

Central Theme: Issues and Challenges in Communication

Issues and challenges in communication were a focal point throughout each interview set. Participants in each group broadly described challenges associated with communication such as social communication issues, parent-school professional communication challenges, communication challenges between the family and the deaf student. Issues with communication were further divided into sub-themes, which were captured through additional coding of interview responses.

Sub-theme 1: Impact of Refugee and Deaf Status on Education

As shown in Table 1, the student, family, and siblings revealed that they initially had no experience with the American education system and very little experience with the primary system within their home country. Lack of experience with education in Burma was reported by the parents and siblings to be largely due to conflict toward the Karenni ethnic group within their home country (such as the burning of schools) and limited educational resources within the refugee camp. While some degree of education was available to children living on the camp, the family described it as "very different," in comparison to education in the United States. Consistent with their limited experience with education, the parents indicated that they had no exposure to specialists such as speech-language pathologists or audiologists in their home country of Burma or host country of Thailand. Although speech-language pathology and audiology has existed in Thailand since 1974 (Dardarananda, R., 1996), the parents indicated that they were not familiar with the discipline and did not believe such services to be available on the refugee camp. Parental comments regarding specialized education services suggested that they were not aware of the differences in roles of school-based professionals. In general, the parents expressed that they tried very hard to understand all of the student's educational needs and opportunities available through the United States school system.

After attending a traditional elementary school with supports for students with hearing impairments, it was recommended that the student attend a specialized school for deaf children. Despite the school for deaf students being approximately two hours from the family home, all study participants indicated that the student has been able to travel home on weekends and holidays, barring issues with scheduling, weather, or transportation difficulties. The family has been able to provide transportation for the past six years and previously received support from volunteers who arranged for the student to travel home.

The parents reported that they do not recall who initiated this suggestion, but they assume it was a teacher or school official. The parents expressed that they were concerned and sad initially because they had never been away from their child, but they trusted that the change was in the student's best interest. Now that the student has been at the school for several years and learned a communication system, the parents feel it was the right decision to attend.

When discussing school, the student shared that they are very active in clubs and organizations. They expressed that participation in sports is an important part of school life. One activity they strongly indicated they dislike was speech therapy. They shared that they do not like to attend and do not understand the importance of speech services. A snowballing technique was used in the series of questions that followed to probe for context in this response; however, the student's' responses were consistently "I don't know."

The student's siblings serve as liaisons between the parents and the school. According to their interview, at least one of them attends any scheduled meeting at school. They interpret for their parents and school officials and also translate school documents, which are provided in English. The student's parents expressed that they prefer the siblings to interpret because they know the situation best, as opposed to a stranger.

Category	Sub-theme	Sample Comments
Educational Experiences	Impact of Refugee and Deaf Status on Education	Student: Does not like speech therapy "at all."
		Student: I'm really involved in a lot of things at my school. I am in clubs and I play sports. I am on committees for my school.
		Student: No other students from refugee backgrounds go to my school.
		Parents: The student went to a local school for a few months, then it was recommended that their child attend a special school for deaf children in a different city.
		Parents: The parents had limited educational experiences in Burma and Thailand.
		Parents: Did not know anything about the US education sys- tem upon arrival.
		Siblings: Had own experiences with public education as they began school in the US, but they did not know about special- ized schools.
		Siblings: It is easier to receive paperwork in English now that we are adults because we can just read it to our parents and explain what it means in Karenni.
		Siblings: The schools used to have to scheduled meetings based on availability of an interpreter, which was hard because there were not many available.
		Siblings: Scheduling meetings has always been difficult be- cause the school is in a different city (two hours away from the family home).
		Siblings: Two oldest siblings interpret at annual meetings.
		Family: Feel there are communication barriers between par- ents and the professionals and teachers who work with the student.

Table 1. Sample Data Organized Based on Education

Sub-theme 2: Impact of Deafness and Refugee Background on Student's Social Experiences

Communication barriers played a significant role in the social aspects of the student's ability to maneuver within Karenni social culture in particular. As noted in Table 2, feelings of isolation due to the inability to effectively communicate while at home has interfered with the student's ability to connect with the Karenni community. The student attributed these feelings of isolation at home and in their community strictly due to their inability to communicate with others away from school. The student and their family both indicated that the student often chooses to remain in their bedroom and looks out the window during gatherings at their home in an effort to avoid the awkwardness of feeling left out. The student expressed that they do not have friends or social groups in their home community and are nervous about graduating and moving away from school friends. The student commented that because they are the only person from a refugee background at the school, they have not developed relationships/friendships with Karenni peers. As a result, they closely relate to American deaf peers and culture. Siblings described the student as being seemingly more withdrawn at home versus how they engage at school. Reportedly, the student is involved in a number of club and sports activities in their all-deaf school.

Category	Sub-theme	Sample Comments
Social Impact	Impact of Deafness and Refugee Background on Student Social Experiences	Student: Feels isolated at home and in home com- munity because they are deaf and unable to com- municate with those around them.
		Student: Unable to communicate with Karenni speakers, making it hard to connect with people from their cultural background.
		Student: Feels more connected with American and deaf cultures.
		Student: Does not know anyone in home city who is deaf.

Table 2. Sample Data Organized Based on Social Impact

Sub-theme 3: Navigating Deaf and Karenni Cross-cultural Experiences

The third theme centered on the student's experiences maneuvering between deaf, Karenni, and American cultures. As a result of their profound deafness since birth, the student was never exposed to the Karenni language, and therefore does not know how to verbalize or read their language in any form. The student cited this as one reason they are unable to communicate with Karenni speakers in their home and community, making it difficult to connect with people from their cultural background. The student also shared that they are uncomfortable at Karenni cultural events because they "don't know anyone" and have "nobody to talk to". During Karenni cultural activities, they commented that they sometimes do not fully understand what is happening, making it difficult to engage. The student expressed that although they do identify with and value their Karenni ethnicity, they have a strong connection and comfort level with deaf culture. In terms of American culture, the student indicated that they feel "more American than Karenni" in many ways.

Table 3. Sample Data Organized Based on Cross-cultural Experiences

Category	Sub-theme	Sample Comments
Challenges in Cultural	Navigating Deaf and	Student: Does not always understand aspects of
Navigation	Karenni Cross-cultural	Karenni culture.
	Experiences.	Student: Recognizes themselves as being tri- cultural; however, identifies most closely with deaf culture.
		Siblings: The family provides the student with food to take to school, but the student prefers American snacks.
		Siblings: The student is easily frustrated when the family doesn't understand things with deaf culture.

Sub-theme 4: Communication History and Multimodal Communication Experiences

Communication difficulty was noted as a primary theme between the student and family as well as the family and service providers. There were various contexts in which communication was described as necessary, yet challenging, between the student and their parents/siblings. For example, the student may need to convey information or wish to communicate with the family during the course of the school week while at school. Since the student travels home to be with their family on the weekends, communication with the family is needed, but difficult. Because the parents do not speak or read English, nor do they use American Sign Language (ASL), communication with their child has been difficult. They expressed that they have not been provided with strategies on how to effectively communicate with their child and struggle to fully understand their child's wants, needs, and feelings.

Adding to the challenge, the siblings are not fluent users of ASL, and also reported communication to be a significant struggle. Use of social media and text messaging has been helpful in the siblings' communication with the student; however, they described it as unreliable and sometimes "not natural". Both the student and the siblings described use of messaging helpful in times of need, but also frustrating when messages are misinterpreted. Through use of an interpreter the student shared that they have a difficult time expressing thoughts and ideas to their family. The older siblings cited the student's lack of understanding of written and spoken English as a cause for the communication breakdowns. Their sentiment is consistent with research that suggests deficits in spoken and written language among deaf students (Williams & Mayer, 2015). The student expressed that it was exhausting having to write out messages before they had use of texting. They also make attempts to use gestures and writing to communicate. Use of photos is also a means by which the family and student attempt to relay information and share about interests and life events. A primary concern for the family is how they will manage communicating with the deaf student after graduation when they return home full time.

Category	Sub-theme	Sample Comments
Barriers and Strategies of for Communication of I	Communication History and Multimodal Communication Experiences	Student: Wishes their family would learn to communicate with them.
		Siblings: Communication between student and siblings occurs primarily via text messages.
		Siblings: Two of the adult siblings are trained interpreters who communicate text messages from the student to parents and oral information from parents to student via text.
		Parents: Since birth, communication has largely been with use of gestures.
		Parents: Do not speak or read English.
		Parents: Do not read Karenni.
		Family: All members want to learn sign language but it is difficult to find someone to teach them while managing their schedule.

Table 4. Sample Data Organized Based on Communication

Sub-theme 5: Transition from Specialized Educational Setting to Family and Community Living

As with the theme of communication difficulty, transition planning was frequently referenced throughout each interview. Planning for the shift from high school to the community, and potentially higher education, is a chief concern for the family. Desires to pursue education beyond high school were communicated throughout the interview. Although

Sub-theme 6: Family Education Regarding Professional Support

The final theme observed in initial analysis emerged as interviewees discussed their understanding and knowledge of professional services related to the student's needs. Upon being asked questions about speech services, the student stated that they felt it was unnecessary. The parents referred to all professionals discussed as either teachers or doctors.

Category 5	Sub-theme	Sample Comments
Transition from High School to Community	Support for Transition	Student: Does not want to continue speech therapy after high school.
and Beyond		Student: Would like to get a summer job.
		Student: Wants to go to college and live as independently as possible and is interested i n living on campus.
		Student: Not sure about how to take ACT or prepare for college.
		Parents: Interested in their child attending college but concerned about safety and support for individuals who are deaf.
		Siblings: Oldest sibling wants student to live with them following graduation because sibling thinks student will need supports and will not be able to live independently.
		Family: Concerned about student potentially going to college because there will not be similar students and will not have support like at the school for the deaf.

Table 5. Sample Data Organized Based Transition Preparation

the student was a high school senior at the time of the interview, they had not yet taken the American College Testing (ACT)and shared that they are unsure of the steps to take for registration with special accommodations. The parents indicated that they would like their child to continue their education; however they are apprehensive due to their uncertainty about whether or not supports exist for deaf students on college campuses. When the role of an Speech-Language Pathologist (SLP) was described, they stated they were unfamiliar with this role. When the role of the audiologist was described, they referred to this professional as an "ear doctor."

Category 6	Sub-theme	Sample Comments	
Knowledge of & Access to Services	Family education regarding professional	Student:Does not understand why speech therapy is necessary.	
	support.	Parents: Unaware of what speech therapy entails.	
		Parents: Unaware that speech therapy was an option for the student.	
		Parents: Aware that there is a specific profession- al who addresses hearing but not aware of term "audiologist."	
		Parents: Did not understand anything about school or hospitals when they arrived in the US.	
		Parents: Finding people who could interpret for Karenni/English was difficult.	
	Siblings: It used to be very hard to understand what people were saying like teachers and doctors because sometimes they assume things about what we know and use words the family is unfamiliar with, without providing meaning or explanation. Some English words do not translate to Karenni and have to be described in order to explain.		
		Siblings: Aware of services that can help with communication, but not aware of what a speech therapist/speech language pathologist is or does.	
		Family: Does not know what services (if any) are available to them and student when they move back home.	

Table 6. Sample Data Organized Based on Specialized Services

DISCUSSION

Findings from this study provided insight into the experiences of a deaf refugee student and their family. During the study, the interviewees revealed numerous factors which impacted their communication, educational, social, and cultural experiences. Variables related to these experiences were bundled into broad themes based on related categories. Communication barriers and concerns regarding transition into a hearing home and community persisted as the most prominent themes throughout all four interviews.

The student respondent indicated a strong connection to their educational experiences after learning ASL. They conveyed a high sense of communication to deaf culture. Although the student revealed difficulty navigating social aspects of the Karenni culture, they did express a desire to develop relationships with others within this community. The student also expressed that they wished their family and Karenni community members would learn alternative ways to communicate.

The parents expressed that they upon arrival in the United States, they had no experience with American-based education and very little experience with formal education in their home country. While they attend educational meetings and medical appointments in their child's interest, they often are unsure of the roles of various service providers. Based on their responses, the parents were informed about educational options before agreeing to allow their child to enroll in the specialized school, which was in a different city. Responses from the student's parents revealed limited direct communication with service providers.

The student's adult siblings revealed that they are heavily involved in discussion and decision-making for the student. They indicated that the eldest sibling serves as the primary point of contact for the school and is a liaison between the school and the family. Transition from high school to home and community was raised as a point of concern by the siblings. Based on their experience with educationally and socially supporting the student, the siblings expressed worry about the student's readiness to live and work independently.

The fourth interview which was conducted with the family (student, parents, and adult siblings) showed consistency between the previous three interviews. Communication barriers continued to resonate as the biggest challenge between the student and family as well as the family and service providers. Differences in experiences and perception was also noted, particularly between the deaf student and older siblings. Despite the student's concerns regarding a sense of connectedness to the Karenni community, the family did not share the same concern. Post-secondary education and employment was a point of discussion between family members during the interview. Questions about community-based resources were also raised and discussed. The family also discussed this in the context of their unique cultural and linguistic needs.

According to Gallaudet Research Institute (2011), 25.2% of students identified nationwide as being deaf, had a home language described as something "other" than English, Spanish, or ASL. As refugee resettlement continues in the United States, it is likely that the cultural and linguistic family profile of deaf students will continue to diversify, which is further evidenced by Gallaudet's (2011) publication. Asians are projected to be among the fastest growing groups across the country slightly second to individuals represented by two or more races (Colby & Ortman, 2014). In fact, a report by Colby and Ortman (2014) estimated the Asian population to increase by 128% between 2014 and 2060. The Colby and Ortman report also projected the U.S. foreign-born population to increase by 85% by the year 2060. This being the case, communication sciences and disorders (CSD) professionals and related providers should not only be prepared to service students from culturally and linguistically diverse backgrounds, but they should also be inclusive of students' families as well. While it can be tempting to avoid additional steps needed in serving students and families from different cultural and linguistic backgrounds, regular communication with family is essential when working with individuals from refugee backgrounds. It should also be noted that involvement of multiple family members, such as in this case study may be a cultural aspect to consider. For example, a survey of Spanish-speaking parents of school-aged children with severe hearing impairment indicated that support and decision-making occurred most often as a collective between parents, grandparents, and at times extended family members (Gubierson, 2013). Consistent communication can also encourage involvement of family members in the decision-making process, as they may provide key insight into factors that can impact generalization of skills across the student's cultures and languages (Mindel & John, 2018).

Consistent communication between service providers, the student, and family may help shape positive experiences and perceptions. Education about service offerings and the various roles of service providers is a critical aspect in involving clients and families from refugee backgrounds in the decision-making process. Clinician assumptions about the family's base knowledge and/or desire to be involved in intervention can result in gaps in support and challenges with generalization of skills into the home and community settings (Mindel & John, 2018).

CONCLUSION

As revealed in data from this qualitative study, service providers may need to account for quality of life beyond the classroom. While students may be well-adjusted to communication methods in the school environment, this does not necessarily translate to the home and community settings. This is not only in regard to modes of communication for students who are deaf, but is also applicable to other populations such as fluency disorders, language disorders, or challenges in feeding and swallowing. A team-based approach to merging communication between school and home may aid in family communication and dynamics. A primary case manager who is proficient in cross-cultural communication may serve as a liaison between service providers and the family. They may also support other team members in understanding cultural dynamics that should be taken into consideration as services are rendered.

While results from this qualitative study may not be completely generalizable to a larger scope of refugee children and their families, the study does provide insight into the unique circumstances that families with similar profiles may experience. Results from this study may also aid clinicians in teambased contexts to better understand the needs of such children and families as they navigate options for effective communication across settings. As cases of children with hearing impairments from refugee backgrounds continue to surface, service providers may look to this and similar studies to support student and family quality of life within the educational and social aspects of their given community.

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THE INFLUENCE OF ETHNICITY AND RESIDENCE ON PRESENCE OF STUTTERING IN CHILDREN

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— ABSTRACT —

Stuttering can be a debilitating disorder that impacts all races and cultures, though there have been few reports that have focused specifically on the influence of race/ethnicity on stuttering. While research in other disciplines suggest regional variability in the presence of health-related conditions, this consideration has been limited in the field of stuttering. Therefore, the purpose of this study was to use population data to compare the presence of stuttering between racial/ethnic groups, as a whole, and between geographical regions. This study utilized data from the National Health Interview Survey, which showed that African American children were at greater odds of experiencing stuttering were greater for African American children in all regions, with the exception of the Northeast. Current findings of racial and regional differences in the presence of stuttering are discussed, along with potential avenues for future research.

Key words: stuttering, race, residence

INTRODUCTION

Stuttering is a neurodevelopmental, communication disorder impacting the sensorimotor processes of speech (Smith & Weber, 2017). As stuttering persists, negative impact can be seen in the behavioral, emotional, and social well-being of the individual (Yaruss, 2010). The prevalence of stuttering is roughly 1% of the United States (US) population and occurs more frequently in males than females (Guitar, 2014). Stuttering is believed to impact all racial/ethnic groups (Yairi & Ambrose, 2013) and all cultures (Van Riper, 1982). However, recent evidence suggests that differences might be present in the rate of stuttering across racial and ethnic groups. In Briley and Ellis' (2018) investigation of coexisting disabilities among children who stutter (CWS), rates of stuttering were found to be greater among African American CWS when compared to white CWS. This report of racial differences in the presence of stuttering is similar to other reports of differences among disability groups found in the literature.

Overall, there have been few recent studies that have explored the influence of race/ethnicity on rates of stuttering, though Boyle et al. (2011) reported racial/ethnic differences in rates of parent reported stuttering. Using merged data from 1997-2008 NHISs, they found rate of stuttering to be significantly greater among non-Hispanic African American children than among non-Hispanic white children. In contrast, Proctor, Yairi, Duff, and Zhang (2008) reported no significant difference in prevalence of stuttering between 2,223 African American children and 941 European American children between the ages of 2 and 5 years. Proctor et al. (2008) reported on studies of prevalence and incidence of stuttering among African American children. However, over half of the nine studies were published prior to 1960. The earlier studies have methodological issues that should be considered, particularly how African American US residents were defined. These issues along with dramatic demographic changes in the African American US population must be taken into consideration when interpreting the findings (Rastogi, Johnson, Hoeffel, & Drewery Jr, 2011). Taken together, current data is needed to clarify the influence of race on stuttering.

Beyond the influence of race, region is a factor that has been found to contribute towards the prevalence of some disabling conditions. In a study by Shin et al (2009), where an overall difference in rate of down syndrome (DS) at birth differed as a function of race/ ethnicity, differences by racial/ethnic group were present in some regions, while other regions exhibited no differences. In a study on estimated prevalence of Autism Spectrum Disorder (ASD), Zablotsky, Black, Maenner, Schieve, and Blumberg (2015) found regional trends in ASD with the highest prevalence in the Northeast (3.17%) and the lowest in the South (1.81%). More recent reports have provided evidence that rate of ASD varies between region and state (Zablotsky, Maenner, & Blumberg, 2019; Xu et al., 2016). Additionally, using adult data from the 2012 National Health Interview Survey (NHIS), Morris, Meier, Griffin, Branda, and Phelan (2016) found geographical variance in the survey item that questioned the presence of a speech, language, and/or voice issue within the past 12 months. These studies point to the possibility of environmental factors influential to the development of disabling conditions.

To our knowledge, there has been limited evidence of regional influence on stuttering. Briley and Ellis (2018) and Merlo and Briley (2019) found regional differences in the percentage breakdown of the total sample of children who do not stutter (CWNS) as compared to CWS. The percentage breakdown for each geographical region showed that the South represented the largest difference between the two groups, with the percentage of CWS in the South contributing greatest to this difference. However, we are unaware of any reports considering the presence of stuttering as influenced by race and region. Therefore, the purpose of this project is to explore the rate of stuttering, as a function of race and geographical region.

METHOD

Study Sample

The current project utilized the same data and analytical approach as previous studies (Briley & Ellis, 2018; Briley, O'Brien, & Ellis, 2019, Merlo & Briley, 2019). In each, the source of the data was the National Health Interview Survey (NHIS). Detailed information on the NHIS and related documentation can be found on the National Center for Health Statistics' website (Center for Disease Control, 2019). In short, the NHIS is a survey that is completed annually by the National Center for Health Statistics to monitor the health of United States citizens. Included in this survey are roughly 35,000-40,000 households, which excludes those actively serving in the military and those residing in corrective institutions, mental institutions, or elderly homes. The NHIS utilizes a multistate sampling method to ensure accurate statistics for those in minority groups (Parsons et al., 2014). From the selected households, one sample child is randomly selected, of which questions are asked by a parent or caregiver (Center for Disease Control, 2018).

The sample for the current project was taken from merged data from 2010-2015 NHIS (Center for Disease Control, 2010-2013; Center for Disease Control, 2014; & Center for Disease Control, 2015) and included those children whose parent/caregiver answered a definitive "yes" or "no" to the following question: "During the past 12 months, has [child name] had any of the following conditions...stuttering or stammering?" For consistency throughout this paper, those children whose parents answered "yes" will be referred to as CWS and those children whose parents answered "no" will be referred to as children who do not stutter (CWNS). Additionally, the sample reported here only included those children identified as either non-Hispanic white, non-Hispanic African American, or Hispanic.

Data Description

Demographic characteristics. Gender, age, geographical region, highest level of education completed by an adult in the family, and total combined family income were reported by the respondents. Baseline data was completed for the total sample and comparisons were made as a function of racial/ethnic group. For racial/ethnic group comparisons, the sample was analyzed between white, African American, and Hispanic CWS.

Reported rates of stuttering as a function of racial/ethnic groups. The overall reported rates of stuttering were reported for the total sample and for white, African American, and Hispanic children. Children within each racial/ethnic group were then categorized into three age groups, and rate of stuttering was reported for children ages 3-5, 6-10, and 11-17 years. Rate of stuttering was also reported within each region of the United States. Specifically, rate of stuttering for each racial/ethnic group was reported for the Northeast, Midwest, South, and West. Lastly, rate of stuttering within each geographical region was subdivided by previously used age groups. These rates were again reported for the total sample and for each racial/ethnic group.

Data Analysis

Data were analyzed using SPSS Version 24 (IBM, 2016), which allows for adequate analysis of the NHIS' complex sampling design. By properly utilizing SPSS' complex samples function, results are able to be generalized to the US population. Gender, geographical region, highest level of education completed by an adult in the family, and total combined family income were reported in percentages and compared across racial/ethnic group. Mean age and standard deviations were reported for all groups. Rate of stuttering was reported using percentages and compared

across all racial/ethnic groups, and the same procedure was used for reporting rate of stuttering within categorical age ranges, geographical regions, and age ranges within each geographical region. Categorical variables were analyzed using chi-square tests of independence and continuous variables were analyzed using Analysis of Variance (ANOVA). Lastly, odds of reporting stuttering were generated for both African American and Hispanic children, with white children used as the reference group. Multiple logistic regressions were performed to determine the odds of reporting the presence of stuttering, while controlling for parent education and total family income.

RESULTS

Demographic Characteristics

The total number of white, African American, and Hispanic children in the 2010-2015 NHIS whose parent/caregivers answered definitively about the presence of stuttering were 46,851. Of those, there were a total of 978 (2.1%) children identified as CWS. The majority of the total sample of CWS were comprised by males (68.2%), and analysis showed no differences in percentage of males across racial/ethnic groups, $X^{2}(1.99, N = 978) = 3.22, p = .317$. The mean age for the total sample of CWS was just under 9 years, M = 8.88, SD = 4.27, and no differences were found in mean age across racial/ethnic groups, F(2, 975) =1.74, p = .176. Significant differences were found in breakdown of racial/ethnic group within geographical region, X^2 (4.89, N = 978) = 123.40, p < .001. Specifically, the South was the geographical region with the largest percentage of white CWS (39.3%) and African American CWS (62.8%). The majority of Hispanic CWS resided in either the South (37.0%) or the West (40.2%). Significant differences were found between racial/ethnic groups as a function of highest education of adult in families of CWS, X^2 (14.34, N = 978 = 179.33, p < .001. Families of white CWS had the highest percentage of master's, professional, or doctoral degrees (16.6%) and families of Hispanic CWS had the largest percentage of completing 8th grade or less only (11.9%) and some high school with no diploma (25.7%). Lastly, total combined income of families of CWS was found to differ across racial/ethnic groups, X^2 (9.17, N = 978) = 123.40, p < .001. The majority of combined incomes were under \$35,000 for families of African American (60.6%) and Hispanic CWS (58.7%), as compared to 38.0% for white CWS. See Table 1 for a breakdown of demographic data by racial/ethnic group.

	Total CWS 978	White CWS 328	African American CWS 272	Hispanic CWS 378	р
Gender (Male)	68.2	71.1	67.9	68.2	.368
Age (4-17 years)					
Mean (standard deviation)	8.88 (4.27)	9.03 (4.37)	9.13 (4.32)	8.56 (4.14)	.176
Region					
Northeast	11.7	13.3	9.1	11.8	
Midwest	20.5	28.0	20.4	11.0	<.001
South	44.8	39.3	62.8	37.0	
West	23.0	19.4	7.6	40.2	
Highest Education of Adult					
in Family					
\leq 8th grade	4.9	1.4	1.8	11.9	
9-12th grade (no diploma)	13.8	4.9	13.0	25.7	
High School Grad. or GED	24.0	20.3	28.7	24.6	
Some college, no degree	21.1	23.7	21.7	17.4	<.001
AA degree, technical	9.7	9.5	11.9	8.2	
or vocational					
AA degree,	4.7	6.1	5.1	2.8	
Academic program					
Bachelor's degree	12.7	17.5	12.8	6.4	
Master's, professional	9.0	16.6	4.9	2.9	
or doctoral degree					
Total Combined Family Income					
\$0 - \$34,999	50.7	38.0	60.6	58.7	
\$35,000 - \$74,999	23.9	22.9	22.6	26.2	<.001
\$75,000 - \$99,999	9.1	13.2	7.7	5.0	
\$100,000 and over	12.9	24.4	5.3	4.8	
Undefined/unknown	3.3	1.4	3.7	5.3	

Table 1. Demographics of non-Hispanic white, non-Hispanic African American, and Hispanic children who stutter in 2010-2015 National Health Interview Surveys

CWS – Children Who Stutter

GED - General Educational Development high school equivalency diploma

AA degree - Associate of Arts degree

Rate of Reported Stuttering as a Function of Racial/Ethnic Group

Differences were found in the rate of reported stuttering when analyzed across racial/ethnic group, X2 (1.97, N = 46,581) = 155.83, p < .001. Reported rates of stuttering were greatest among African American children (3.6%) and least among white children (1.4%). Differences remained present when racial/ethnic groups were compared within each categorized age range. Specifically, African American children had a significantly greater percentage of reported rate of stuttering in the 3-5 year old range (4.8%), X2 (1.93, N = 9,228) = 34.43, p < .001; the 6-10 year old range (3.9%), X2 (1.97, N = 14,420) = 44.13, p < .001; and the 11-17 year old range (2.9%), X2 (1.96, N = 23,203) = 74.20, p < .001. Baseline racial/ethnic differences were present when comparing rate of stuttering within each geographical region. Most notable were differences in rate of stuttering in the Midwest between African American children (3.7%) and white children (1.3%), X2 (1.82, N = 9,429) = 40.82, p < .001, and differences in rate of stuttering in the South between African American children (3.7%)

dren (4.0%) and white children (1.7%), X2 (1.92, N = 17,581) = 64.69, p < .001. When analyzing racial/ ethnic groups' rate of stuttering among age groups and within in region, differences were most notable in the South. Within this region, African American children had a significantly higher rate of stuttering in the 3-5-year age group (6.3%) than white children (2.9%), X2 (1.94, N = 3,519) = 17.34, p = .003. Within

the South, significant differences were also seen in the 6-10-year age group, X2 (1.98, N = 5,428) = 23.98, p = .001 and the 11-17-year age group X2 (1.98, N =8,634) = 23.36, p < .001, with African American children exhibiting the greatest percentage of stuttering in each age group (4.7% and 2.4%, respectively). See Table 2 for a breakdown of rates of stuttering across racial/ethnic group.

Table 2. Reported rates of stuttering among non-Hispanic white, non-Hispanic African American, and	l
Hispanic children in 2010-2015 National Health Interview Survey	

	Total Children = 46,851	White = 23,242	African American = 8,066	Hispanic = 15,543	р
Total number of children who stutter (unweighted count)	978	328	272	378	
Overall rate of stuttering (weighted %)	2.1	1.4	3.6	2.6	<.001
Age Ranges (in years)					
3-5 (n = 9,228)	2.9	2.1	4.8	3.4	<.001
6-10 $(n = 14, 420)$	2.4	1.7	3.9	3.0	< .001
11-17 (n = 23,203)	1.5	1.0	2.9	1.9	< .001
Rate of stuttering within in each region (weighted %	1 1	1 1	9.1	9 F	001
Northeast $(n = 1,288)$	1.0	1.1	2.1	2.0	.001
Midwest $(n = 9,429)$	1.8	1.3	3.7	2.9	< .001
South $(n - 17, 381)$ We st. $(n - 18, 552)$	2.4	1.1	4.0	2.1 9.5	< .001
Rate of stuttering within in region, by age groups in years (weighted %)					
Northeast					
3-5 (n = 1,386)	1.9	1.4	1.0	3.8	.032
6-10 $(n = 2,213)$	1.9	1.6	1.2	3.4	.070
11-17 (n = $3,689$)	1.1	0.6	3.2	1.3	<.001
Midwest					
3-5 (n = 1,800)	1.9	1.2	4.4	3.0	.010
6-10 (n = 2,908)	1.9	1.6	3.3	2.2	.197
11-17 $(n = 4,721)$	1.7	1.1	3.7	3.3	.002
South					
3-5 (n = 3,519)	3.9	2.9	6.3	3.5	.003
6-10 (n = 5,428)	2.8	1.9	4.7	3.0	.001
11-17 $(n = 8,634)$	1.5	1.0	2.4	2.0	<.001
West					
3-5 (n = 2,523)	2.9	2.4	3.1	3.3	.573
6-10 (n = 3,871)	2.5	1.6	4.9	3.2	.016
11-17 $(n = 6, 159)$	1.5	1.1	3.0	1.5	.053

In logistic models, with white children serving as the reference group and controlling for baseline differences in parent education and total family income, African American children were at greater odds of experiencing stuttering (OR = 1.79, 95% CI 1.40, 2.30), while Hispanic children were not (OR = 1.18, 95% CI .932, 1.50). Using this same analytical approach, Hispanic children did not show increased odds in any of the geographical regions. However, African American children showed greater odds in three of the four geographical regions: the Midwest (OR = 2.18, 95% CI 1.25, 3.77); the South (OR = 1.64, 1.64)95% CI 1.13, 2.38); and the West (OR = 2.06, 95% CI 1.21, 3.51). Odds of stuttering were not greater for African American children in the Northeast (OR =1.23, 95% CI .588, 2.57) (See Table 3).

Table 3. Weighted measures of stuttering among non-Hispanic white, non-Hispanic African American, and Hispanic children in the 2010-2015 National Health Interview Surveys

2010-2015 NHIS sample. The overall rate of stuttering in white children was 1.4%, compared to 2.6% among Hispanic children and 3.6% among African American children. To our knowledge, data on race differences in rate of stuttering has been relatively scarce, and most recent reports were highlighted by Yairi and Ambrose (2013). Contrary to current findings, Proctor et al. (2008) reported no significant difference in prevalence of stuttering between 2,223 African American children (2.6%) and 942 European American children (2.44%) between the ages of 2 and 5 years. The prevalence figure reported by Proctor et al. (2008) was specifically for African American children aged 2-5 years, which was considerably smaller than that reported among the 3-5-year-old African American children in the current sample (2.6% vs. 4.8%). Similar in methodology to the current study, Boyle et al. (2011) used NHIS data from 1997-2008 where they reported an overall prevalence of 1.27% for non-Hispanic white children compared to 2.63% for non-Hispanic African American children

	Afric	an American Ch	ildren	Hispanic Children			
	OR	(95% CI)	р	OR	(95% CI)	р	
Total	1.79	(1.40-2.30)	< .001	1.18	(.932-1.50)	.167	
Northeast	1.23	(.588 - 2.57)	.578	1.09	(.738 - 1.62)	.654	
Midwest	2.18	(1.25 - 3.77)	.006	1.14	(.694-1.87)	.603	
South	1.64	(1.13-2.38)	.010	1.19	(.865631)	.289	
West	2.06	(1.21 - 3.51)	.008	1.13	$(.825 \cdot 1.57)$.431	

White children represent the reference group.

Odds ratio adjusted for parent education and total family income.

DISCUSSION

The purpose of this study was two-fold: to explore rates of stuttering as a function of race and to explore rates of stuttering as a function of race within geographical regions. As stated previously, prevalence of stuttering is generally accepted to be around 1% of the population with an incidence of 5% (Guitar, 2014). The variation in these rates is due to natural recovery in some children who stutter (Yairi & Ambrose, 2013). Therefore, rates of stuttering in a sample of diverse ages, such as the present sample, would generally be expected to fall within this 1% -5% range.

The primary findings of this project were the heightened odds of stuttering among African American children and regional differences in odds of stuttering among African American children in the and 1.96% for Hispanic children, aged 3-17 years. In comparison, rates of stuttering were higher for all racial/ethnic groups in the current sample, though rate of stuttering among African American children remained the greatest. In addition to the prevalence of the overall current sample being significantly greater among African American children, differences between groups in each segmented age demarcation were also significant. For each age range, rates of stuttering among African American children remained greatest. Also, and as expected, rate of stuttering for each racial/ethnic group decreased as a function of age group, where the rates for the 11-17year old children settled highest for African American children (2.9%) as compared to white children (1.0%) and Hispanic children (1.9%).

For the total sample, after controlling for parent education and total family income, African American

children were at greater odds of experiencing stuttering than white children. In contrast, significant differences were not found in odds of stuttering between white and Hispanic children. Increased odds of stuttering among African American children were found in the Midwest, the South, and the West. Interestingly, African American children were not at greater odds of stuttering in the Northeast, when controlling for parent education and total family income. While other health-related differences as a function of region have been previously reported, this is the first examination of such, to our knowledge, in the study of stuttering.

The effect of region on the presence of stuttering prompts speculation into influences that would heighten the odds for African American children in certain regions of the US. Current data does not offer explanation for these findings, but a programmatic line of research could potentially provide evidence to these unknown contributors. Smith and Weber's (2017) multifactorial, dynamic pathways (MDP) theory of stuttering is one that could be useful in helping to understand current findings. The MDP proposes that stuttering, at its core, is a sensorimotor disorder, where the influence of faulty neuronal signals, controlling the system of speech, are the source of observable and unobservable deviations (Smith & Weber, 2017). Further, deviations to the system (i.e., symptoms of stuttering) are positively associated with increased linguistic, emotional, and cognitive demands; each undergoing development during the time period of stuttering onset and natural recovery (Smith & Weber, 2017). Influenced by the developmental course of each, sufficient or insufficient systems for fluent speech would emerge. Contributing to the trajectory of development are genes, the child's environment, and epigenetics (Smith & Weber, 2017).

Briefly, epigenetics is change in gene expression, induced by a plethora of variables, while DNA sequence remains unchanged (Weinhold, 2006). Strong evidence of environmental factors playing a role in the presence of stuttering comes from twin studies, where concordance of stuttering between monozygotic and dizygotic twins suggests genetic and environmental influences (Felsenfeld, Kirk, Zhu, Statham, Neale, & Martin, 2000). Broadly, suspected environmental influences critical to epigenetic changes include hazardous materials/chemicals (Baccarelli, & Bollati, 2009), diet (Schagdarsurengin & Steger, 2016), sleep (Masri, & Sassone-Corsi, 2013), and familial interactions related to emotional and behavioral well-being (McGowan & Szyf, 2010). One example of an interaction specific to environmental influences on stuttering is the finding that increased duration of breastfeeding led to a decrease in odds of stuttering persistence. The authors hypothesized that the benefits of breastfeeding were facilitation of proper brain maturation and expression of genes, conducive for fluent speech (Mahurin-Smith, & Ambrose, 2013). In addition to stuttering (Starkweather, 2002), other communication disorders such as autism and specific language impairment have been considered through the lens of epigenetics (Rice, 2013; Waye & Cheng, 2018). The possibility of identifying variables that lead to increased odds of stuttering among a specific racial group within specific regions, would begin to unravel the conjectured interplay of genetics and culture on the presence and persistence of stuttering (Starkweather, 2002). Recently, epigenetics has been proposed as a possible contributor towards racial differences in other diseases and conditions, including: cardiovascular disease (Kuzawa, & Sweet, 2009); cancer and preterm birth (Vick & Burris, 2017); and chronic pain (Aroke et al., 2019); possibly induced by such things as inequities, inequalities, or distress during developmental years. Therefore, investigation is warranted in those characteristics, specific to certain geographical regions of the United States, that lead to increased likelihood of a neurologically based disorder, such as stuttering, among African American children.

While present findings are informative, several limitations should be considered when interpreting current results. First, data is acquired via parental report. Therefore, novel studies should be designed to provide data where diagnosis can be verified by a licensed speech-language pathologist. Second, parents may not be fully in tune with the full range of symptoms that comprise the disorder of stuttering. Therefore, it might be stated that current estimates are more likely an underestimate than an overestimate. Third, while the overall sample constitutes a relatively large representation of children who stutter, analysis of age breakdowns within region resulted in smaller samples for individual analyses. Specifically, the smallest samples for each region were for 3-5-year-old African American children, and while relatively small, their unweighted counts still included the following: 228 children in the Northeast; 283 children in the Midwest; 915 children in the South; and 141 children in the West. Lastly, the NHIS does ask the question if speech therapy was provided in the school setting. However, along with the inquiry of school-based speech therapy is the inclusion of occupational and physical therapy within the same survey question. Still, from the current sample, only 79 of the 978 CWS answered this question. Similar questions were asked about speech services in other settings, but data remained insufficient to confidently infer meaning from results. Recent evidence has indicated that minorities in US public schools are less likely to be identified as having a speech or language impairment (Morgan et al., 2015; Morgan et al., 2017; Robinson & Norton, 2019). Regarding this disproportionately of service provision, it is not clear the extent of impacts on current findings. However, if service provision is disproportionate at the school-age years, it is reasonable to assume that a similar trend would be found in the pre-school-age years. The potential exists, then, that lack of service provision in the area of speech and language for minority children may have an influence on eventual increased prevalence rates of stuttering. Further research is needed to clarify this issue.

In summary, results from the current study suggest that, when compared to white children, African American children are at greater odds of experiencing stuttering, and regional differences are present in African American children's odds of experiencing stuttering. Data from the current study do not provide explanation of these findings, though they do support inquiry into what brings about increased odds of stuttering among African American children in all geographical regions except for the Northeast. Future successes in this regard will be needed to improve outcomes for those African American children susceptible to the disorder of stuttering and will likely contribute to better understanding of the etiology of stuttering as a whole.

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A DESCRIPTION OF SELF-GENERATED NARRATIVES FROM AFRICAN AMERICAN PRESCHOOLERS

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— ABSTRACT —

This study examined macrostructure characteristics of spoken narrative production from self-generated narratives of African American (AA) preschool children as analyzed by the Index of Narrative Complexity (INC; Peterson et al., 2008). Twenty-six children who were enrolled in two full-day Head Start classrooms in a single Head Start building participated in this study. Narratives samples from a prior study were used from an intervention study in which children created picture books and told them to a researcher. The narratives of the children from the control group who did not receive the intervention were collected and analyzed for narrative characteristics. Higher narrative element scores and increased density of narrative elements were noted as indicated by the Index of Narrative Complexity (INC; Peterson et al., 2008) as age groups increased. The results from the current study supports the notion that self-generated narratives may provide children with an opportunity to generate narrative elements independently. Self-generated narratives of AA children may supply a sound context for involving cultural as well as linguistic behaviors that provide less rigidity to storytelling.

KEY WORDS: narrative, assessment, African American English, preschool

INTRODUCTION

Research exploring self-generated narratives of preschool African American (AA) children is limited. Although there have been many studies providing information about typical narrative production in European American (EA) children, few studies provide information about AA preschoolers' spoken narrative production (Curenton & Justice, 2004; Price, Roberts, & Jackson, 2006; Terry, Mills, Bingham, Mansour & Marencin, 2013)story literary technique (SLT. In addition, spoken narratives abilities in preschool children have been found to predict later language and literacy success (Griffin, Hemphill, Camp, & Wolf, 2004). This is especially important to culturally and linguistically diverse populations such as AA preschoolers who have been considered "at risk" for academic challenges. Furthermore, it has been noted that AA narratives do not necessarily represent the narratives of the classroom and are often judged based on narratives produced by EA children— whose narratives reflect those found in the classroom (Champion, Seymour, & Camarata, 1995; Michaels, 1981). Without a strong understanding of AA spoken narratives, prejudice within educational programming may occur when the favored discourse of the classroom has not been adopted.

Therefore, more research is necessary to properly assess and identify typical versus disordered narrative characteristics within the AA preschool population and to inform culturally and linguistically appropriate practices in the preschool setting. Furthermore, understanding what is culturally and linguistically appropriate for AA preschoolers may support teaching practices in academic settings where this population is considered to be "at-risk" (Hughes, McGillivray, & Schmidek, 1997; Mills, Watkins, & Washington, 2013).

One of the many ways to assess language is through obtaining a narrative sample. Spoken narrative assessment is one tool recommended in the research literature to evaluate language skills of individuals from culturally and linguistically diverse populations such as AA children because of the reduction in test bias that exists when comparing them to standardized assessment measures (Schraeder, Quinn, Stockman, & Miller, 1999). Professionals such as speech-language pathologists (SLPs) use spoken narratives as assessment and intervention tools because of the developmental relationship between storytelling and language skills (Hughes et al., 1997).

Although both story retell and story generation tasks have been considered appropriate methods for eliciting spoken narratives, story retells in children are investigated more frequently (Merritt & Liles, 1987; 1989). However, story generation may provide a better representation of the AA preschool children's language abilities in a more relaxed, and limitless format within the child's cultural realm of storytelling (Champion, 1995; Merritt & Liles, 1987, 1989; Hughes et al., 1997).

The purpose of this current study is to examine narrative characteristics via story grammar features of AA preschoolers when assessing self-generated narratives. This information may assist with assessment, intervention, and educational programming for children in the preschool setting. In addition, it may provide professionals such as speech-language pathologists with access to more information about cultural and linguistic variations found within the spoken narratives of AA preschoolers.

Assessing Narrative Macrostructure and Story Grammar

Professionals such as speech-language pathologists, researchers, and education specialists assess narratives because they provide a plethora of information regarding cognitive and language abilities. The information obtained from narrative assessments can predict later language and literacy skills in young children (Bishop & Edmundson, 1987; Griffin et al., 2004; Hughes et al., 1997). Included in the assessment of narratives is the analysis of macrostructure. When professionals assess macrostructure of narratives, they often examine the child's ability to remember and understand material presented in a chronological and cohesive order. Macrostructure analysis includes a method of evaluating the inclusion of story grammar elements. Stein and Glenn (1979) identified story grammar elements that have been used by researchers to take a chronological approach to narrative analysis using story grammars in clinical practice (Schneider & Dubé, 2005; Soodla & Kikas, 2010). These elements include setting, initiating event or problem, internal response, internal plan, attempt, consequence, resolution or reaction, and ending (Hughes, et al, 1997). Schneider and Dubé (2005) discussed the two major components of a story grammar model which include structural pattern and story grammar elements. These researchers defined a complete structural pattern as those containing an initiating event, attempt, and an outcome.

One purpose for macrostructure analysis is to understand a child's ability to comprehend, organize, and use language. Narrative macrostructure analysis can be evaluated once elicited using visual and/or auditory stimuli such as pictures and verbal prompts and/or personal experiences (Hughes et al, 1997). Macrostructure analysis can also be used to determine which story grammar elements are present or absent within a child's fictional narrative production based on story structure level judgment.

Clinical research evaluating EA preschoolers indicates that prior to story structure level achievement, preschoolers are typically able to produce scripts from familiar activities. Next, they participate and eventually move to what is known as *descriptive* sequences. Descriptive sequences include describing what characters are doing or what they will do without an actual cause for the action. Specific grammar elements used at the preschool age within the descriptive sequence level may include characters, settings, and customary actions without causal relations. Following these initial abilities, young children use the structure *action sequence* level which can be described as sequences that list actions in chronological order without causal order. Specific grammar elements used at the preschool age within the action sequence level may include actions and attempts that occur chronologically but without a causal order. Finally, young children use the structure *reactive sequence* which are described as a list of linked actions that have no plan nor clear objectives. Specific grammar elements used at the preschool age within the *reactive sequence* may include actions and attempts which involuntarily cause other actions and attempts but lack planning or goals for actions and attempts (Hughes et al., 1997; Table 4.3 p. 121; McCabe and Rollins, 1994). It is not until around age eight years old when a complete episode for generated stories becomes evident. At this time goals for a complete episode, which includes an initiating event, an action, a direct consequence for an action, are obvious and efforts to solve the problem are made clear (Hughes et al., 1997; p. 123).

With an understanding of narrative assessment and macrostructure development within the young EA population, professionals are able to compare and contrast differences that may or may not exist within the narrative development of minority groups such as AA children. The following paragraphs will attempt to provide information about what was previously reported and what is currently known about AA narrative development.

African American Narratives

AA children are capable of proficient narrative production as well as developing these abilities at a comparable rate to that of EA children (Burns, De Villiers, & Peterson, 2012; Curenton & Justice, 2004). Additionally, AA culture impacts narrative development in preschool children and includes communication forms that vary from EA narrative development (Champion et. al, 1999).

Professionals must be aware of the impact of home language cultural differences between EA and AA narrative development to offer a better representation of AA children within academic settings (Champion et. al, 1999; Stockman, 2010). However, few studies have investigated AA narrative abilities beyond comparing them to EA children's narrative production. More research is needed to examine the narrative skills within the AA population to identify what can be seen as typical development. It is important to determine what can be typically noted within narratives and cultural practices in storytelling of AA preschool children to combat the likelihood of cultural and linguistic mismatch. Cultural and linguistic mismatch may result in misidentification of children from this population. For example, in a study of AA children's macrostructural narrative production, Champion (2001) concluded that AA children produce a repertoire of narrative skills that vary from those of EA children due to the incorporated West African forms of storytelling. These narratives include content that reflect social language behaviors found within the West African culture that may not be reflected within that of the EA dialect. This content includes performance, moral centered, and dispute narratives which support the fact that culture variations should be considered when assessing AA narratives.

Other studies of AA preschoolers examined the development of narrative macrostructure within the population (McGregor, 2000; Champion, 2003; Price et al., 2006). For example, in a study conducted by Price et al. (2006), the structural development of 65 AA preschoolers at age four were assessed prior to kindergarten. These researchers found that fouryear-old narrative tasks included story grammar elements such as main characters, attempts, initiating events and endings. In addition, the researcher found that before kindergarten, the development of AA preschool narratives macrostructure skills was consistent with those of EA preschoolers. Additionally, as AA children increased in age from four years old to kindergarten entry their narratives contained an increase in elements such as characters, initiating events, internal responses, attempts and endings. As AA children's narrative skills develop from early to later preschool years, these children learn to produce a variety of narrative types and these narratives contain elements that are comparable to that of EA preschoolers (Price et al, 2006).

In short, research has shown that differences and similarities exist within the narratives of AA children that require more identification. Our study seeks to describe the variety of macrostructure of narrative production that can be found within AA preschool children. We seek to offer a more comprehensive view of what these children bring to the academic setting that represents their cultural and linguistic abilities.

Story Retells and Story Generation

Both story generation and story retells have been considered effective methods for narrative elicitation because they provide a description of language use in connected discourse. However, when given the opportunity to create a story, a true representation of narrative skills, may allow researchers to assess more authentic story telling skills. Lever & Senechal (2011) noted that children learn how to construct a story early in their language development and may demonstrate the ability to construct stories that more accurately assesses language and narrative abilities than a story retell. Although story retells may be more easily evaluated, story retells may limit the narrative assessment process to memorizing and restating story components without actually addressing the child's ability to produce language to determine what interventions may be necessary (Griffin et al, 2004; Lever and Senechal, 2011).

Self-generated narratives may allow children to access specific cultural and linguistic storytelling methods that they may not be able to use when retelling stories that are pre-determined and reflective of EA cultural storytelling practices. This more open-ended story telling structure, may provide AA children the opportunity to produce narratives during narrative assessments that give more cultural and linguistic flexibility in storytelling modality.

In summary, few studies have examined the narrative development of AA preschool children. A description of story components noted in the self-generated narratives from AA preschoolers may provide a more holistic view of narrative development. Examining AA preschool narratives will help to describe language abilities, cultural and linguistic differences, and highlight what features are generally noted within the macrostructural components of self-generated narratives. By making these observations, it may provide clinicians with an awareness of differences as well as similarities of self-generated narratives when narrative samples are collected and analyzed. An understanding of this population's narrative abilities may reduce the misidentification which may be found when there is a mismatch in what is expected within the academic setting. To this end, the current study sought to answer the following question:

What are the macrostructure narrative language characteristics present in self-generated narratives produced by typically developing African American preschool children, as analyzed by the INC (Petersen et al., 2008), during a storybook writing activity within the early preschool classroom setting?

METHODS

Participants

Data were extracted from an original study which investigated a language-based approach to early writing (Hobek, 2014). During this study, an experimental group of children created their own picture books and narrated their self-generated stories to a researcher after the completion of their books over a five-month intervention period. For the purposes of the current study, the narratives of the control group of children from the original study, who did not receive the picture book writing intervention, were analyzed for developmental narrative characteristics. This control group of children produced self-generated narratives through creating and retelling picture books (see below) for a pre- and post-elicitation only. This occurred once in both January and in May.

The narratives of twenty-six African American (AA) children from the sample group, who had been enrolled in two full-day Head Start classrooms located in a single Head Start, were analyzed for this study. This program was located in a mid-sized city in the Midwest. The participants were from low income homes as determined by their gualified enrollment in a federally funded Head Start program for children living in poverty. The sample consisted of 13 boys and 13 girls ranging from 3 years, 3 months to five years, 1 month at the time of enrollment in the study. The participants were not receiving speech, language, or other educational services documented by an Individual Education Plan (IEP). All participants completed and passed Head Start mandated screenings, including speech, language, and hearing, as documented by the Head Start center.

Procedures

Eliciting Narratives. Data were collected at two different times, January and April, self-generated narratives were collected from the sample of children to compare to pre- and post-narratives from the experimental group. The following information indicates the procedures of narrative elicitation for this sample group during the original study. During these two data collection times, the children created picture books during structured writing times in the classroom. Each session was approximately 30 minutes long, which was determined by the children's decisions regarding how long they wanted to work to complete their books. The classroom teacher and a speech-language pathologist (SLP) provided individual support and developmentally appropriate instruction (Copple & Bredekamp, 2009) to guide the children to focus on the following areas: topic generation, drawing pictures, writing a message to go along with the pictures, and developing the spoken narrative of their stories.

The teacher and SLP mediated both writing forms and developing stories through side-by-side interactions with children. They began each session moving around the classroom, sitting at the table next to the children, and asking starter questions such as "What are you going to write about today?" and "What is your story going to be about?". Throughout the process of creating the books, the teacher and SLP continued moving around the classroom and sitting next to the children with the additional prompts such as "Tell me about your story", "what is going to happen next?". After finishing their stories, the children were encouraged to share them with either the teacher or SLP. The books were collected after the story creation setting and children were then asked to come into a quiet room and tell the researcher their story.

Data Collection

The children were audio recorded when they told their story to the researcher. The researcher used the prompt: "Tell me your story" and used follow-up prompts to encourage the children to tell the story. As the children were telling their stories from the book, the researcher encouraged them to continue by providing responses such as "Uh-huh" or repeating what the children said. According to Peterson and McCabe (1983), such responses encourage children to continue their spoken narratives without giving them cues regarding expectations of the narrative structure. See figure 1 for a sample product collected after the intervention session.

Data Analysis

The audio-recordings of the children's stories were transcribed and scored for analysis of spoken narrative macrostructure elements using the Index of Narrative Complexity (INC) (Petersen, et al., 2008). The INC (Peterson et al., 2008) was used to code data for the dependent variables. INC categories are weighted based on a narrative's complexity as well as its cohesion. The weight of each element as well as its importance is based on academic EA narrative styles (Peterson et al., 2008). The INC includes categories for measuring complexity such as characters, setting, initiating events, internal responses, plans, action/attempts, complications, consequences, narrator evaluations, formulaic markers, temporal markers, and causal adverbial clauses. Narrative elements such as character, initiating events, plan, and *consequence* have the highest possible weights ranging from 0 to 3 points. The remaining narrative elements setting, internal response, action/attempt, complication, narrative evaluation, and knowledge of *dialogue* have the highest weights ranging from 0 to 2 points. The macrostructure of a narrative includes its overall organizational pattern and its structural characteristics (Hughes et al., 1997). This scoring system was chosen because it allows for identifying incremental changes in the complexity of narrative skills that were useful in determining progress in development over the short duration of this study. A composite score is calculated to reflect the overall complexity of the narrative. According to Petersen et al. (2008), the INC was found to be a tool that can be scored consistently, can be used across varying elicitation formats, and has high correlations with the Test of Narrative Language (Gillam & Pearson, 2004) with good reliability. Although the preliminary

Figure 1. Sample of child's writing and spoken narrative collected for data analysis. E= the examiner's response and C= the child's response.



E January 26th. E {Child26} will you tell me about your story? C I play. $E \ Ok \ turn <> the pages when you/'re ready.$ C <I XXX and> C And I share with friend/s. C And I said, "Would you play with me please?" E Ok. C They said, "Sure". E They said sure? C Well I play/ed with them. E You play/ed with them? C And they want to play with me. E And they play/ed with you. C The end. E Wow that/'s a great story. E Is there anything else you want to tell me about your story?

E This is {child26}.

study was to assess the reliability and validity of this tool included children 6 to 9 years of age, the INC has been used with minimal modifications to demonstrate progress in preschool children's retelling skills as a result of spoken narrative intervention (Spencer & Slocum, 2010).

Reliability

All transcription, coding, and scoring was conducted by the primary investigator and four research assistants. Two research assistants were trained to score the narratives with the Index of Narrative Complexity (INC). They were provided at least four hours of scoring practice narratives. The interrater reliability was 86% for the INC total score for 10% of the narrative transcripts. When disagreement occurred, both coders reviewed the transcripts to determine an agreed-upon score.

RESULTS

The data from the participants were organized into the following age groups for analysis and scoring: 3:0-3:5 (n= 6), 3:6-3:11 (n=8), 4:0-4:5 (n=11), 4:6-4:11(n=8), 5:0-5:5(n=5). Table 1 displays the number of children and the percent of use for the INC narrative element within the age groups. Figure 2 displays the total mean narrative element scores per age group. The mean composite score increased along with the age ranges. The largest increase occurred between the age groups 3:0-3:5 and 3:6-3:11. The following sections review the information obtained for each narrative element from the INC.

Character

The mean *character* element scores ranged from 0.5 in 3:0-3:5 year olds to 2.0 in 5:0-5:5 year olds. Thirty-three percent of children age 3:0-3:5 and 100% of children age 4:0-4:5 used at least one *character* element. In summary, there was generally an increase in the mean *character* element score and the percentage of children who used at least one *character* element.

Setting

The mean setting element scores ranged from of 0.75 in 3:6-3:11 year olds to 0.4 in 5:0-5:5 year olds. The percentage of use varied across the age ranges from 62.50% in 3:6 - 3:11 year olds, 45.45% in 4:0 - 4:5 year olds, 62.50% in 4:6 - 4:11 year olds and 40% in 5:0 - 5:5 year olds. In summary, setting was not used in 3:0 - 3:5 year olds and there was variation in the means and percentages for children using at least one setting element.

Initiating Event

The mean *initiating event* element scores ranged from 0.625 in 3:5-3:11 year olds to 0.6 in 5:0-5:5 year olds. The percentage of use varied across the age ranges from 37.50% to 50.00 % of children using at least one *initiating event* element. In summary, *initiating events* was not represented in 3:0-3:5 year olds. There was variation in the means and an increase in the percentages for children using at least one *initiating event* element.

Internal Response

The mean *internal response* element scores ranged from 0.33 in 3:0-3:5 year olds to 0.2 in 5:0-5:5 year olds. The percent of use varied across the age ranges with 16.67% to 20.00% of children using at least 1 *internal response* element. In summary, *internal responses* was not represented in 4:6 – 4:11year olds. The means varied among the age groups and the percent of use increased as the age groups increased.

Plan

The mean *plan* element scores ranged from 0.25 in 3:6-3:11 year olds to 0.2 in 5:0-5:5 year olds. The percent of use scores ranged from 12.5% to 27.27% in 3:6-3:11 year olds and 5:0-5:5 year olds who used at least 1 *plan* element. In summary, *plan* was not represented at the 3:0-3:5 age group and the percent of use increased as the age groups increased.

Action/Attempt

The mean *action/attempt* element scores ranged from 0.16 in 3:0 - 3:5 year olds to 0.67 in 5:0 - 5:5year olds. The percent of use varied across the age ranges, with 9% to 50.00% of children using at least 1 *action/attempt* element. In summary, *action/attempts* were represented within all age groups. The means and percent of use scores increased as the age groups increased.

Complication

The mean *complication* element score was 0.09 in 4:6-4:11 year olds and 0.2 in the 5:0-5:5 year olds. The percent of use score was 9.09% in 4:0-4:5 year olds and 20% in 5:0-5:5 year olds. In summary, *complication* was not represented in all age groups. The mean scores and percent of use scores increased as the age groups increased.

Consequence

The mean consequences element score was 0.25 in 3:6-3:11 year olds and 4:6-4:11 year olds. The percent of children who used at least 1 narrative element in 3:6-3:11 year olds and 4:6-4:11 year olds was 25% and 12.50% respectively. In summary, consequences

was not represented in the all age groups. The mean and percent of use scores were the same in 3:6 - 3:11 year olds and 4:6 - 4:11 year olds.

Narrator Evaluation

The mean *narrator evaluation element score was* 0.25 in 3:6 - 3:11 year olds and 4:6 - 4:11 year olds. The percent of use was the same in 3:6 - 3:11 year olds and 5:0 - 5:5 year olds with 12.50% of children using at least 1 *narrator evaluation* element. In summary, *narrator evaluation* was not represented in all age groups. The mean and percent of use scores were the same in 3:6 - 3:11 year olds and 4:6 - 4:11 year olds.

Knowledge of Dialogue

The mean knowledge of dialogue score was 0.12 in 3:6 - 3:11 year olds, 0.18 in 4:0 - 4:5 year olds, 0.38 in 4.6 - 4:11 year olds and 0.17 in 5:0 - 5:5 year olds. The percent of use was 12.50% in 3:6 - 3:11 year olds, 18.18% in 4:0 - 4:5 year olds, 25.00% in 4:6 - 4:11 year olds, and 20.00% in 5:0 - 5:5 year olds who used 1 knowledge of dialogue element. In summary, knowledge of dialogue was not represented in 3:0 - 3:5 year olds. The percent of use varied across the age ranges, from 12.50% to 25.00% of children using at least 1 knowledge of dialogue element. The mean scores increased in all age groups, however, there was a decrease in 5:0 - 5:5 year olds.

Overall, 3:0 - 3:5 year old participants used at least one narrative element within their self-generated story within the categories of character, internal response, and action/attempt. By age 5:5, each narrative element had at least 12.50% usage and increased in density of characters, setting, initiating events, internal responses, plans, action/attempts, complications, consequences, and narrator evaluations. There were narrative elements that appeared to generally increase within the later age ranges such as *charac*ter, setting, action/attempts, and knowledge of dia*logue*. There were also narrative elements that did not appear to increase with age such as complication and *narrator evaluation*. Surprisingly, more narrative element categories, percentage of usage, and intricacy of narratives were found in 4:0 - 4:5 and 4:6-4:11 year olds than 5:0-5:5 year olds.

Table 1. Number of children using the story grammar element at least once and percent of children who included INC story coding element in their narratives.

	Age Group									
	3:0-3:5		3:6-3:11		4:0-4:5		4:6-4:11		5:0-5:5	
	n(6)	%	n(8) %		n(11) %		n(8) %		n(5) %	
Character	2	33	6	75	11	100	7	87.5	5	100
Setting	0	0	5	62.5	5	45.4	5	62.5	2	40
Initiating Event	0	0	3	37.5	4	36.3	4	50.0	2	40
Internal Response	1	16.6	2	25.0	1	9.0	0	0	1	20
Plan	0	0	2	25.0	3	27.2	1	12.5	1	20
Action/Attempt	1	16.6	4	50.0	5	45.4	4	50.0	3	60
Complication	0	0	0	0	1	9	0	0	1	20
Consequence	0	0	2	25	0	0	1	12.5	0	0
Narrator Evaluation	0	0	1	12.5	0	0	1	12.5	0	0
*KOD	0	0	1	12.5	2	9	2	25.0	1	20

KOD=knowledge of dialogue





DISCUSSION

This study described macrostructure characteristics of retells from self-generated picture books created by AA preschoolers between the ages of 3:0 - 5:5 as evaluated by the INC (Peterson et al., 2008). Our goal was to determine what macrostructure narrative language characteristics were present in self-generated narratives produced by typically developing AA preschool children. Our results were analyzed by the INC (Petersen et al., 2008), during a storybook writing activity within the early preschool classroom setting.

The current study found developmental progression in the mean number of narrative elements as well as the percentages of AA children using macrostructure elements from the ages of 3:0 to 5:5 years old. Changes in narrative development were marked by an increase in numbers of macrostructure elements used, as well as an increase in complexity of the macrostructure elements as our participants matured.

Our results were supported by previous studies showing developmental progression in the macrostructure complexity of preschoolers' spoken narratives (Curenton & Justice, 2004; Khan, Gugiu, Justice, & Bowles, 2016; Price et al., 2006). For example, a study conducted by Khan et al. (2016) examined age-related progressions on individual story-structure components in young children's narratives. The researchers found a developmental trend when analyzing narrative episode-structure (e.g. setting, goal, conventional ending) in children (73% white) from ages 3 to 6 years.

Macrostructure of Self-Generated Picture Books

We described narrative abilities at varying age groups through macrostructure elements as analyzed by the INC. At the 3:0-3:5 age group the narrative elements setting, initiating events, plan, complication, consequence, narrator evaluation, and knowledge of the dialogue were absent. Most of the narrative elements that were absent at 3:0-3:5 began to emerge within the 3:6-3:11 age group, with the exception of complication. The children continued to use many of these elements across the age groups; however, each element was not always represented. From one age range to the next, there were more narrative elements used as well as increases in complexity of use resulting in higher means and percentage points as the ages increased. There were, however, variations in the narrative elements used within a given age range. There were also variations in INC points awarded to individual children among all ages. Within some age groups there were only one or two children using a given narrative element; however, because the INC awards additional points for the complexity of a narrative element, higher percentages and means were awarded for a given age group. We expected an increase in narrative element use as the age groups progressed; however, we did not expect the 4:0-4:5 and the 4:6-4-11 age groups to use more complex narrative elements than the 5:0-5:5 age group resulting in a higher percent of narrative element use. We believe these results were due to the limited number of participants within the 5:0 -5.5 age group as well as the variation in the nature of the task.

We found that children in our study were able to judge story structure requirements needed to allow the listener to understand the narrative even though all narrative structure skills had not been mastered. This was similar to Hudson and Shapiro (1991), who found that narrative elements demonstrate children's ability to understand early judgment of story structure requirements. These abilities became more apparent as the children within their study matured. In addition, our study found that the narrative elements plans and consequences usage increased with age. Although there was some variation among the age groups, consequences increased with an increase in age as well. According to the INC, these elements demonstrate how children within our study understand the intent to act on or solve initiating events (plan) and resolving the problem or not resolving the problem (consequences) within narratives. These findings were similar to those of Hudson and Shapiro (1991) who found story grammar elements such as those demonstrating plans of characters, *causality*, and consequences were correlated with an increase in age. These findings may indicate that self-generated stories of typical developing AA children contain the same elements that help to identify the abilities of typical developing EA children who tell stories via varying methods.

African American Self-generated Stories and Story Retells

When interpreting the results of our study, we found that AA preschool children most frequently used the story grammar elements of character, setting, initiating event and action/attempt when producing self-generated narratives. These story grammar elements are consistent with expectations of story structure levels typical of preschool children in producing a descriptive sequence, action sequence or a reactive sequence that include characters, surroundings, and actions without clear goal-directed behaviors (Hughes et al., 1997; Table 4.3 p. 121). Our findings are similar to other study findings regarding development of story grammar elements found within story retells elicited from AA preschoolers (Curenton & Justice, 2004; Price et al., 2006; McGregor, 2000). Upon further review, however, we found some specific similarities and differences in the rate of occurrence of story grammar elements from our study on self-generated stories to others with story retells. Some of the similarities that were found included the use of character and internal response in self-generated and retelling of stories. For example, our study's results for the narrative element character was 100% for the 4:0 - 4:5 age group and 87.5% for the 5:0 -5:5 age group. These results were similar to those of Price et al. (2006) who conducted a study describing AA children's narrative retell abilities at 4 years old (M=48.2 months) and at kindergarten entry (M=62.6 months), as well as McGregor (2000) who conducted a study describing AA children's narrative retell abilities of 3, 4, and 5 year olds. The percent use of *char*acter in story retells for Price et al. (2006) was 95.5% of 4 year olds (4:2) and 97% by kindergarten entry (5:2). The children in the McGregor (2000) used character for 4 year olds at 85% and 90% at 5 years old.

Our study found *internal response* was used by 9.09% of 4:0 - 4:5 year olds and 20.00% of 5:0 - 5:5 years old. These findings for this narrative element was similar to what Price et al. (2006) found with 4.5% used by 4 year olds and 21.2% by kindergarten entry. From this information, we can note that AA preschool children demonstrate an understanding of including characters in their stories, and are developing in the use of the psychological states of these characters just as they do from other story retells.

In contrast, there were some differences from our study's story grammar element development in self-generated narratives than there were in the story retelling research of AA children. For example, the narrative element setting was used by 40% of the 5:0 - 5:5 year olds in our study. The structural element setting was used by 90% of 5 year olds in the McGregor study. There were also differences in the narrative element knowledge of dialogue, which was used by 20% of the 5:0 - 5:5 year olds in our study. A similar narrative element *dialogue* was used by 40% of 5 year olds in the McGregor study. These differences in percent use of *setting* and *dialogue* may be due to the differences in the methods of elicitation between our study and the McGregor study. In the McGregor study the examiner asked the participants to narrate the story Corduroy from a storybook that they had viewed as a video story on several occasions (McGregor, 2000). This particular story had both *setting* and *dialogue* that was already created in which participants would only have to recall. In our study the participants' narratives were elicited following a classroom writing activity. The participants were instructed to write stories by creating books through drawing and print. Once the storybooks were created, the participants were asked to tell the story. It may be the case that with self-generated narratives, in which story grammar elements need to be created, the development of some story grammar elements will occur at older age ranges than the same story grammar elements of story retells.

Finally, there was variation in the production of *initiating events*. For our study, *initiating events* were used by 36.3% of the 4:0 - 4:5 age group and 40% of the 5:0 – 5:5 age group. In the McGregor (2000) study, the description of the narrative element *complicat*ing actions, defined as the problem facing the main characters, was similar in definition to the initiating events for our study. The structural element complicating action was used by 35% of 4-year-olds and 50% of 5-year-olds in the McGregor study, which is consistent with the results of our study. In contrast, Price et al. (2006) found that initiating events were used by 6% of 4-year-olds and 20% at kindergarten entry. These differences are more difficult to interpret; however, all three elicitation procedures varied from one another. According to Peterson and McCabe (1983), caution should be taken when measuring and interpreting children's narratives, as the elicitation context can affect the story produced and that the topic of discourse may also influence length and complexity of the narratives. Production of narratives may be influenced by interest level of the task. For example, in the Price et al. (2006) study, the narratives were elicited by a short, standardized narrative assessment, created for the purpose of eliciting narratives (Bus Story Language Test; Refrew, 1991); however, the narratives in the McGregor (2000) study were elicited from an authentic picture book, Corduroy, which had also been viewed as a video on several occasions by the children. It could be assumed that watching videos and retelling from a children's picture book, may be more engaging than retelling from a standardized tool. In our study, with the elicitation method of self-generated stories, the child may be more able and motivated to create a "problem" (initi*ating event*) to their own story as there is freedom to create events, as opposed to relying on memory to recall a specific problem of a story. According to a study by Swanson, Fey, Mills, and Hood (2005), the child's willingness to participate in the tasks (story retell, story generation, and sentence imitation) influenced the production of stories. The authors concluded that story generation was favored by all of the children because "they could talk about their own experiences, knowledge and interests" and "they did not have a specific story they were supposed to replicate" (p. 139).

Our result showed that self-generated narratives may provide an opportunity for children to generate elements on their own without the increased cognitive load from the attempts to retell a previously presented story. Generating story elements is important for having a true representation of the children's story telling abilities that may reduce the need to rely on memory. However, these self-generated narratives need to be interpreted with caution, as there may be some differences if compared with the results of narratives elicited from story retells. In addition, self-generated narratives can be a method of eliciting narratives that assist in increasing the connection with culture. Because previous research has shown AA children have more experience with oral storytelling (Champion; 1999, 2003; McGregor, 2000; Price et al., 2006; Terry et al., 2013), self-generated narratives may provide a better framework for connecting to cultural and linguistic methods that give more flexibility to storytelling modality (Champion, 1998; Champion et al., 1999; Merritt & Liles, 1989; Southwood & Russell, 2004).

Limitations and Future Research

Although the results of this investigation provide valuable information about self-generated narratives in AA preschool children, there are limitations. First, the sample size was small and there was an unequal distribution of children within each age range making generalizations difficult. Second, there were substantial variations among each age group and between individuals within the same age group making the ability to make normative conclusions a challenge regarding self-generated narratives of preschool children. Furthermore, the self-generated narratives from the children in our study were elicited in a classroom during an instructional activity. Researchers have noted that methods of elicitation may impact narrative production. Lastly, the INC was not designed for preschool children but for children who are school age.

Future research should focus on comparing AA children's narrative macrostructure use from storybook retells to self-generated narratives. In addition, it would be interesting to note if self-generated narratives can identify cultural and linguistic differences of AA preschoolers within the population that may not be noted when using tools that are used with EA children. It would also be interesting to determine if there are cultural and linguistic differences that may be noted when comparing self-generated narratives of AA preschoolers and EA preschoolers.

CONCLUSION

Based on our findings, self-generated storytelling appears to be a sound method for eliciting narratives and describing the developmental progression of AA preschool children. AA preschool children's narrative skills showed occurrences of causality, understanding of behaviors and goals, as well as social and psychological stages found in the macrostructure used within their narratives. Self-generated narratives may also provide a better platform for making cultural and linguistic connections because the children are creating their own story from their own experiences.

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COVID-19 AND THE MAD DASH TO TELEPRACTICE:

A TUTORIAL TO ESTABLISH COMMUNITY-BASED TELEREHABILITATION FOR APHASIA USING WEBEX VIDEOCONFERENCING

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— ABSTRACT —

Telepractice is an approach that has been used successfully to treat acute stroke in individuals residing in rural communities. Yet until very recently, progress in the use of telepractice approaches for aphasia has been slow to emerge. However, the recent COVID-19 pandemic has forced the field of Speech-Language Pathology (SLP) to rapidly develop and implement new models of service provision and particularly in the area of aphasia rehabilitation. A wealth of research has shown that telepractice approaches for aphasia rehabilitation or "telerehabilitation" can be utilized to provide evidenced-based treatment for aphasia while overcoming access to care issues for individuals with aphasia. Such approaches have never been so urgently needed given the dramatically changing landscape in field of SLP since the emergence of COVID-19 in the US. In this tutorial we describe the use of WebEx, a videoconferencing program, as one potential approach to provide comprehensive aphasia telerehabilitation treatment in a community-based setting.

Key words: aphasia, speech-language pathology, telerehabilitation

BACKGROUND

Aphasia is a disorder that occurs after stroke that reduces a stroke survivor's communication ability (language comprehension, language expression, reading, writing, attention, cognition) and frequently requires rehabilitative care (American Speech-Language-Hearing Association, 2018). A recent study showed that approximately 18% of individuals discharged from US hospitals with a primary diagnosis of stroke have aphasia (Ellis, Hardy, Lindrooth & Peach, 2017). Estimates indicate that more than 2.5 million Americans are currently living with aphasia (Simmons-Mackie, 2018). Aphasia is independently associated with worse stroke outcomes, and patients with aphasia experience longer hospital lengths of stay and at greater costs of care (Boehme, Martin-Schild, Marshall & Lazar, 2016; Lazar & Boehme, 2017). Individuals with aphasia require speech-language pathology services (along with physical therapy and occupational therapy) to have the best opportunity for a successful recovery.

Limited Rehabilitation Services in Rural Areas

Many individuals with aphasia who reside in rural areas have limited access to speech-language and other rehabilitation services. Speech-language service providers in rural regions are limited due to high vacancy rates, high turnover rates and lengthy delays in hiring speech-language pathologists (SLPs) (Brome, 2010). To accommodate the healthcare needs of individuals residing in rural areas, telemedicine approaches have been proposed as an approach to offer speech-language services (telerehabilitation) (Theodoros, 2008). Telemedicine approaches for speech-language services can offer individuals with aphasia: (a) equitable access to services, (b) greater time efficiency for the SLP and patients, (c) improved client focus due to increased frequency and intensity of treatment, (d) improved caseload management for clinicians and (e) reduced treatment costs and travel expenses (Hill & Miller, 2012). Evidence also suggests that telemedicine approaches can improve functional outcomes and enhance patient satisfaction and quality of life (McCue, Fairman, & Pramuka, 2010).

Utilization of Telepractice Approaches For Treatment of Aphasia

Telepractice, or the application of telemedicine technologies to provide rehabilitation treatments, has been shown to be efficacious in offering distant speech-language services to patients with aphasia, stuttering, voice disorders, laryngectomy, and swallowing (Cherney & van Vuuren, 2012; Theodoros, 2008; Weidner & Lowman, 2020). Studies outside of the US have shown that telepractice approaches can be utilized to reduce service inequities among individuals residing in rural areas (Bradford, Caffery, & Smith, 2016; Fairweather, Lincoln & Ramsden, 2016). A recent comprehensive review of telepractice approaches for adult speech-language services indicated that they may be successfully utilized to treat aphasia as well as other conditions such as primary progressive aphasia, dysphagia and communication disorders associated with Parkinson's disease. (Weidner & Loman, 2020). Regarding aphasia specially, Georgeadis, Brennan, Barker and Baron examined the impact of telerehabilitation compared to face-toface treatment of story retelling among adults with left and right hemisphere stroke and TBI (Georgeadis, Brennan, Barker & Baron, 2005). The telerehabilitation was administered in a separate room but in the same building as the clinician, and results showed that there were no significant differences in outcomes between the face-to-face and the telerehabilitation delivery. Dechene and colleagues examined an in-home telerehabilitation approach with three patients with aphasia to improve naming (Dechene, et al., 2013). Patients demonstrated improvement in confrontational naming (naming pictures) and reported satisfaction with the approach. Although these preliminary studies demonstrate the potential use of telerehabilitation for speech-language services after stroke, overall the use of telerehabilitation for the treatment of aphasia has been slow to evolve. Additionally, the use of telerehabilitation as an approach for comprehensive aphasia treatment that addresses more than one language domain (expression, comprehension, reading, etc) has yet to emerge.

The COVID-19 Pandemic and Urgent Need to Establish Telepractice Programs

In December 2019, no one could have seen how the coronavirus 2019 or COVID-19 (aka: novel coronavirus) pandemic would change the landscape of SLP service provision for conditions like aphasia. It was at this time that China reported a cluster of cases of pneumonia of an unknown cause. These cases were later diagnosed coronavirus disease (McMichael et al, 2020). In January 2020, the first case of COVID-19 was diagnosed in the US followed by a major outbreak of cases in Seattle, Washington in February, 2020 (McMichael et al, 2020). Since then, Americans have become very familiar with COVID-19 as many states have issued shelter-in-place mandates and required "social distancing" (physical distancing/physical separation) to limit the community spread of the contagious virus (Haffajee & Melo, 2020). Persons at high risk for severe illness from COVID-19 are those 65 years and older; those residing in nursing homes; people of all ages with underlying medical conditions such as moderate to severe asthma, serious heart conditions, diabetes, and persons who are immunocompromised (CDC, 2020). To date, the healthcare systems in cities like Seattle, New York, Los Angeles and New Orleans have been devastated by the sheer number of individuals with COVID-19 and the associated deaths. Moreover, early findings suggest that in some areas of the US, African Americans are contracting and dying from COVID-19 at higher rates than other racial/ethnic groups (Johnson & Buford, 2020).

Hospitals have not been alone in their significant burden. The rehabilitation disciplines like Speech-Language Pathology (SLP) have all become overwhelmed by the impact of social-distancing and shelter-in-place mandates that limit the human interaction; the centerpiece of rehabilitation. Not only providers, but also training programs have needed to seek alternative service delivery models such as telepractice to ensure individuals with communication disorders continue to receive the care they so desperately require to improve their communication abilities (American Speech Language Hearing Association, 2020a). Similarly, major healthcare plans who have been resistant to the reimbursement of telepractice approaches have changed course during the COVID-19 pandemic to extend reimbursement for telepractice approaches for the field (American Speech Language Hearing Association, 2020b).

The American Speech Language and Hearing Association has offered a substantial amount of information regarding telepractice approaches during this time of dramatic service provision reform (American Speech Language Hearing Association, 2020c). General guidelines to help clinicians get started with telepractice approaches have been made available (Andricks & Smith, 2020). Yet for some who are new to telepractice and teleconferencing in general, additional information is needed. Therefore, the purpose of this paper is to provide a template for the development and provision of SLP services via telepractice for aphasia rehabilitation using the WebEx teleconferencing program. WebEx is HIPPA compliant and offers a range of features needed for successful telepractice. This paper was designed to offer clinicians core information regarding the establishment of an aphasia telerehabilitation program particularly in light of the significant pressure being placed on clinicians to establish telepractice programs in the context of COVID-19. See Table 1 for a summary of key definitions related to the tutorial's contents.

<u>Aphasia Telerehabilitation Platform</u>: WebEx (<u>http://www.webex.com/</u>) is a cloud-based videocon-

ferencing program that allows real-time exchange of video and audio for individuals at a distant location via a secure internet connection. WebEx offers both full-screen and side-by-side sharing views which allow the clinician and client collaborative sharing for the administration of aphasia treatment (See Figure 1).

Figure 1. Depiction of Client's Active View of WebEx Aphasia Telerehabilitation Session



The collaborative sharing feature provides a means for the clinician to share and utilize the treatment materials required for the administration of the aphasia treatment. WebEx also allows the client to see the clinician and treatment stimuli simultaneously, thereby enhancing the patient's experience similar to in-person treatment. Additionally, the features of WebEx allow treatment provision via a laptop computer in a community setting.

Traditional Telerehabilitation Approach

<u>Aphasia Pre-Treatment Evaluation</u>: Aphasia client evaluations are completed prior to commencing telerehabilitation services at the treatment administration site. Traditional pretreatment evaluation procedures are completed which include: a comprehensive aphasia evaluation, a functional communication measure, a motor speech examination and a measure of telerehabilitation treatment credibility. The evaluator must decide whether the individual with aphasia is a candidate for aphasia telerehabilitation based on a range of factors including: aphasia severity, extent of treatment needs, transportation availability to a remote treatment site and willingness/ability to receive treatment via telerehabilitation at a remote treatment site.

<u>Telepractice Connection between Treatment Ad-</u> <u>ministration Site and Remote Treatment Site</u>: Clients report to the remote treatment site at the scheduled day and time (See Figure 2).





Clients are met at the remote treatment site by a student facilitator who leads them to the treatment room. Student facilitators are either master's level or doctoral level students enrolled in a communication sciences and disorders program. Student facilitators serve a primary role to connect with the treatment administration site via WebEx and troubleshoot any observed problems.

The clinician at the treatment administration site logs into WebEx via a university defined login process using a username and password. Once logged in, the clinician at the treatment administration site starts the treatment session by starting a "WebEx meeting" by pressing the start meeting button. After the WebEx meeting is started, the treatment administration site initiates the connection with the remote treatment site by using the WebEx invite function. The WebEx invite function allows entry of an email address to invite participants to a meeting initiated by the treating clinician at the treatment administration site.

To create an efficient, consistent process for connection with the treatment site, the team uses a Gmail email account, specifically created for the telerehabilitation project to send out session invitations. The invite from the treatment administration site is transmitted and received in the Gmail account created for the project. The email inviting the remote treatment site to a WebEx meeting is then received and the student facilitator opens the email and clicks the "start meeting" button. A connection is initiated with the treatment administration site and the session then begins.

<u>Treatment Approach</u>: The general aphasia treatment approach used was the Language-Oriented Treatment (LOT) (Bandur & Shewan, 2008; Shewan & Bandur, 1986). LOT is designed to address a range of language issues among individuals with aphasia. The LOT approach is highly structured and offers important advantages with regard to treatment fidelity and replication. Treatment targets for receptive deficits include: improving discrimination of speech sounds, improving access to word meanings and changing the individual's communication environment to support auditory comprehension. Treatment targets for expressive deficits include: semantic processing (e.g., semantic cueing, semantic judgments, categorization and word-to-picture matching) and accessing phonological word forms such as phonemic cueing, cueing spoken output with written letters, repetition and reading aloud. Treatment materials are identified and created to address receptive and expressive skills as outlined in LOT.

Screen share feature: Specific treatment tasks for aphasia are administered via the WebEx sharescreen feature. The share-screen feature allows the use of internet websites or materials created specifically for the unique needs of the client. WebEx's interface offers two options to initiate screen sharing. The first option is found on the WebEx's top toolbar, which screen sharing is accessed by selecting the tab entitled "Share" and then "My Screen" (WebEx, 2018). The second option for initiating screen sharing is found among the several meeting controls, found on the bottom, center of the screen. These meeting controls are hidden when not in use and then appear again when the user's cursor is moved (Cisco WebEx, 2018). Among these controls, the "Share content" button can be initiated by selecting the corresponding up-arrow labeled icon. When selected, the "Share content" button displays a thumbnail view of active screens and available applications from the meeting's host computer (Cisco, 2018). At any point during the session, the meeting's host can discontinue screen sharing. The screen sharing utility offers clinicians the capability of using a variety of resources during the therapy session that otherwise may not be accessible on the remote treatment site's computer (Cisco WebEx, 2018). This feature allows the clinician a plethora of options for the provision of individualized treatment, to address the unique difficulties experienced by each client.

Some patients also have related motor speech production disorders (apraxia and dysarthria) that result in difficulty producing speech due to muscle weakness, incoordination and sequenced movements (Duffy, 2005). Although motor speech disorders are not the primary focus of the telerehabilitation treatment, treatment of motor speech production disorders are guided by the Mayo Clinic approach for treatment of motor speech disorders, which is a systematic treatment approach that emphasizes: (a) slowing the rate of speech, (b) improving the breath support to enhance loudness and (c) increasing tongue and lip movement. Aphasia telerehabilitation treatment sessions typically lasted 45-60 minutes.

Aphasia Post-Treatment Evaluation: Post-treatment client evaluations is completed at either the treatment administration site or the remote treatment site. The comprehensive aphasia evaluation, functional communication measure, and motor speech examination are completed post-treatment. In addition, treatment acceptability, credibility and satisfaction scales are completed (Atkinson & Greenfiled, 2004; Devilly & Brokovec, 2000). Finally, a post-treatment exit interview is completed to allow patients and family members to provide their perceptions of the benefits (or harms) of the clinical methods applied and their perceptions of how to more effectively deliver the telerehabilitation treatments.

Computer and internet specifications: The aphasia telerehabilitation treatment is provided via Lenova Thinkpad T570 laptop computers at both the aphasia treatment site and the aphasia remote site. The ThinkPad computers have Intel Core i7-7600U Processors with a 15.6 full high definition FHD (1920x1080) display screen. The computers operate with Windows 10 64-bit operating systems. Both sites use internal computer microphones and speakers. WebEx recommends broadband/high speed internet with minimum connections of 1.5mbps minimum/3mbps. The minimum internet specifications are available at both sites.

<u>Troubleshooting</u>: Problems occurring during the telerehabilitation process have been primarily limited to internet connectivity issues, prompting poor audio and video transmissions. On occasion, the in-

ternet is down or running at slower speeds at the remote sites. In such cases, the student facilitator can reconnect to WebEx using an IPhone hotspot or dedicated hotspot device purchased for the project. Similarly, slower than usual internet speed can also result in poor video quality or signal buffering requiring the same approach for resolution. Finally, when the video does not connect automatically, the video is connected using the video symbol in the lower center portion of the screen. Audio problems occur on occasion and are related to the audio not connecting automatically. In such cases, the audio connection is connected using the audio symbol in the lower center portion of the screen. Whether video or audio connection issues, the treating clinician at the treatment administration site can see the absence of audio or video connection in the "Participants" panel on the right side of the screen. Finally, WebEx has a chat function which allows the two sites to communicate even in the absence of audio and video connections. Additional minor issues may arise that are specific to the host and remote settings, such as placement of seating to optimize natural and artificial lighting and consideration of surrounding environment of both sites to minimize noise distractions.

DISCUSSION

This tutorial has discussed the potential use of WebEx to provide comprehensive aphasia treatment in a telerehabilitation format. The process described here could easily be restructured using other HIP-PA compliant teleconferencing programs given that most have very similar features. Additionally, the process could be tailored to a home environment where the facilitator at the community-based site could easily be replaced by a caregiver at the client's home. The benefits of operating a telerehabilitation program from a community-based site is to promote reintegration to social contexts. When this is not an option, or the client is not yet ready to reintegrate socially, this approach can be applied to the home setting. Not to be lost in this discussion is the fact that graduate student clinicians-in-training at university programs can use WebEx to provide telerehabilitation services to clients with aphasia and thus meet portions of their academic clinical education requirements. In summary, the use of telerehabilitation has the potential to reduce: a) delays in receiving services, b) the inconvenience of accessing services at distant urban facilities and c) costs to patients related to travel to receive services, particularly among rural residing residents. Early evidence shows that individuals with aphasia are satisfied with receiving aphasia treatment via telerehabilitation approaches and believe that it is an acceptable and credible approach to treatment. Finally, we believe that telerehabilitation offers a safe and viable service delivery option for persons with aphasia and speech-language pathologists in the face of the COVID-19 pandemic.

ACKNOWLEDGEMENTS

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

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Table 1. Key Definitions

Terms	Definitions
Aphasia	Language disorder resulting from stroke or other neurological disorder or injury
Language Oriented Treatment	Language focused approach to the treatment of aphasia
Remote Treatment Site	Location where client with aphasia goes to receive treatment from a treating therapist at the treatment administration site.
Telerehabilitation	Use of technology that allows a clinician to provide rehabilita- tion services to a client at a different location
Treatment Acceptability	Client's report of acceptance of a treatment
Treatment Credibility	Client's report of whether a treatment approach is credible
Treatment Administration Site	Location where treating therapist will administer aphasia treatment via WebEx to a client with aphasia who is at a dif- ferent (remote) location
Treatment Satisfaction	Client's report of satisfaction with treatment
Videoconferencing	Transmission of video and audio via the internet that allows video and audio communication between two different locations
WebEx	Videoconferencing program used to provide aphasia telereha- bilitation treatment
WebEx Remind & Invite	WebEx videoconferencing feature that is sent to the remote treatment site to allow videoconference connection with treat- ment administration site
WebEx Screen Sharing	WebEx videoconferencing feature that allows the treating ther- apist to share the contents of their screen with the client with aphasia at the remote treatment site

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