ASSESSING HEALTH RELATED QUALITY OF LIFE, LANGUAGE IMPAIRMENT,

AND PSYCHOSOCIAL FACTORS IN POST-STROKE APHASIA

by

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ABSTRACT

Aphasia, an impairment of language comprehension and production typically due to an acquired brain injury or stroke, has been shown to negatively impact an individual's quality of life (Hilari, Needle, & Harrison, 2012). It has also been shown that people with aphasia (PWA) have an increased risk of developing depression (Kauhanen et al., 2000). There are few current assessments or screening tools which focus on depression in aphasia and the relationship between mood disorders and prognosis for language recovery. This type of screening tool is critical to identify a PWA's susceptibility for depression because depression elongates and/or prevents language recovery (Hackett & Anderson, 2005). To develop a more patient-centered quality of life screening measure, a focus group with PWA was planned. Participants would have been asked questions on their health-related quality of life based on physical, psychosocial and language impairment influences, and shared their opinions on what most impacted their quality of life post-stroke. Based on this information, questions were planned to be implemented as part of a brief quality of life screening tool specific to stroke survivors with aphasia. It is hoped that this screening tool will be used by speech-language pathologists to refer stroke survivors with aphasia to the correct mental health services as early as possible in the recovery process.

DEDICATION

For my uncle, a stroke survivor with aphasia.

Eric Palangas

1966-2015

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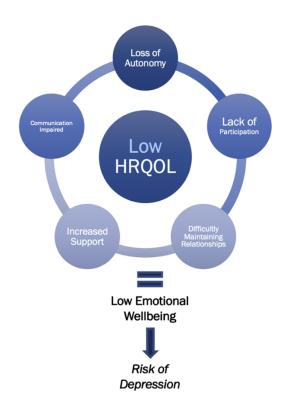
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INTRODUCTION

In the United States, approximately 795,000 strokes occur annually. In 2017, an estimated 140,000 Americans died from stroke, making it the fifth leading cause of death in the United States (CDC, 2017). Globally, in 2013 there were 6.5 million stroke deaths, making stroke the second-leading cause of death behind ischemic heart disease (Benjamin et al., 2017). Stroke survivors who sustain significant brain damage often live with chronic disability or impairment (NIDCD, 2019). It has been estimated that onethird of stroke survivors will develop aphasia (Engelter et al., 2006). Aphasia is an impairment of language due to damage to frontal or temporal brain areas typically in the left hemisphere. Aphasia impairs multiple aspects of a person's ability to communicate and has varying levels of severity. For example, aphasia can impact language comprehension, spoken language expression, as well as reading and writing. In the United States, one million people are currently living with aphasia. Current research suggests that aphasia can negatively impact a person's health related quality of life (HRQOL; Hilari, Cruice, Sorin-Peters, Worrall, 2015). HRQOL for a person with aphasia (PWA) is defined as that individual's overall success in performing daily activities and living independently (Brown, Davidson, Howe, & Worrall, 2011).

The factors associated with quality of life in stroke survivors are autonomy, participation in daily activities, maintaining meaningful relationships, support from caregivers and medical staff, and effective communication (Brown, Davidson, Howe, & Worrall, 2011). When someone develops aphasia, HRQOL is lowered due to the loss of autonomy, lack of participation, difficulty in maintaining relationships, a need for

increased support, and impaired communication (see Figure 1). A low HRQOL results in poorer emotional well-being, which poses a risk for depression. People with aphasia are known to have an increased risk of developing depression (Engelter et al., 2006). In fact, one-third of stroke strokes were found to be depressed within 5 years after their stroke (Kauhanen et al., 2000). With this increased risk of depression for stroke survivors, it is critical to identify a person with aphasia's susceptibility for depression. Depression elongates and can potentially prevent language recovery (Hackett & Anderson, 2005). Figure 1. Factors contributing to low health related quality of life in post-stroke aphasia.



In a recent study, speech-language pathologists in the United Kingdom were surveyed about their views on the importance and role of psychosocial effects in PWA. They strongly agreed that managing these factors is important for the success of interventions for PWA (Brumfitt, 2009). In another recent large-scale survey conducted in the United Kingdom, it was found that SLPs strongly agreed that PWA's psychological well-being should be addressed during treatment so that these individuals can be referred to appropriate mental health services (Northcott, Simpson, Moss, Ahmed, & Hilari, 2017).

Communication deficits have been demonstrated to be associated with depression and therefore, by inference, with quality of life (QOL). However, any direct relationship between communication involvement and QOL remains unestablished. Many researchers have examined QOL in stroke survivors but have not been able to demonstrate a direct relationship. However, standard QOL measures do not routinely include items that are communication dependent.

The goal of this thesis is to examine how psychosocial and emotional factors, such as depression, impact a stroke survivor's language recovery and how this relationship can be better understood through the development of a quality of life screening tool specific to stroke survivors with aphasia. Currently, SLPs utilize multiple assessments to screen for mood, depression and HRQOL. By developing a single screening tool which encompasses all of these domains, an SLP can more easily facilitate a PWA's access to educational and mental health services if needed.

Health-Related Quality of Life

HRQOL for a person with aphasia (PWA) is defined as that individual's overall success in performing daily activities and living independently. This definition is derived from a meta-analysis of qualitative studies conducted with PWA, caregivers, and speechlanguage pathologists to synthesize overarching themes of HRQOL in this population. A positive HRQOL includes effective communication, autonomy, participation in daily activities, meaningful relationships, and support (Brown, Davidson, Howe, & Worrall,

2011). When aphasia occurs, it can negatively affect QOL. When communication is impaired, a PWA begins to lose their independence and experience negative effects on their emotional well-being. The loss of independence makes it difficult for a PWA to participate in daily activities which then affects their ability to maintain meaningful relationships. PWA also require more support to combat their lowered HRQOL.

In a study by Lam and Wodchis (2010), residents in a long-term care hospital were asked to rate which of several health conditions had the greatest impact on their quality of life. Neurological diseases were among those rated with the greatest impact on HRQOL, with aphasia having the largest negative relationship. In fact, aphasia was rated among the most harmful health conditions such as cancer.

Using current HRQOL diagnostic tests and scales, Chou (2015) assessed stroke survivors to find common determinants of HRQOL. The author identified strong relationships between HRQOL and the following factors: psychosocial well-being, number of strokes, enrollment in rehabilitation therapy, and socio-demographics. Among psychosocial factors, social participation was found to be the strongest determinant of HRQOL, most likely influenced by how much communication is affected post-stroke. A factor shown to improve HRQOL in stroke survivors was their enrollment in rehabilitation therapy delivered positively and consistently. Socio-demographic factors also influenced HRQOL in stroke survivors, including a person's social role, family role, and work involvement. These factors are highly related to the psychosocial factors mentioned previously. As a result, if a PWA has greater family and work involvement, their psychosocial well-being is positively impacted.

In a study of participants with mild to moderate chronic aphasia conducted by Cruice, Worrall, and Hickson (2010), individuals were personally interviewed to identify domains of QOL. The goal of this study was to utilize the individual's perspective, not the examiner's perspective, to conceptualize which QOL factors are most relevant. Ten main factors were found to influence QOL. The first four domains were the core of a PWA's QOL: activities, verbal communication, people, and body functioning. Activities included work, personal interests, entertainment, social functions, domestic duties, sports, literacy, and trips. Crucially, almost all of these activities require some form of communication. PWA also described communication to be difficult due to their difficulty producing and understanding language. Importantly, this study also highlights the crucial role of an SLP in providing the support and education a PWA needs to utilize their communicative strengths to be successful in their daily activities.

Mental Health

An inability to communicate effectively has a negative impact on PWA. Negative effects stemming from the inability to communicate impact an individual's emotional well-being. The negative impact of a communication impairment also hinders successful performance of daily activities. This loss of autonomy can lead to further problems for PWA, such as adverse effects on social and emotional well-being. Social factors, such as social support and isolation, and emotional status, such as distress and depression, influence these individuals' HRQOL. Several studies have shown that lower scores on measures of language and overall mood correlate with low HRQOL.

It is well-established that PWA have an increased risk of developing depression (Kauhanen et al., 2000). In fact, almost one-third of stroke survivors were found to be

depressed in a five-year period post-stroke (Hackett, Yapa, Parag, & Anderson, 2005). Losing the ability to communicate as an adult has negative consequences for emotional well-being and social interactions. Speech-language pathologists (SLPs) have an important role of referring PWA to the correct mental health services as part of the treatment process. Since PWA are at risk for depression, a speech-language pathologist may need to identify warning signs through an initial screening.

In a recent study, Galligan, Hevey, Coen, and Harbison (2016) analyzed the association between psychological and physical factors in stroke survivors. Significant relationships were found between anxiety (i.e., general, health-related, and stroke-specific) and fatigue, and between depression and fatigue in stroke survivors. Clinicians should take note of these factors for post-stroke interventions. Specifically, post-stroke fatigue combined with anxiety and/or depression could extend rehabilitative services.

Ayerbe, Ayis, Wolfe, and Rudd (2013) conducted a meta-analysis to look at the combined effect of the incidence, prevalence, cumulative incidence, duration, predictors or associated outcomes of depression after stroke. Populations with disability and a history of depression pre-stroke should be monitored by clinicians closely due to their high risk of depression. Depression post-stroke has been linked to a lower QOL and eventual mortality. Clinicians working with these high-risk populations need to take precautions and intervention methods to decrease the effects of post-stroke depression. Early identification of depression post-stroke is also needed.

Hilari et al. (2010) examined what factors predict short-term and long-term psychological distress in PWA. Individuals were interviewed in the hospital as a baseline, then three and six months later. They found stroke severity to be the strongest predictor

of emotional distress at the initial interview. At the three- and six-month interviews, social factors predicted more emotional distress. The study also found that individuals who are predisposed to loneliness and lack social support could experience more distress during post-stroke recovery. When treating PWA, findings of this study argue that clinicians need to monitor psychological factors, such as loneliness, to improve long term outcomes for PWA.

ASSESSMENTS

After having reviewed the literature on QOL and mental health in stroke survivors, I will now turn to a review of assessments in this clinical population. Currently available assessments focus on overall quality of life, with little attention paid to the relationship between psychosocial and emotional factors, and language impairment. Moreover, current measures make it difficult for clinicians to assess how depression may impact quality of life in aphasia and the individual's prognosis for language recovery.

Assessment of Depression and Mood Disorders in Post-Stroke Aphasia

Five widely-cited assessments used to diagnose depression in stroke survivors and PWA were identified (see Table 1). The stroke specific assessments are the *Burden of Stroke Scale* (BOSS; Doyle, McNeil, Hula, & Mikolic, 2003), *Stroke Specific Geriatric Depression Scale* (SS-GDS; Cinamon, Finch, Miller, Higgins, & Mayo, 2011) and the *Post Stroke Depression Rating Scale* (PDRS; Gainotti et al., 1997). The aphasia specific assessments are the *Aphasic Depression Rating Scale* (ADRS; Benaim, Cailly, Pernnou, & Pelissier, 2004), and the *Stroke Aphasia Depression Questionnaire Hospital Version* (SADQ-H; Lincoln, Sutcliffe, & Unsworth, 2000).

Assessment	Abbreviation	Brief Description
Aphasic Depression Rating Scale	ADRS	The ADRS was designed to assess
		somatic symptoms. It is an
		observational/interview 9-item tool
		that requires training to administer.
Burden of Stroke Scale	BOSS	The BOSS was designed to assess
		the physical limitations, emotional
		distress, and cognitive limitations in
		relation to the burden of a stroke in a
		65-item assessment.
Post Stroke Depression Rating Scale	PDRS	The PDRS was designed to identify
		depressive symptoms in a 53-item
		tool administered by a trained
		professional.
Stroke Aphasia Depression	SADQ-H	The SADQ-H was designed to
Questionnaire-Hospital Version		assess somatic symptoms and
		behavior. It is an observational 21-
		item tool that requires no training to
		administer.
Stroke Specific Geriatric Depression	SS-GDS	The SS-GDS was adapted from the
Scale		Geriatric Depression Rating Scale. It
		is a self-report or clinician
		administered 17-item screening tool.

Table 1. Assessments of depression in stroke and aphasia.

Aphasic Depression Rating Scale (ADRS; Benaim et al., 2004)

The ADRS is a simple observational interview scale which asks six questions pertaining to a PWA's physical abilities and three questions on mood. The ADRS's

mobility questions differ from other scales because it requires the examiner to observe a PWA's facial mobility and apparent sadness.

Burden of Stroke Scale (BOSS; Doyle et al., 2003)

The BOSS assesses the impact of a stroke on a person's life through 21 questions focused on physical limitations. For example, questions target lack of mobility, swallowing, and ability to perform self-care. The BOSS targets communication and its effects on the ability to participate in social roles with 13 questions in this area. Post Stroke Depression Rating Scale (PDRS; Gainotti et al., 1997)

The PDRS has a greater emphasis on depressive symptoms typically experienced with major depressive disorder. Stroke survivors are asked to answer questions about their thoughts on guilt, suicide, sleep patterns, anxiety, social participation, and emotion regulation.

Stroke Aphasia Depression Questionnaire-Hospital Version (SADQ-H; Lincoln et al., 2000)

The SADQ-H emphasizes the physical limitations of a stroke. The SADQ asks 11 questions pertaining to these limitations, five questions on mood, and five questions on social participation.

Stroke Specific Geriatric Depression Rating Scale (SS-GDS; Cinamon et al., 2011)

The SS-GDS is adapted from the Geriatric Depression Rating Scale (GDS; Yesavage et al., 1982). The SS-GDS has half of the questions of the original assessment. This self-report or clinician-administered test focuses on psychosocial self-perceptions and the ability to perform activities in daily life. Questions are related to motor function after stroke, emotions and energy, mood, and depressive symptoms.

Assessment of Quality of Life in Post-Stroke Aphasia

Seven widely-cited measures used to examine QOL in stroke survivors and PWA were identified (see Table 2). The *Stroke Impact Scale* (SIS; Duncan et al., 2003) and the *Stroke Specific Quality of Life Scale* (SSQOL; Williams, Weinberger, Harris, Clark, & Biller, 1999) were created for stroke survivors. The *Functional Outcome Questionnaire for Aphasia* (FOQ-A; Glueckauf et al., 2003), the *Sickness Impact Profile to Assess Quality of Life* (SA-SIP; (van Straten et al., 1997), the *Stroke and Aphasia Quality of Life Scale* (SAQOL; Hilari, Byng, Lamping, & Smith, 2003), the *Assessment for Living with Aphasia* (ALA; Worrall, Hudson, Khan, Ryan, & Simmons-Mackie, 2016) and the *Quality of Life Questionnaire for Aphasics* (QLQA; Spaccavento et al., 2014) were designed for PWA.

Assessment	Abbreviation	Brief Description	
Assessment for Living	ALA	The ALA was designed to assess	
with Aphasia		psychosocial factors. It is a 38-item self-	
		rated assessment with 5 domains: aphasia	
		impairment, participation, environment,	
		personal, and life with aphasia.	
Functional Outcome	FOQ-A	The FOQ-A was designed to assess	
Questionnaire for Aphasia		communicative and comprehension	
		abilities. It is a 32-item caregiver rated	
		scale.	
Quality of Life	QLQA	The QLQA was designed to assess loss	
Questionnaire for Aphasics		of autonomy, difficulty in maintaining	
		personal relationships, and dysfunction in	
		daily activities due to aphasia. It is a 37-	
		item scale administered by an SLP.	
Sickness Impact Profile to	SA-SIP	The SA-SIP was designed to assess body	
Assess Quality of Life		care, movement, social interaction,	
		mobility, communication, emotional	
		behavior, household management,	
		alertness behavior, and ambulation. It is a	
		30-item scale administered by a clinician	
		or completed by a stroke survivor.	
Stroke and Aphasia	SAQOL	The SAQOL was designed to assess four	
Quality of Life Scale		domains: physical, psychosocial,	
		communication, and energy. It is 39-item	
		self-report scale completed by a PWA.	
Stroke Impact Scale	SIS	The SIS was designed to assess mood,	
		communication, social roles, reliance,	
		memory and thinking. It is a 61-item	
		self-report scale.	
Stroke Specific Quality of	SSQOL	The SSQOL was designed to assess	
Life Scale		energy, family roles, language, mobility,	
		mood, personality, self-care, social roles,	
		thinking, upper extremity function,	
		vision, and work/productivity. It is a 49-	
		item self-report scale.	

Assessment for Living with Aphasia (ALA; Worrall et al., 2016)

The ALA has an emphasis on participation in activities and personal functioning. Other themes covered are independence, moving on with life after stroke, and language impairment. Only five out of 38 questions focus on language impairment.

Functional Outcome Questionnaire for Aphasia (FOQ-A; Glueckauf et al., 2003)

The FOQ-A has a sole emphasis on communication and comprehension of language. FOQ-A analyzes the functionality of communication present in PWA in different environments and social interactions. The FOQ-A stresses the importance of communication in a PWA's life.

Quality of Life Questionnaire for Aphasics (QLQA; Spaccavento et al., 2014)

The QLQA focuses on loss of autonomy, difficulty in maintaining interpersonal relationships, and dysfunction in daily activities due to aphasia. Results support the sensitivity of a PWA's emotional well-being post-stroke. This measure also highlights the role that aphasia plays in social isolation and emotional distress which lowers HRQOL. Sickness Impact Profile to Assess Quality of Life (SA-SIP; van Straten et al., 1997)

The SA-SIP covers a variety of topics including body function, social interactions, emotion regulation, and household performance. The SA-SIP only has three questions focused on communication.

The Stroke and Aphasia Quality of Life Scale (SAQOL; Hilari et al., 2003)

The SAQOL specifies four psychometric domains of questions: physical, psychosocial, communication, and energy. Less than half of the 39 original questions are related to psychosocial well-being and communication. Only nine questions are specific to language.

Stroke Impact Scale (SIS; Duncan et al., 2003)

The SIS covers a variety of areas related to HRQOL. Many questions are in the areas of independence, mobility, meaningful activities, mood, and memory. The SIS has only seven questions related to communication. The final question asks PWA to rate on a scale from 0-100 the amount of recovery progress they feel they have made.

Stroke Specific Quality of Life Scale (SS-QOL; Williams et al., 1999)

The SS-QOL is a larger assessment with a broad range of categories. The themes with the most questions are mobility, mood, self-care, social roles, upper extremity functioning, and language.

Rationale

When treating PWA and attempting to improve their QOL, it is critical to understand how depression and other mental health issues are tied to the individual's language impairment (Koleck et. al., 2017). Creating a screening tool for post-stroke depression would provide insight into each person's specific risk factors for depression because of their communication disorder, which would then allow an SLP, and an interdisciplinary rehabilitation team, to create a more personalized treatment approach. The development of this screening tool is critical because depression elongates and/or prevents language recovery for PWA, so there is a great need to identify depressive symptoms as early as possible (Hackett & Anderson, 2005).

METHODS

In the following section, I will describe the methods for the proposed study, which was scheduled to be conducted during February-March 2020. Due to the COVID-19 outbreak, the study could not be completed.

Participants

I planned to recruit 20-30 participants in each focus group (10-15 stroke survivors and 10-15 caregivers). To recruit participants, a stroke support group in Brewer was attended in February 2020. At this meeting, potential participants were provided with background information on the research project and were invited to attend the focus group in March 2020. Participants were all native American English speakers. All participants were fully competent (i.e., no cognitive impairments or impaired judgment or decision making), as determined by self-report. Individuals with severe cognitive impairments that affected the understanding of instructions would not have been enrolled in this study. This project was approved by the Institutional Review Board of the University of Maine in January 2020 (see Appendix A). All participants in this study would have received a \$5 gift card for their participation.

Focus Group

Before taking part in the focus group, all participants would have been asked to complete a brief questionnaire to obtain background demographic information, information related to their stroke and medical history (see Appendix B). Participants and their caregivers would have also completed a consent form (see Appendix C). The focus group would have been conducted in a large room with seats arranged in a large circle as

recommended by Krueger and Casey (2015). The investigators would be sat next to each other in front of a screen displaying a PowerPoint presentation. Audio and video recording would also have been set up. The participants would have been read an introductory script at a steady and clear pace (see Appendix D). This script outlines how the discussion would have taken place. The focus group discussion would then begin where the participants would be asked the following set of questions (see Table 3). The focus group was planned to last approximately 60-90 minutes.

	Theme	Question
1	Physical	How long ago did each of you have a stroke?
2	Physical	Tell us about recovering from this experience.
3	Physical	Raise your hand if you have received speech or physical therapy.
4	Psychosocial	What kinds of resources were provided after having a stroke?
5	Psychosocial	Did your SLP ever discuss mental health or mood post-stroke?
6	Language Impairment	Please describe your communication abilities after your stroke.
7	Language Impairment	How did your communication abilities affect your quality of life?
8	Language Impairment	Think back to a moment when language failed you, please describe that experience.
9	Language Impairment	How did communication affect your ability to maintain relationships after your stroke?
10	Psychosocial	Raise your hand if you live with a caregiver or family member. How did your caregivers or family members provide support to you?

Table 3. Focus Group Questions.

The questions were organized according to QOL themes obtained from previous research. Within each theme, several questions were asked to elicit discussion. The initial questions are commonly included in standardized stroke and aphasia assessments to develop a rapport with the stroke survivors, and to better understand what it is like to live with a stroke.

When interacting with stroke survivors with communication problems, it is important to adapt communication styles to best support these individuals' communicative needs. A recommendation from a recent study was to move away from asking open-ended questions as in a traditional focus group by altering the way questions are asked, suggesting words and stating ideas when stroke survivors are struggling to produce their intended response. It is also helpful to have caregivers affirm the stroke survivor's response (Luck & Rose, 2007).

After visiting the Brewer stroke support group in February 2020, some changes to the focus group would need to be implemented in order to improve the feasibility of the study. First, we would need to ensure there was an equal contribution from the participants. More specifically, we would need to consider how to increase participation from quieter group members since it was found a few members tended to dominate the discussion. A solution for this would be to break the focus group into smaller groups to allow those quieter individuals to have a chance to express their opinions. A smaller group size would also allow stroke survivors who are struggling with their language to have a calmer environment to facilitate discussion.

Second, a proposed change to the study could be to modify the style of language in the introductory presentation and specific focus group questions. When interacting

with the group during the initial presentation of the study, members were hesitant to interact with the investigators. In order to develop a better rapport with group members, the wording of questions could be modified. For example, focus group question 5 above, "Did your SLP ever discuss mental health or mood post-stroke?" could be changed to "Did your SLP ever ask how you were feeling?". During the initial meeting, group members were responsive to learning the purpose and personal motivation for the study. The group enjoyed learning why the investigators were attempting to have a discussion with them and learning about their personal motivations.

ANTICIPATED RESULTS

The themes of the focus group questions were derived from the five-major health related quality of life factors determined through the literature review and analysis of current assessments. These five factors are: 1) loss of autonomy, 2) lack of participation, 3) difficulty in maintaining relationships, 4) increased need for support, and 5) communication impairment. When analyzing the structure of current assessments, it is common to organize the questions in a range of targeted themes or sub-themes. As a result, the focus group questions were categorized into themes based on physical, psychosocial, and language impairment. These themes were targeted because current assessments for PWA typically include few questions related to the effects of language impairment.

The goal of the themes selected for the focus group questions was to gain insight from PWA on the effects of language impairment on their mood and HRQOL. If this data had been collected, there would have been potential to find whether factors such as language impairment, were an indicator of depression or mood disorders in PWA who may therefore have a need to be referred to mental health counseling.

Development of the Screening Tool

The HRQOL areas which could benefit from further exploration when developing a screening tool for PWA are physical limitations and social communication. In assessments of assessment of depression and mood disorders in post-stroke aphasia, physical limitations of a person's stroke are assessed. In assessments of HRQOL, physical limitations are not consistently addressed. Physical limitations are an important

indicator of how a PWA will recover. Social communication is an important theme of HRQOL for people with and without language impairments. Social communication is a domain that covers a variety of subdomains and areas that make a PWA's HRQOL positive. The subdomains or topics of social communication commonly found in the current HRQOL assessments are: ability to retrieve and produce correct words, ability to comprehend others, ability to express emotion, ask or advocate for self, and maintain meaningful relationships.

Hilari et al. (2010) supports including social factors as a predictor of emotional distress. In this study, stroke severity was the strongest predictor of emotional distress early on. However, at the three and six-month period, social factors predicted more emotional distress. Individuals who are predisposed to loneliness and lack social support could experience more distress during post-stroke recovery. This study recommended the need for clinicians to monitor psychological factors, such as loneliness, to improve long term outcomes for PWA.

Spaccavento et al. (2014) compared the QLQA against other common HRQOL assessments. The QLQA questionnaire focuses on the loss of autonomy, difficulty in maintaining interpersonal relationships, and dysfunction in daily activities due to aphasia. These themes differentiate the QLQA from current assessments used for stroke patients to assess QOL, such as the SAQOL. Recovery from communication and physical impairments was faster in PWA when treated, while improvement in psychosocial wellbeing took much longer. This study supports aphasia as a factor influencing social isolation and emotional distress, thus lowering HRQOL.

In another study by Lee, Lee, Choi, and Pyun (2015), PWA were analyzed based on the amount of activities they participated in and the relationship with QOL factors. It was found that PWA who were depressed showed significantly decreased community integration and quality of life. Thus, these results argue that it is important to monitor community integration, daily functioning, and social participation as important indicators of HRQOL. Similarly, in a study conducted by Chou (2015), strong relationships were found between HRQOL and the following factors: psychosocial well-being, number of strokes, enrollment in rehabilitation therapy, and socio-demographics. Chou found psychosocial factors such as social participation to be the strongest determinant of HRQOL. Social participation was most likely influenced by how much communication is affected post-stroke. Social participation is an important psychosocial aspect of maintaining a positive HRQOL.

As mentioned previously, Cruice, Worrall, and Hickson (2010) interviewed people with mild to chronic aphasia to identify the HRQOL domains most relevant to their lives. Ten main factors were derived from this study and the first four domains were considered the core of a PWA's QOL: activities, verbal communication, people, and body functioning. The activities include work, personal interests, entertainment, social functions, domestic duties, sports, literacy, and trips. It is important to emphasize that each of these activities requires some form of communication.

Based on the literature reviewed and an in-depth analysis of current assessments, several questions are recommended to be included in a screening tool to identify if a PWA is at risk for depression (see Table 4). The screening tool would elicit responses

using a rating scale of severity or yes/no responses. The screening tool would have the

potential to be self-administered or with the help of a caregiver.

Table 4. Potential Screening Tool Question	S
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Communication & Psychosocial	Style of Question
1. Ability to read	Rating
2. Ability to write	-
3. Ability to understand others	
4. Ability to understand the TV	
5. Ability to feel understood when talking to others	
6. Ability to explain ideas to others	
7. Ability to communicate wants and needs to caregivers	
8. Ability to use phone	
9. Ability to speak with people who are not familiar	
10. Ability to speak clearly	
11. Ability to speak quickly	
12. Ability to retrieve the correct words	
13. Ability to advocate for myself	
14. Ability to participate in conversations	
15. Ability to maintain role in family life before stroke	
16. Ability to maintain meaningful relationships	
17. Ability to participate in community activities	
18. Ability to remember current events	
19. Ability to continue to work	
20. I have a support system of friends, family, and medical providers.	Yes/No
21. I have support in different environments regarding talking.	Yes/No
22. Impact of aphasia on quality of life	Open Ended
23. Knowledge of aphasia	
24. How have physical limitations affected your social life?	
25. How has your language impairment affected your social life?	
26. How have your emotions affected your social life?	
Emotions & Mood	
27. Pre-stroke, were you diagnosed with any mental health concerns?	Yes/No
28. Depression, anxiety, or other	Open Ended
29. Rate the impact of your stroke on your overall mood.	Rating
30. How have physical issues affected your emotions?	Open Ended
31. My mood is mostly	
32. Level of loneliness experienced.	Rating

Table 4 Continued		
33. When my communication is impaired, I feel	Open Ended	
34. Perspective of future		
35. Feelings of embarrassment	Rating	
36. Feeling positive thoughts		
37. Feeling independent		
38. Feeling guilty		
39. Feeling irritable		
40. Feeling confident		
41. Feeling interested in activities		
42. Feeling interested in eating		
43. Feeling independent		
44. Feeling able to manage my emotions		
Physical Limitations		
45. How many strokes have you experienced?	Open Ended	
46. Before your stroke, were you diagnosed with any disabilities?	Yes/No	
47. Have you had previous physical impairments?		
48. Impact of stroke on quality of life	Rating	
49. Severity of stroke		
50. Ability to complete household duties		
51. Ability to continue hobbies and activities before my stroke		
52. Ability to maintain physical activity		
53. Ability to perform self-care		
54. Ability to move upper extremities		
55. Ability to swallow		
56. Ability to sleep through the night		
57. Ability to stay awake during the day		
58. Ability to stand		
59. Level of overall tiredness		
60. Level of tiredness after speaking		

DISCUSSION

When comparing current assessments for HRQOL, mental health, and mood in stroke survivors, few questions focus on how language impairment affects these individuals' QOL. A screening tool specific to HRQOL, mood, and language impairment is needed for SLPs to direct PWA to the correct mental health services. SLPs often use assessments for post-stroke depression as screening tools, though these measures are not designed specifically to be used this way. Clinicians agree that psychosocial factors are important to consider in the recovery process. For example, Brumfitt (2009) surveyed SLPs about the role of psychosocial effects in PWA and found that they strongly agreed that these factors are important for the success of interventions for PWA. In another survey, Northcott, Simpson, Moss, Ahmed, and Hilari (2017) demonstrated that PWA's psychological well-being should be addressed during treatment so that these individuals can be referred to appropriate mental health services.

Multiple studies support the idea that impaired communication has negative effects on PWA regarding their emotional well-being and successful performance of daily activities. A study by Hilari, Cruice, Sorin-Peters, and Worrall (2015) found aphasia to have a negative impact on HRQOL. Maintaining independence and completing daily activities was considered an important factor by Brown, Davidson, Howe, and Worrall (2011). PWA experience loss of autonomy as well as adverse effects on social and emotional well-being due to a lowered HRQOL. Several studies demonstrate that social factors, such as social support and isolation, and emotional status, such as distress and depression, influence these individuals' HRQOL. When these social factors are affected

in PWA, their HRQOL is lowered. This low HRQOL results in a poor emotional wellbeing making PWA at risk for depression.

Hilari et al. (2010) examined what factors predict short-term and long-term psychological distress in PWA. These individuals were interviewed in the hospital as a baseline, then three and six months later. The study found stroke severity to be the strongest predictor of emotional distress at the initial interview. At the three- and sixmonth interviews, social factors predicted more emotional distress. The study also found that individuals who are predisposed to loneliness and lack social support could experience more distress during post-stroke recovery. When treating PWA, this study recommended the need for clinicians to monitor psychological factors, such as loneliness, to improve long term outcomes for PWA.

Chou (2015) recommends consistent enrollment in rehabilitation therapy centered on the socio-demographic factors which influence HRQOL, including a person's social role, family role, and work involvement. These socio-demographic factors correlate with the psychosocial aspect of HRQOL. If a PWA is more involved in these roles, it has a positive influence on their psychosocial wellbeing.

Cruice, Worrall, and Hickson (2010) highlighted the importance of an SLP in providing the support and education a PWA needs to utilize their communicative strengths to be successful in their daily activities and communication. Ayerbe et al.'s (2013) meta-analysis supports the need for clinicians working with these populations to use intervention methods to decrease the effects of post-stroke depression. SLPs play a key role in early identification of depression post-stroke. Through the development of a screening tool for depression in relation to both language and physical impairments post-

stroke, PWA can be offered appropriate services that will in turn potentially improve their HRQOL, lengthen their life span, and lead to better rehabilitation outcomes.

Speech-language pathologists frequently work on interdisciplinary teams. Terrill (2018) discusses three main points in a study of interdisciplinary teams working with mild stroke survivors. First, clinicians should be conducting mental health screenings to allow patients to access educational resources. Second, there are several screening tools that can be used to screen stroke survivors for depression. Lastly, more research is needed to determine best practices for mild stroke survivors. Lack of mental health screenings in mild stroke survivors can result in a lengthened recovery process.

Applications

A successful application of identifying early warning signs of low mood in PWA is the Aphasia Success Knowledge (ASK) early intervention program (Worrall et al., 2016). The ASK program was created to educate family members about symptoms of aphasia. This program intends to reduce caregiver burden and improve the mental health of all involved which would provide a better QOL for PWA and their caregivers. This program includes modules on aphasia and stroke, basic communication strategies, strategies for managing mood, and strategies for maintaining social network support. ASK has proven to be successful thus far as an early intervention program for family members and caregivers. As speech-language pathologists can play a critical role in screening PWA for mood disorders, it is possible that ASK may also be effective for SLPs to implement into their practice to improve QOL and mood for PWA and their caregivers.

In addition, there are multiple online programs that have the potential to improve mental health in PWA. A recent study by Clunne, Ryan, Hill, Brandenburg, and Kneebone (2018) assessed eight e-mental health programs to determine which one was most sustainable and suitable for PWA. The researchers assessed general features, evidence produced, and communicative accessibility. The study was conducted as if a PWA was searching for online health care themselves. Using Google and suggested terms, the study found eight aphasia specific programs. Participants from local aphasia support groups who self-reported mental health difficulties participated in the study by completing one module of a randomized e-mental health program with the support of the research assistants or caregiver. They were then asked to fill out a survey indicating their level of satisfaction with the program module. Out of the eight programs, four were shown to lessen the symptoms of depression in the general population, but due to a small sample size, were not found to reduce depression in PWA. The programs showed potential to benefit PWA if communicative accessibility was given a higher priority by adding aphasia-friendly text, font, and visual support. With these additions, e-mental health services could therefore provide PWA with an accessible way of attaining therapy due to their higher risk of depression post-stroke. While there are several existing programs and more being developed, additional research needs to be conducted.

CONCLUSION

This thesis analyzed the impact of aphasia on HRQOL. It has been shown that post-stroke aphasia puts a person at risk for depression and lengthened recovery of their language. Current assessments were compared for identifying depression and HRQOL in PWA. The literature on mental health and quality of life in PWA was also reviewed. Through an analysis of current assessments and literature, suggested questions for a screening tool for mood disorders and HRQOL in PWA were created. A future screening tool that incorporates some or all of these questions has the potential to identify a PWA's risk for depression. This assessment could be used by SLPs to refer their client for mental health services earlier to increase a PWA's recovery. This screening tool would need to be further developed and validated by professionals in the field of speech-language pathology.

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APPENDICES

APPENDIX A: IRB APPROVAL

APPLICATION FOR APPROVAL OF RESEARCH WITH HUMAN SUBJECTS Protection of Human Subjects Review Board, 400 Corbett Hall

PRINCIPAL INVESTIGATOR: Sophia Palangas FACULTY SPONSOR: **Christopher Grindrod** EMAIL: sophia.palangas@maine.edu EMAIL: christopher.grindrod@maine.edu

TITLE OF PROJECT: Assessing Health Related Quality of Life, Language Impairment, and Psychosocial Factors in Post-Stroke Aphasia

START DATE: January 15, 2020 PI DEPARTMENT: Communication Sciences & Disorders

STATUS OF PI: FACULTY/STAFF/GRADUATE/UNDERGRADUATE Undergraduate

If PI is a student, is this research to be performed:

\boxtimes	for an honors thesis/senior
	for a doctoral dissertation?
	other (specify)

thesis/senior thesis/capstone?	for a master's thesis?
dissertation?	for a course project?

Submitting the application indicates the principal investigator's agreement to abide by the responsibilities outlined in Section I.E. of the Policies and Procedures for the Protection of Human Subjects.

Faculty Sponsors are responsible for oversight of research conducted by their students. The Faculty Sponsor ensures that he/she has read the application and that the conduct of such research will be in accordance with the University of Maine's Policies and Procedures for the Protection of Human Subjects of Research. REMINDER: if the principal investigator is an undergraduate student, the Faculty Sponsor MUST submit the application to the IRB.

FOR IRB USE ONLY Application # 2019-11-10 Review (F/E): F Expedited Category: ACTION TAKEN: Judged Exempt; category Modifications required? Accepted (date) Approved as submitted. Date of next review: by Degree of Risk: ı

\mathbf{X}	Approved	l pending modifications.	Date of next review:	by1/14/2021	Degree of Risk:	Minima
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Modifications accepted (date): 1/15	/2020
Not approved (see attached stateme	ent)

Judged not research with human subjects

FINAL APPROVAL TO BEGIN

1/15/2020 Date

10/2018

APPENDIX B: BACKGROUND QUESTIONNAIRE



NEUROLINGUISTICS AND APHASIA RESEARCH LAB DEPARTMENT OF COMMUNICATION SCIENCES AND DISORDERS STROKE PARTICIPANT BACKGROUND QUESTIONNAIRE

1. Confidentiality Statement

As part of this research project, we are requesting that you provide information about your background, language and development, medical history, and hobbies and interests. Please answer the questions below as completely and accurately as possible. All information will be kept confidential. Thank you for your time and cooperation.

2. General Information

Year and Mo	onth of Birth:					
Gender: C	I Male □	Female				
Education (h	ighest level a	chieved):	High Schoo	ol 🛛 Coll	ege (BA)	Graduate
□ Other						
Race:		White			Hispanic/	
		African A	merican		Native Ha	awaiian/Pacific
Islander						
		American	Indian/Alaska	Native 🛛	mea	
		Asian			Other	
3. Language First languag	-		listory			
Other langua	ge(s) learned	:				
Language co	nsidered to be	e native la	nguage:			
Languages sp	ooken at hom	e during c	hildhood:	_		
Did you reac	h all of your	developme	ental milestones	s on time?	□ Yes	□ No
4. Medical E Please indica	e e	e any weal	kness or loss of	movement	in your lin	ıbs:
Right arm:	□ good str	rength	□ a little wea	ık 🗖	very weak	□ paralyzed
Right leg:	□ good st	rength	\Box a little we	ak 🛛	very weak	□ paralyzed
Left arm:	□ good st	rength	\Box a little we	ak 🛛	very weak	□ paralyzed
Left leg:	🛛 good sti	ength	□ a little wea	ak 🛛	very weak	□ paralyzed

Please indicate the status of your vision: (check all that apply)

- **Given and Series and**
- **Given and Series and**
- poor vision even with glasses
- difficulty seeing things on the right side
- difficulty seeing things on the left side

Can you hear adequately in one-on-one conversations? □ Yes □ No □ Unknown How long have you been living with aphasia? years months How long have you been involved in speech-language therapy? years months Please describe any previous history of speech-language therapy as best you can below.							
Booution	<u>Butt</u>						
Date of your stroke:							
·							
Are there any indications that you are currently depressed? \Box Yes \Box No							
If yes, please describe:							
5. Hobbies & Interests	1/ • 1 •	2					
What are your hobbies an	id/or special interests	5?					

What organizations do you participate in (e.g., church, community)?

APPENDIX C: CONSENT FORMS



CONSENT FORM: STROKE SURVIVORS (FOCUS GROUP 1)

Research Project: Assessing Quality of Life in Post-Stroke Aphasia Principal Investigator: Sophia Palangas, Undergraduate Student Faculty Sponsor: Christopher Grindrod, PhD, Assistant Professor Department of Communication Sciences and Disorders

PURPOSE

You are being asked to participate in a research project conducted by the abovenamed individuals. The goal of this project is to examine how psychosocial and emotional factors impact a stroke survivor's language recovery. We are also interested in how this relationship can be better understood through the development of a quality of life screening assessment specific to stroke survivors with aphasia. This research is necessary so that speech language pathologists can refer people with aphasia to the appropriate mental health services when needed. In order to participate in this study, you must be at least 18 years old, a stroke survivor and must have no cognitive impairments, such as dementia.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to complete a brief background questionnaire and be part of a group discussion. During the discussion, you will be asked questions about your quality of life, mood, support you received after having a stroke, and your language recovery experience. Your responses will be video recorded. The recordings will be used to look at whether opinions or experiences differ across individuals. If you prefer not to be video recorded, you can sit behind the camera where you can still participate, but will not be filmed. The background questionnaire will take approximately 10 minutes to complete and the group discussion will last approximately 1.5-2 hours.

RISKS

Minor risks are the time commitment, inconvenience, and mental fatigue. You will be given a list of local and community resources for your information.

BENEFITS

There is no direct benefit to you. This study has the potential to further the development of a screening tool that will be used by speech language pathologists to make referrals to mental health services for stroke survivors with aphasia. Your participation in this study is helping to develop a brief quality of life screening assessment.

COMPENSATION

You will be given a \$5 Amazon or Hannaford gift card after the group discussion. You are free to stop at any time and you will receive full compensation.

CONFIDENTIALITY

Your answers will be confidential and only used for this project. I encourage you to not discuss what will be said in the discussion once it is completed. Since it is a group format, I cannot guarantee that your answers will not be discussed by fellow members.

Your answers will be video recorded and transcribed later so that we can look at any differences in individual responses. To ensure your privacy and confidentiality, all of your data will be assigned a unique identification code corresponding to you. The electronic key used to link your name with the identification code will be saved using additional security on a password-protected computer different from the one used to store the data for this study. Only the investigator(s) will have access to the password-protected computers with the electronic key, recordings and transcriptions. All data will be kept in a secure location in a locked filing cabinet in the faculty sponsor's locked research lab. All data and the key will be destroyed by December 31, 2020.

VOLUNTARY

Your participation is completely voluntary. You can decide to not participate in the discussion of any topic or skip any questions that you prefer not to answer.

CONTACT INFORMATION

If you have questions about this study, you may contact Sophia Palangas (207-581-2014; sophia.palangas@maine.edu) or Dr. Christopher Grindrod (207-581-2014; christopher.grindrod@maine.edu). If you have any questions about your rights as a research participant, please contact the Office of Research Compliance, University of Maine (207-581-2657; umric@maine.edu).

STATEMENT OF CONSENT

Your signature below indicates that you have read and understand the above information and agree to participate. You will receive a copy of this form.

SIGNATURE

DATE



CONSENT FORM: CAREGIVERS (FOCUS GROUP 1)

Research Project: Assessing Quality of Life in Post-Stroke Aphasia Principal Investigator: Sophia Palangas, Undergraduate Student Faculty Sponsor: Christopher Grindrod, PhD, Assistant Professor Department of Communication Sciences and Disorders

PURPOSE

You are being asked to participate in a research project conducted by the abovenamed individuals. The goal of this project is to examine how psychosocial and emotional factors impact a stroke survivor's language recovery. We are also interested in how this relationship can be better understood through the development of a quality of life screening assessment specific to stroke survivors with aphasia. This research is necessary so that speech language pathologists can refer people with aphasia to the appropriate mental health services when needed. In order to participate in this study, you must be at least 18 years old and the primary caregiver of a stroke survivor.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to be part of a group discussion. During the discussion, your spouse or partner will be asked questions about their quality of life, mood, support they received after having a stroke, and their language recovery experience. You may be asked to clarify or expand on their responses. Your responses will be video recorded. The recordings will be used to look at whether opinions or experiences differ across individuals. If you prefer not to be video recorded, you can sit behind the camera where you can still participate, but will not be filmed. The discussion will last approximately 1.5-2 hours.

RISKS

Minor risks are the time commitment, inconvenience and mental fatigue.

BENEFITS

There is no direct benefit to you. This study has the potential to further the development of a screening tool that will be used by speech language pathologists to make referrals to mental health services for stroke survivors with aphasia. Your spouse or partner's participation in this study is helping to develop a brief quality of life screening assessment.

COMPENSATION

You will be given a \$5 Amazon or Hannaford gift card after the group discussion. You are free to stop at any time and you will receive full compensation.

CONFIDENTIALITY

Your answers will be confidential and only used for this project. I encourage you to not discuss what will be said in the discussion once it is completed. Since it is a group format, I cannot guarantee that your answers will not be discussed by fellow members.

Your answers will be video recorded and transcribed later so that we can look at any differences in individual responses. To ensure your privacy and confidentiality, all of your data will be assigned a unique identification code corresponding to you. The electronic key used to link your name with the identification code will be saved using additional security on a password-protected computer different from the one used to store the data for this study. Only the investigator(s) will have access to the password-protected computers with the electronic key, recordings and transcriptions. All data will be kept in a secure location in a locked filing cabinet in the faculty sponsor's locked research lab. All data and the key will be destroyed by December 31, 2020.

VOLUNTARY

Your participation is completely voluntary. You can decide to not participate in the discussion of any topic or skip any questions that you prefer not to answer.

CONTACT INFORMATION

If you have questions about this study, you may contact Sophia Palangas (207-581-2014; sophia.palangas@maine.edu) or Dr. Christopher Grindrod (207-581-2014; christopher.grindrod@maine.edu). If you have any questions about your rights as a research participant, please contact the Office of Research Compliance, University of Maine (207-581-2657; umric@maine.edu).

STATEMENT OF CONSENT

Your signature below indicates that you have read and understand the above information and agree to participate. You will receive a copy of this form.

SIGNATURE

DATE

APPENDIX D: FOCUS GROUP SCRIPT

Pre-Development Focus Group Script (adapted from Krueger & Casey, 2015)

Welcome. Thanks for taking the time to join us to talk about quality of life in stroke survivors. My name is Sophia Palangas and with me is Dr. Chris Grindrod. We're both from the University of Maine. We are conducting a research project to examine how psychosocial and emotional factors impact a stroke survivor's language recovery and how this relationship can be better understood through the development of a quality of life screening assessment specific to stroke survivors. There is a need for a screening assessment for speech language pathologists to refer stroke survivors to the appropriate mental health services when needed.

You are being asked to participate in this study because you attend a weekly stroke support group and can provide insight on how we can develop a screening assessment. We are visiting today to hear your personal experiences and opinions on your language recovery experience after having a stroke. With your viewpoints, we can potentially help others who are in a similar situation as you.

Given the group format of the discussion, I encourage you to not discuss any information after we are done. Since it is a group format, I cannot guarantee your answers will not be discussed by fellow group members.

There are no wrong answers, only differing points of view. Please feel free to share your point of view even if it differs from what others have said. Keep in mind that we're just as interested in negative comments as positive comments, and at times the negative comments are more helpful.

There are guidelines for this discussion to help you all voice your thoughts. It will help if only one person talks at a time. If several of you are talking at the same time, the recording will be difficult to interpret and we'll miss your comments. My role is to guide you through the discussion, while you talk to each other. Sometimes I may need to interrupt to get through all the questions.

You may have already noticed the video camera. If you prefer not to be video recorded, you can sit in a location behind the camera where you can still participate in the discussion, but will not be filmed. We're recording the session because we don't want to miss any of your comments. People say helpful things in these discussions and we can't write fast enough to get them all down. We will be on a first name basis tonight, and we won't use any names in our reports. We will keep what you say confidential. Our reports will go back to the University of Maine but, again, no names will be written in the transcription.

I've got a number of questions that I want to ask, but my job is really to listen. This will be more interesting for all of us if we treat this like a conversation. If someone says something, feel free to follow-up on it or share a different point of view. You don't need to address all your comments to me.

If you have a cell phone, please put it on silent mode. If you need to take a call, please step out and then return as quickly as possible. If you need to use the restroom, it is located (insert location).

You will receive a \$5 gift card as a thank you for participating in our project at the end of the group discussion.

Let's begin. We've placed your first names on cards in front of you to help us remember each other's names. Let's find out more about each other by going around the table. Let's go around the room and introduce ourselves. Please share your name and how long you have been attending the stroke support group.

We will now begin the discussion.

This concludes the group discussion. Thank you all for participating. If you have any questions for Dr. Grindrod and I, we will be happy to stay and talk. We will leave our contact information if you think of any questions later.

AUTHOR'S BIOGRAPHY

Sophia Palangas was raised in Weare, New Hampshire and graduated from Bishop Brady High School in 2016. Majoring in Communication Sciences and Disorders, Sophia has minors in Psychology, Interdisciplinary Disability Studies, and Leadership Studies. In the spring of 2019, Sophia studied abroad in Maastricht, Netherlands and received the Charles V. Stanhope Fellowship, Bill and Betsy Pullen Leitch '55 Conference and Study Abroad Fund Award, and an Office of International Programs Scholarship. She was a Co-Vice President of All Maine Women, Co-Coordinator, Secretarial-Membership Chair, and Site-Leader of Alternative Breaks, a Co-President and Volunteer Chair of Women's Club Ice Hockey, and a member of the National Student Speech Language Hearing Association. She has received a Center for Undergraduate Research Fellowship, multiple College of Natural Sciences, Forestry and Agriculture Merit Scholarships, two University of Maine Student Government Inc. Leadership Scholarships, and multiple scholarships from the St. George Greek Orthodox Cathedral. Since her first year, Sophia was a volunteer Undergraduate Research Assistant in the Neurolinguistics and Aphasia Research Lab under the supervision of Dr. Christopher Grindrod. Upon graduation, Sophia plans to pursue a Master of Science in Communication Sciences and Disorders at the University of New Hampshire to become a speech-language pathologist.